Coordinating Healthcare in Parkinson's Disease: How to Prepare for Medical Appointments

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Renew! Retreat

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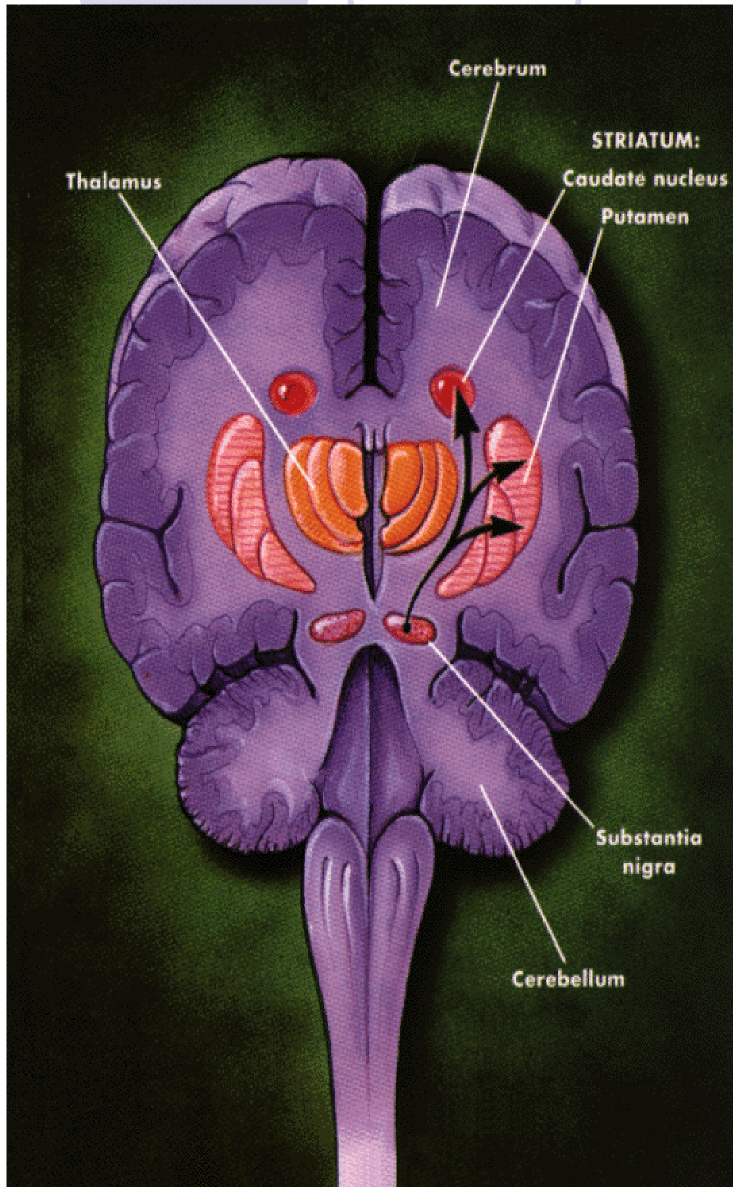
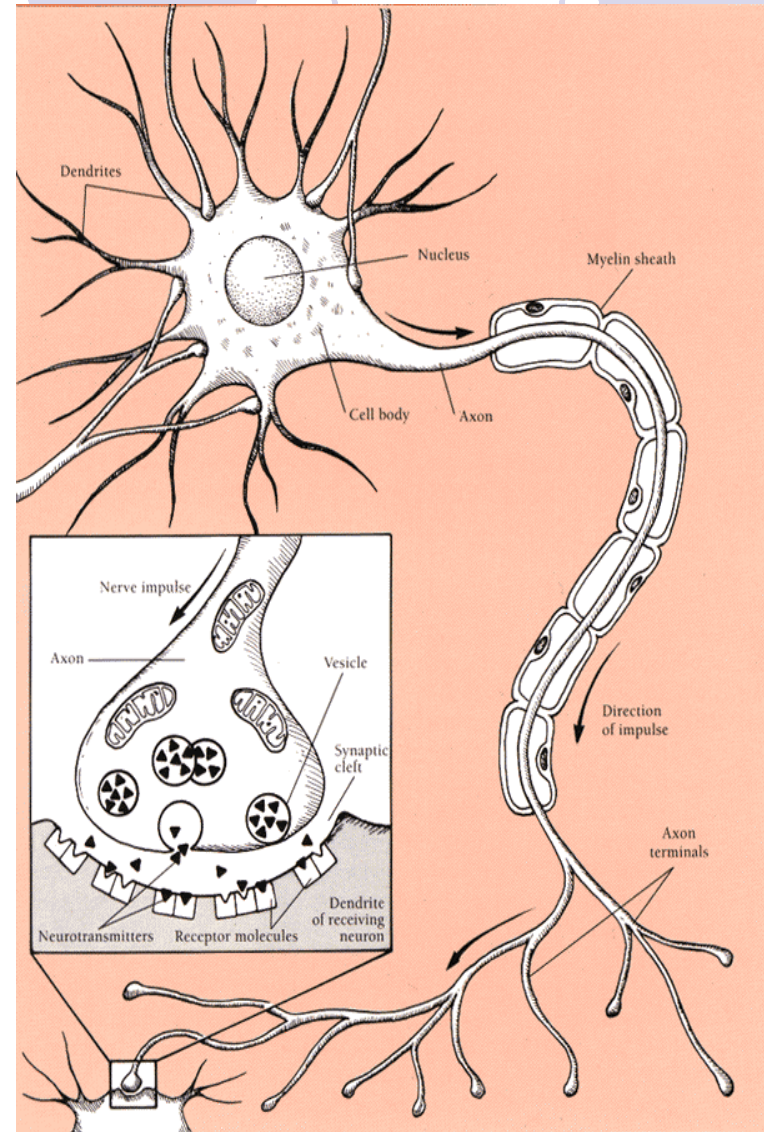
What is Parkinson's Disease?

