

Partnering with your Doctor to Manage Parkinson's Disease

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Today's Agenda

- Importance of partnering with your doctor
- Basic but critical knowledge for patients and families
- Motor and Non-Motor PD symptoms with focus on TREATABLE symptoms
- What to expect from your medication
- General Tips

Why is partnership so critical?

- You are the only authority on *your* PD
- Not everyone will see a Parkinson's specialist
 - specialist shortage
 - travel distance
 - alternating care with general neurologist or PCP

I want to help you to:

- Know what to expect at your doctor visits
- Understand your symptoms and share a common language
- Recognize motor AND non-motor symptoms, especially TREATABLE symptoms ★
- Know which symptoms are better dealt with by a non-neurologist ★
- Know what to expect from your Parkinson medication
- Recognize your side effects
- Set the agenda for your office visit- time is limited!

What to Expect – 1st visit (30m-1.5h)

- What has led someone to believe you have PD?
 - What are your symptoms? When did they start? Are they progressing?
 - Does anything make them better or worse? (medications?)
- Medical History/ Surgical History
- Medications/ Med Allergies
- Family History (especially of neurological diseases)
- Social history (environmental exposures, bad habits, support systems, barriers to treatment)
- General neurological examination/ Parkinson's specific examination
- Diagnosis
- Plan for Treatment and Follow-up
- Any questions?

What to Expect – Return Visits (15-30m)

- Shorter, less structured
- Did you implement the plan made at the last visit?
- How did it work for you?
 - What symptoms did it work for? **
 - What symptoms did it NOT work for? **
 - Any side effects? **
- Any new symptoms? **
- Parkinson's examination with comparison to previous visit
- Updated plan for treatment and follow-up
- Any questions? **

PD: What are the Symptoms?

- Motor Symptoms
- Non-motor Symptoms
 - Autonomic
 - Neuropsychiatric
 - Sleep-related
 - Sensory/miscellaneous

PD Motor Symptoms

- Tremor ★★ ★
- Medical terminology: tremor
 - Which body parts affected?
 - One side more affected?
 - When do you see it? Resting vs with use vs both?
 - Anything make it better or worse?
- How to check for this? Dr. will observe in different positions and under stress
- Treatable? Generally **
 - Most people will benefit from PD medication but ~20% of people have no benefit → DBS can be an option
 - Most people who benefit still have breakthrough tremor → with stress

PD Motor Symptoms

- Muscle Stiffness / Tightness / Loss of Flexibility ★★
- Medical terminology: Rigidity
 - May be obvious and painful, may be subtle
 - Examples: neck stiff, affected arm or leg sore, decreased arm swing, posture change, change in facial expression
 - Hard to differentiate from arthritis in some
- How to check for this? Dr. will move your neck and limbs through range of motion and feel for resistance
- Treatable? Generally
 - PD medication + PT/OT

PD Motor Symptoms

- Slow Movement / Small movement ★★ ★
- Medical terminology: Bradykinesia / Hypokinesia
 - How much longer does it take you to do things?
 - Handwriting?
 - Fine motor skills / dexterity?
- How to check for this? Dr. will observe repetitive movements of arms and legs
- Treatable? Generally
 - PD medication + OT

PD Motor Symptoms

- Gait changes ★★
- Medical terminology:
 - Stooped posture
 - Shuffling
 - Festination/Propulsion
 - Start hesitation/ Freezing
- How to check for this? Dr. will observe gait
- Treatable? Partially
 - PD medication + Physical therapy

PD Motor Symptoms

- Balance problems ★
- Medical terminology: Postural instability
 - Have you fallen or can you catch yourself?
 - Is there a pattern to the falls? How often? In which scenarios? In what direction?
- How to check for this? Dr. will observe your gait and do a 'pull test'
- Treatable? Not easily
 - Physical therapy, assist devices