- A **progressive**, **chronic**, complex disorder of the nervous system
- Caused by the **slow, gradual**, degeneration of cells that produce dopamine
- **Dopamine** is a Neurotransmitter (chemical messenger)
- Dopamine is produced by the cells within the **Substantia Nigra** (black substance)

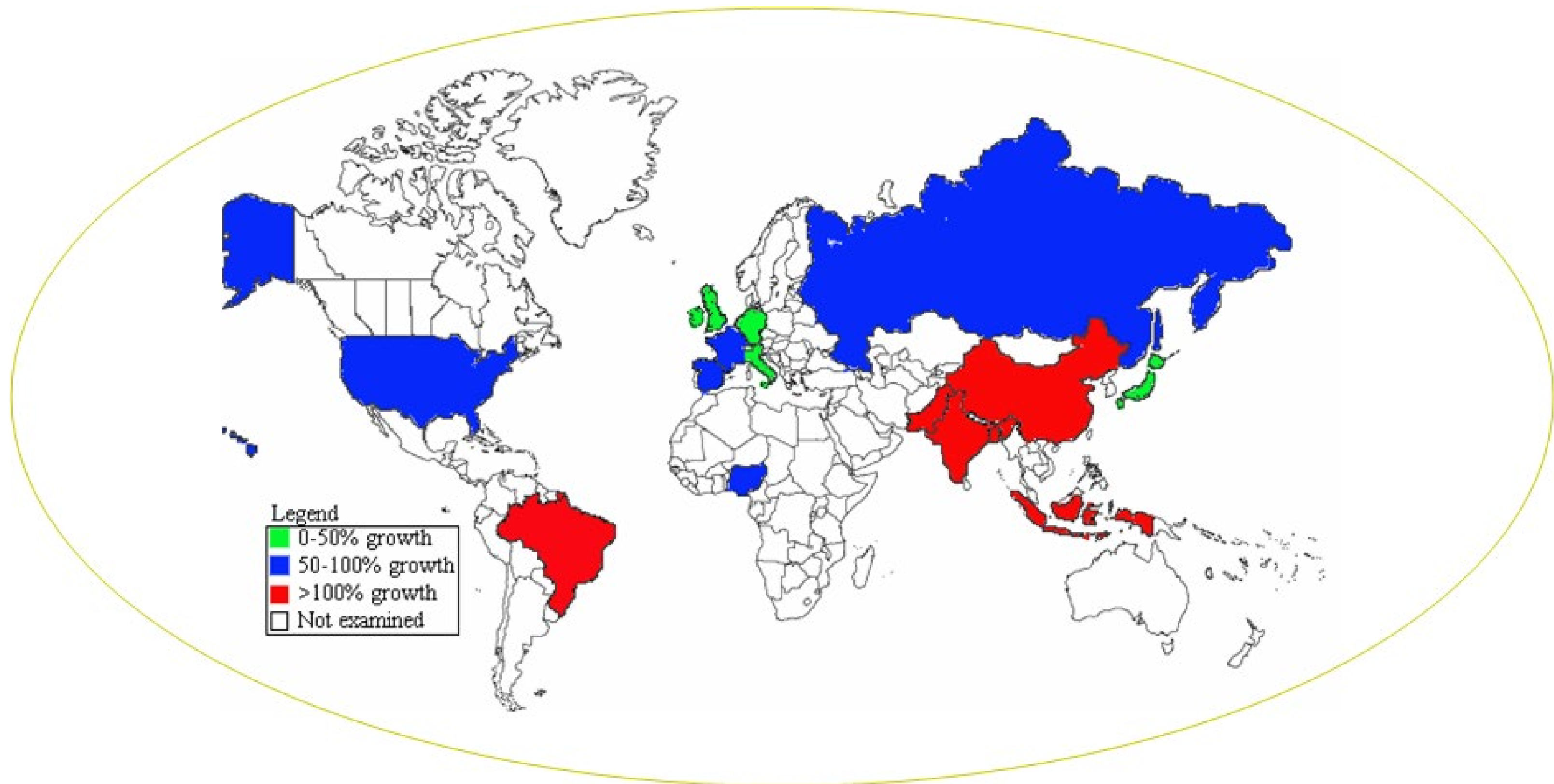
Dopamine System in Human Brain





The burden of Parkinson disease is growing

Change in number of people with Parkinson disease in the world's most populous nations from 2005 to 2030*



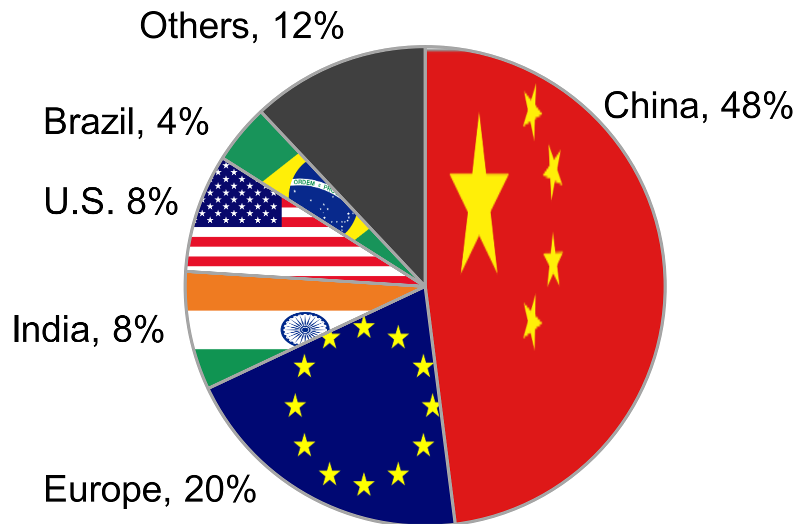
*Among individuals over 50 in the world's ten most and Western Europe's five most populous nations

Source: Neurology 2007;68:384-6

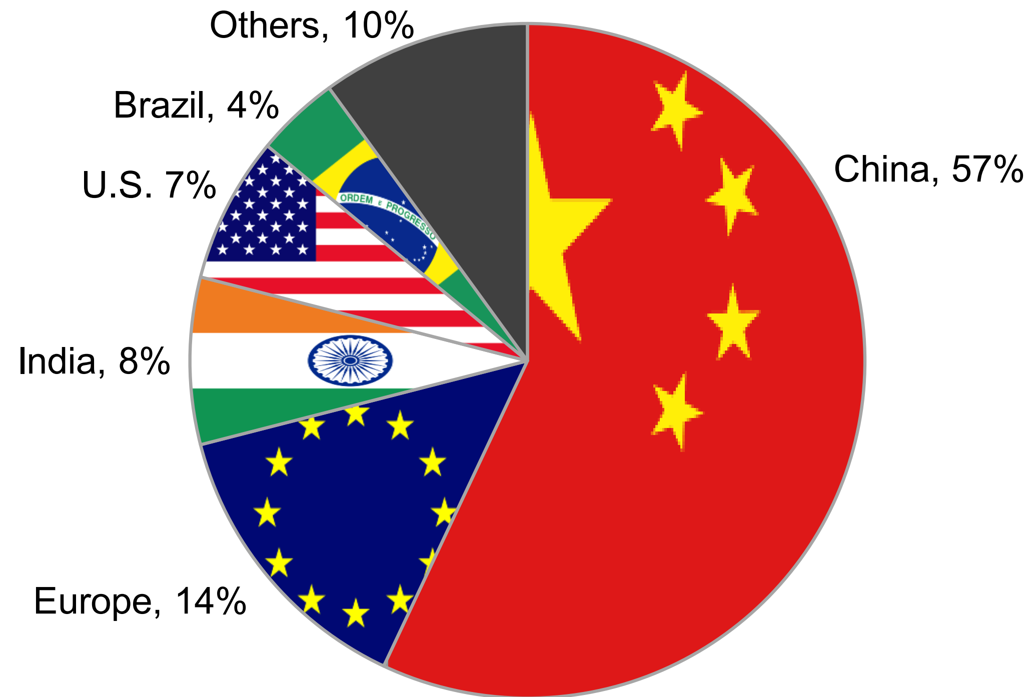
The burden affects the whole world

Distribution of individuals with Parkinson disease by country, 2005 and 2030*

2005
100% = 4.1 million individuals



2030
100% = 8.7 million individuals



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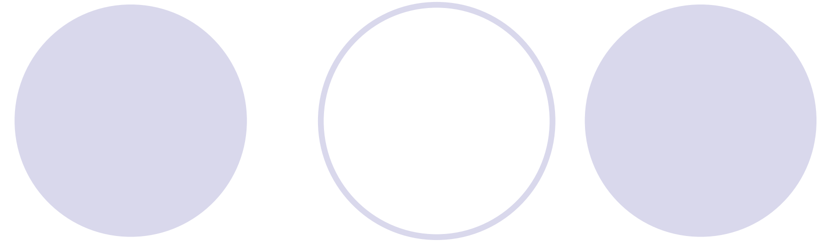
Motor Symptoms



- Tremor
- Rigidity
- Bradykinesia
- Impaired Balance (often later in disease)

Non-Motor Signs of PD

- Less likely to affect movement, coordination or mobility
- Can be categorized in 4 areas:
  - Dysautonomia
  - Sleep Abnormalities
  - Mood Changes
  - Cognitive Issues
- May arise during different times throughout the trajectory of PD
- Part of the **“salad bar”** mentality of the disease - no two patients are alike