PD Motor Symptoms

- Muscle cramping ★★
- Medical terminology: Dystonia
 - Different symptoms in different body parts:
 - Charlie horse type cramping of calf muscles or feet
 - Twisting or tilting of head
 - “Pisa syndrome” of trunk
- How to check for this? Dr. will observe during rest and movement
- Treatable? Generally, depends on location
 - PD medication and sometimes Botulinum toxin (Botox)

PD Motor Symptoms

- Speech changes ★
- Medical terminology:
 - Hypophonia- low volume
 - Dysarthria- poor articulation
 - Palilalia- involuntary repetition
 - **A “masked face” can also interfere with emotional aspects of communication
- How to check for this? Dr. will observe spontaneous speech, reading
- Treatable? Partially
 - PD medication + Speech therapy

PD Motor Symptoms

- Trouble swallowing ★
- Medical terminology: Dysphagia
 - Can have obvious choking; coughing after liquids; or NO symptoms!
 - Silent aspiration is dangerous and leads to “aspiration pneumonia”
- How to check for this? Formal swallow evaluation by speech therapy
- Treatable? Partially
 - Behavior modifications, speech therapy for swallow exercises, expiratory muscle strength training (EMST)

Dr. Patterson, you forgot dyskinesia...

Dyskinesia

- involuntary writhing movements of the head, trunk, and limbs
- a side effect rather than a PD symptom
- typically occurs with medication's peak effect

PD Non-motor Symptoms

Category 1: Autonomic dysfunction –

- Problems with the system that automatically regulates several bodily functions (heart rate, blood pressure, digestion, excretion, sexual function, etc)

PD Non-motor Symptoms

- Lightheadedness with position change ★★★
- Medical terminology: Orthostatic Hypotension (OH)
 - Blood pressure drop from lying to sitting, sitting to standing
 - Can lead to loss of consciousness OR may be subtle
- How to check for this? BP measurement in multiple positions in clinic or at home (Keep a BP cuff at home)
- Treatable? Yes
 - Hydration! Other behavioral measures
 - Reduce or stop BP medications
 - Review medication list for other culprits (even some PD medications)
 - OH medication: midodrine, fludrocortisone, droxidopa, mestinon

PD Non-motor Symptoms

- Constipation ★★★
- Medical terminology: same
 - Precedes motor symptoms of PD by many years
 - Can be severe and lead to impaction
 - Gastroparesis- can impact effectiveness of PD medication
- How to check for this? n/a
- Treatable? Yes
 - Avoid opioids, minimize iron supplements, other constipating meds
 - Hydration, dietary fiber, probiotics, stool softeners, laxatives, suppositories, enemas, some prescription medications

PD Non-motor Symptoms

- Problems with urination ★★
- Medical terminology: Frequency, urgency, or incontinence
- How to check for this? Urologist may perform specialized testing
- Treatable? Sometimes
 - In men, may be prostate-related
 - In women, may be pregnancy/childbirth-related
 - **Urologist** may prescribe medications (Warning: side effects)
 - Pelvic floor physical therapy

PD Non-motor Symptoms

- Problems with sexual function ★
 - Bothersome but not often discussed; Usually loss of function, but can also develop hypersexuality
 - Men: Erectile dysfunction "ED" 60-80% of men, twice as common as healthy peers
 - Women: Decreased arousal and lubrication / Difficulty reaching orgasm
- How to check for this? Specialty evaluation by **urology or gynecology**
- Treatable? Sometimes
 - Medications, pelvic PT
 - Meds like Viagra/Cialis can cause OH

PD Non-motor Symptoms

- Drooling ★★★
- Medical terminology: sialorrhea
 - Increased saliva production + decreased swallowing
 - Mouth open, head forward = drooling
- How to check for this? n/a
- Treatable? Yes
 - Botulinum toxin
 - Atropine drops, glycopyrrolate drops, etc