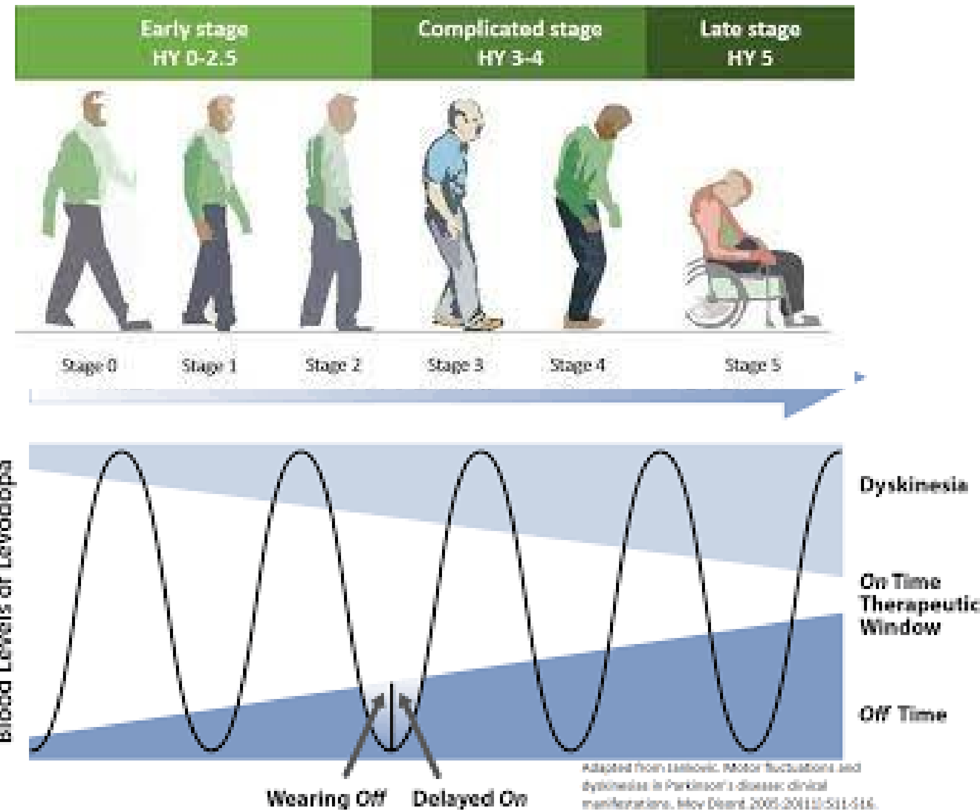
Motor Symptom Medications

- MAO-B Inhibitors
  - Azilect (rasagiline)
  - Eldepryl/Zelepar (selegiline)
  - **Xadago (safinamide)**
- Dopamine Agonists
  - Requip (ropinerole) IR and ER
  - Mirapex (pramipexole) IR and ER
  - Neupro (rotigotine) patch
  - Apokyn (apomorphine) injection
  - Kynmobi (apomorphine) sublingual
- Levodopa
  - Sinemet (carbidopa/levodopa) IR and ER
  - Stalevo (carbidopa/levodopa/entacapone)
  - Parcopa
  - **Rytary (carbidopa/levodopa capsules)**
  - **Inbrija (inhaled carbidopa/levodopa)**
  - **Duopa (carbidopa/levodopa enteral suspension)**
- COMT-Inhibitors
  - Comtan (entacapone)
  - Tasmar (tolcapone)
  - **Ongentys (opicapone)**
- Anticholinergics
  - Artane (trihexyphenidyl)
  - Cogentin (benztropine)
- Amantadine
  - Symmetrel
  - **Osmolex (amantadine IR + ER)**
  - **Gocorvi (amantadine ER)**

<u>**May be used independently or together!**</u>

Healthcare Needs in PD Change Over Time

- Early
  - Education
  - Mild symptom control
  - “Proactive” therapies
- Mid-Stage
  - More focused symptom control, motor fluctuation management
  - Specialty care referral
- Advanced
  - Cognitive issues
  - Activities of Daily Living assistance



Advanced Therapeutics

Surgical therapies are usually indicated when medication options have been exhausted for symptom control.

- Thalamotomy/Pallidotomy
  - Permanent, effective for specific symptoms
- Deep Brain Stimulation
  - Reversible, adjustable
- MRI Focused Ultrasound
- Continuous Levodopa Therapies
  - Duopa, Subcutaneous treatments on horizon

What is Parkinson's and What's Not?