PD Non-motor Symptoms

Category 2: Sleep-related problems

PD Non-motor Symptoms

- Dream enactment ★★★
- Medical terminology: REM Sleep behavior disorder (RBD)
 - REM sleep = dream sleep, restorative sleep
 - RBD also precedes motor symptoms of PD by many years
 - Person with PD may be unaware
 - May cause daytime fatigue
- How to check for this? Can confirm with sleep study
- Treatable? Yes
 - Melatonin (if mild), Clonazepam (works 80-90% of the time)
 - Note: PD meds may increase vivid dreams

PD Motor Symptoms

- Restless Legs ★★★
- Medical terminology: Restless Legs Syndrome (RLS)
 - Uncomfortable sensation with uncontrollable urge to move the legs
- How to check for this? n/a
- Treatable? Generally
 - Check for iron deficiency
 - PD meds (dopamine agonists, C/L usually help), rarely need other classes of RLS medications

PD Motor Symptoms

- Daytime sleepiness ★
- Medical terminology: Excessive daytime somnolence
 - Not necessarily related to PD
 - Check for sleep apnea, insomnia, RBD, medication effects
- How to check for causes of this? Sleep study, review medication list
- Treatable? Maybe
 - Treat identifiable causes
 - Stimulating medications (selegiline, SNRIs, etc)

PD Non-motor Symptoms

Category 3: Sensory / Miscellaneous

PD Non-motor Symptoms

- Reduced or absent sense of smell
- Medical terminology: hyposmia/anosmia
 - Precedes motor symptoms of PD by many years so many place blame elsewhere
 - May lead to decreased appetite
- How to check for this? n/a
- Treatable? No

PD Non-motor Symptoms

- Dry eyes ★
- Medical terminology: xerophthalmia
 - related to infrequent blinking
 - How to check for this? n/a
- Treatable? Yes
 - Artificial tears, fish oil?

PD Non-motor Symptoms

- Double vision ★★
- Medical terminology: diplopia
 - Usually perceived as blurry vision
 - Related to convergence insufficiency → eyes won't come together to focus up close
 - Can also be related to dry eyes
- How to check for this? **Ophthalmology** evaluation
- Treatable? Yes
 - Prism glasses

PD Non-motor Symptoms

- Waxy/oily, flaky skin ★
- Medical terminology: seborrheic dermatitis
 - Usually around forehead, nose, scalp, eyebrows
- How to check for this? n/a
- Treatable? Partially
 - Creams can be recommended by a **dermatologist**

PD Non-motor Symptoms

- Skin cancer
- Medical terminology: Melanoma
 - 2-7x higher risk in PD
- How to check for this? Annual skin exam by **PCP or dermatologist**

PD Non-motor Symptoms

Category 4: Neuropsychiatric

PD Non-motor Symptoms

- Low mood ★★☆☆
- Medical terminology: Depression
 - Can be hard to diagnose – symptom overlap
 - Affects 40% of those with PD
 - It's chemical
- How to check for this? Screening questionnaire
- Treatable? Yes
 - Holistic approach
 - Antidepressants
 - May need to consult with a psychiatrist if symptoms are not responding

PD Non-motor Symptoms

- Worry, nervousness ★★☆☆
- Medical terminology: Anxiety
 - Not tied to disease progression
 - Affects 40% of those with PD
 - It's chemical
 - May be an 'off' phenomena related to PD meds
- How to check for this? Screening questionnaire
- Treatable? Yes
 - Avoid triggers like sensory overload
 - Medications; may need to consult with a psychiatrist

PD Non-motor Symptoms

- Loss of motivation, disinterest ★
- Medical terminology: Apathy
 - May or may not be related to depression or cognitive impairment
 - Frustrating for caregivers
- How to check for this? Family report
- Treatable? Somewhat
 - Holistic approach
 - External motivation
 - Exercise
 - Sometimes medications

PD Non-motor Symptoms

- Problems with memory or thinking
- Medical terminology:
 - Mild cognitive impairment- not severe enough to interfere with work or home life
 - Dementia – interferes with work or home life
 - 50% affected
 - Not like Alzheimer's; usually affects concentration, planning, decision-making, multi-tasking, word-finding, processing speed
- How to check for this? Clinic screen or neuropsychological testing
- Treatable? Not generally