- PD is **slowly progressive**
- Sudden, overnight or over several days progression is usually **not** characteristic of PD
- Infection, drug interactions or other medical issues can cause PD symptoms to worsen quickly
- Cognitive changes, hallucinations, increased tremor or balance issues are the "usual suspects"

The Primary Care Provider

- Should be the “hub” of all medical issues
- The person that each specialist reports to
- Request that all records are sent to the PCP
- Geriatricians specialize in comorbidities/polypharmacy

Ensure that this is a trustworthy, accessible, local, comfortable relationship!

The Neurology Team

- Primary providers for Parkinson's treatment
- Will often refer out for other specialty care
  - Therapy, Psychiatry, Urology, GI, Sleep
- Should also be advised of **all** medication changes
- Movement Disorder Specialist
  - May be **primary** or **once yearly** consultant
- Most important is **competency**, **accessibility** and ability to **communicate**
- Second opinion ok!
- People with PD benefit from **comprehensive care team**

Typical Neurology Visit

- History of Present Illness
  - “How are things going?”
  - Following up on prior action items
  - Discussion of new problems/concerns
  - Best time to get questions on the table
- Review of Systems
  - Often asking about cognition, mood, sleep, swallowing, speech, constipation, urinary issues
- Neurologic Exam
- Discussion of new plan

Unified Parkinson's Disease Rating Scale

Objective rating scale

- Measures motor and non-motor symptoms, activities of daily living and motor complications
- Used to determine level of motor disability and impact of treatment on symptoms
- Part III – Motor exam
  - Often done during each visit or periodically to evaluate regiment changes
- Also used in clinical trials to determine efficacy of treatments

MDS UPDRS Score Sheet

Hoehn & Yahr Staging

	Early PD		Mid-stage PD	Advanced PD	
Stage of Parkinson's Disease	1	2	3	4	5
Severity of Symptoms	MILD Symptoms of PD are mild and only seen on one side of the body (unilateral involvement)	MILD Symptoms of PD on both sides of the body (bilateral involvement) or at the midline	MODERATE Symptoms of PD are characterized by loss of balance and slowness of movement	SEVERE Symptoms of PD are severely disabling	SEVERE Symptoms of PD are severe and are characterized by an inability to rise
	SYMPTOMS Tremor of one hand Rigidity Clumsy Leg One side of the face may be affected, impacting the expression	SYMPTOMS Loss of facial expression on both sides Decreased blinking Speech abnormalities Rigidity of the muscles in the trunk	SYMPTOMS Balance is compromised Inability to make the rapid, automatic and involuntary adjustments All other symptoms of PD are present	SYMPTOMS Patients may be able to walk and stand unassisted, but they are noticeably incapacitated Patient is unable to live an independent life and needs assistance	SYMPTOMS Patients fall when standing or turning May freeze or stumble when walking Hallucinations or delusions.

PD ParkinsonsDisease.net / Stages of Parkinson's Disease

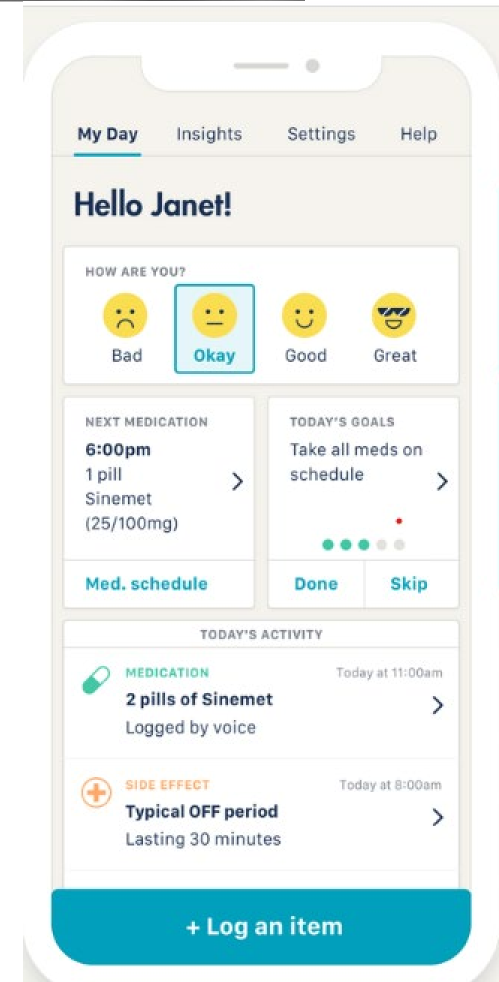
Stage	Modified Hoehn and Yahr Scale
1	Unilateral involvement only
1.5	Unilateral and axial involvement
2	Bilateral involvement without impairment of balance
2.5	Mild bilateral disease with recovery on pull test
3	Mild to moderate bilateral disease; some postural instability; physically independent
4	Severe disability; still able to walk or stand unassisted
5	Wheelchair bound or bedridden unless aided

How can I make the most of my visit?

- Be organized
- Ask questions
- Take notes
- Bring a partner

Be Organized!

- Keep a medication list that is easy to access and update
- Organize pill containers
- Know provider names/contact information – make them easy to locate
- Bring DBS programmers/device pumps to visits
- Request copies of your medical records and keep your own file
  - Power of Attorney
  - Advanced Directive
  - Emergency Contacts
- Use technology!
  - StrivePD
  - Health Apps

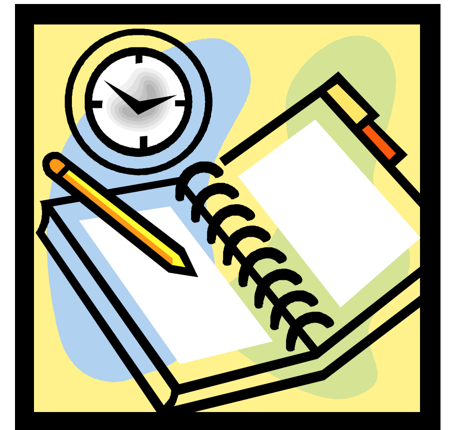


Ask Questions!

- Know the who, what, when, why and how of medicines
  - Who prescribed?
  - What other things interfere with it?
  - When do I take it?
  - Why am I taking this?
  - How much?
- Ask for explanation of choices
  - Will this make PD better, worse or not affect it at all?
  - Do I really need this?
- Call the office!
  - If starting a new medication, experiencing a side effect, having a procedure or joining a research study, let your healthcare team know.
- Care Management offered by some insurance plans
  - Helps to manage care between doctor's visits
  - Access to health education, nursing and pharmacy monitoring

Take Notes

- During and outside provider visits
- Keeping a diary on a calendar can help to track symptoms relative to time of day/medication dosing
- Write down questions as they arise
- Keep everything in a dedicated notebook and bring it to visits



Carepartners

- Keep someone in the loop with your medical affairs
- Can be spouse, friend, family member
- Bring them to visits or have a talk after each one
- “Two heads are better than one!”

Hospitalization in PD

- Reasons for ER visit/hospital stay:
  - Infection
  - Cognitive changes (delirium, hallucinations)
  - Falls/injuries
  - Scheduled surgery

- People with PD hospitalized **50% more than their peers**
- Often causes **disease worsening**
  - Medications given off schedule
  - Contraindicated drugs administered
  - Therapy delayed or ineffective

Be Aware in Care!

1. *Aware in Care* Bag—Pack your bag with your Parkinson's medication and your Aware in Care materials
2. Hospital Action Plan—Read about how to prepare for your next hospital visit—whether it is planned or an emergency
3. Parkinson's Disease ID Bracelet—Wear your bracelet at all times in case you are in an emergency situation and cannot communicate
4. Medical Alert Card—Fill in your card with emergency contact information and place in your wallet
5. Medication Form—Complete this form and keep copies

Taking a more active role in your health care can help **both** you and your medical team to have smooth transitions and good communication.

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American Parkinson Disease Association

Seppi, K., Weintraub, D., Coelho, M., et al. (2011). The Movement Disorder Society Evidence-Based Medicine Review Update: Treatments for the non-motor symptoms of Parkinson's disease. *Movement Disorders*, 26(3) 399-406.