PD Non-motor Symptoms

- Seeing things that are not there or believing things that are not true ★★
- Medical terminology: hallucinations, delusions, psychosis
 - Only 20-30% experience these and severity ranges from mild to severe
 - More common in those with cognitive impairment
 - More common when ill
- How to check for this? Patient and caregiver report
- Treatable? Generally
 - Review current medication list
 - Generally only treat if insight is lost
 - Seroquel/quetiapine, Nuplazid/pimavanserin, Clozaril/clozapine

PD Non-motor Symptoms

- Impulsive behavior ★★☆☆
- Medical terminology: Impulse Control Disorder (ICD)
 - Compulsive shopping, gambling, computer use
 - Hypersexuality/sexual preoccupation
 - Person with ICD often has limited insight
 - Underreported
- How to check for this? Patient and caregiver report
- Treatable? Generally
 - Might be a PD symptom but often a medication side effect

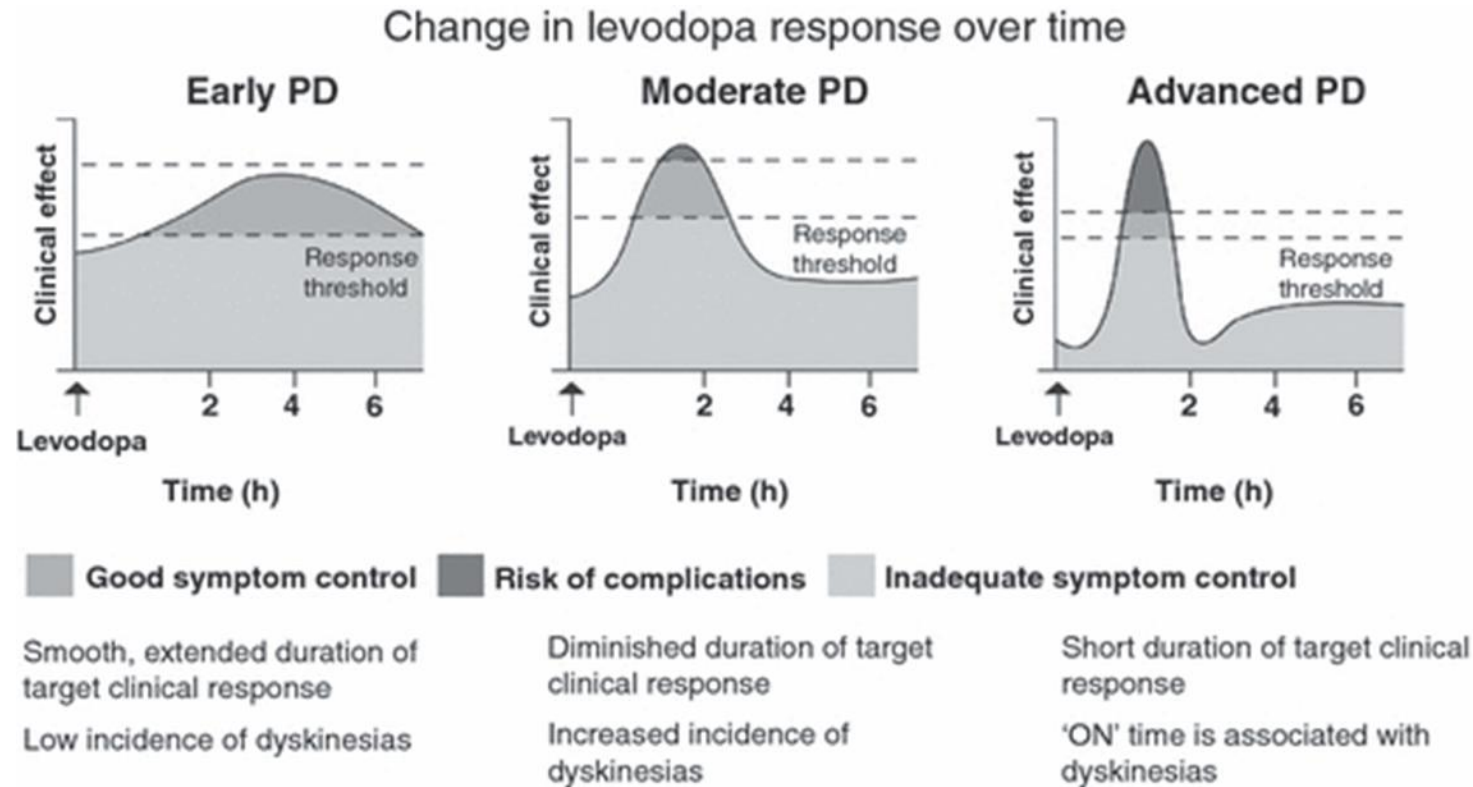
Summary of PD Symptoms

- 1) What are your bothersome PD symptoms?
- 2) Which of your symptoms are expected to get better with PD medicine?
- 3) Which are best treated by a different type of medication or doctor?
- 4) Which of your symptoms are actually medication side effects and not PD symptoms (ie dyskinesia)?

What To Expect from Parkinson's Medications

- It depends what you are taking and how long you have had PD
- Generally, PD medication helps the motor symptoms only
 - Response is not 100%
- Early in the course of PD, you should not expect to feel ON/OFF; you just take it and gauge benefit
- Eventually, you probably will note ON/OFF... this is when your reporting becomes CRITICAL (we only see a snapshot in clinic)

Change in carbidopa-levodopa (Sinemet) Response Over Time



Patient Journal

- Do you think your medicine is working? Does it help with your motor symptoms (tremor, stiffness/cramping, slowness, walking)?
 - To what extent?
- Do you ever lose benefit before the next dose is due? “Wearing off”
 - Timing
- Do you have side effects? Nausea, lightheadedness, dyskinesia, impulse control problems?
 - Timing
- Your doctor will adjust the dose depending on your report and their observations
 - May adjust # of pills per dose, frequency of doses, or change medication totally
 - Maximum dose is based on side-effects

General Tips- Write down your questions

- And give your list to your doctor at the beginning of the visit

General Tips- Bring your care partner(s)

- Someone who knows you well to help share observations
- Someone who is going to help you remember what was discussed during the appointment

General Tips- If Dr. seems short on time...

- You may be able to have short but frequent visits where you address one or two items and save the rest for next time
- Sometimes academic/research centers, nurse practitioners, or physician assistants have longer appointment slots

General Tips- Remind your doctor

- To order PT/OT/Speech therapy
 - we forget when you had your last refresher

General Tips- Driving

- Research shows that doctors are not very good at predicting ability to drive safely
- Sometimes, neither are patients with neurologic disorders
- Other observers in the car are often best
- If in question, bring it up and your Dr. can direct you to a driving evaluation

General Tips- Exercise

- The closest thing we have to a panacea for Parkinson Disease
- Treat it like it's your job; do it even if you hate it
- Just about everything is beneficial- choose what you like and will do

General Tips- Movement specialist

- If you are doing well, you may choose to have your primary care Dr or a general neurologist manage your Parkinson Disease
- If you are not, consider traveling to see a movement disorders specialist

FAQ: Research

- Stem cells: Research only, no current clinical use
- Vaccines/antibody studies: Research ongoing
- Nilotinib: Leukemia drug (tyrosine kinase inhibitor)
 - Studies completed: ineffective

FAQ: Marijuana/cannabinoids

Existing research shows no clear benefit in PD

- 2014 AAN guideline: Oral cannabis extract probably ineffective for treating levodopa-induced dyskinesias

Possible benefits: anxiety, sleep, pain

Possible Risks: low blood pressure dizziness, hallucinations, sleepiness/drowsiness

Challenges

Questions?



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