# Navigating Healthcare Needs in Parkinson's Disease

Arita McCoy, MSN, CRNP
Johns Hopkins Parkinson's Disease and Movement Disorder Center

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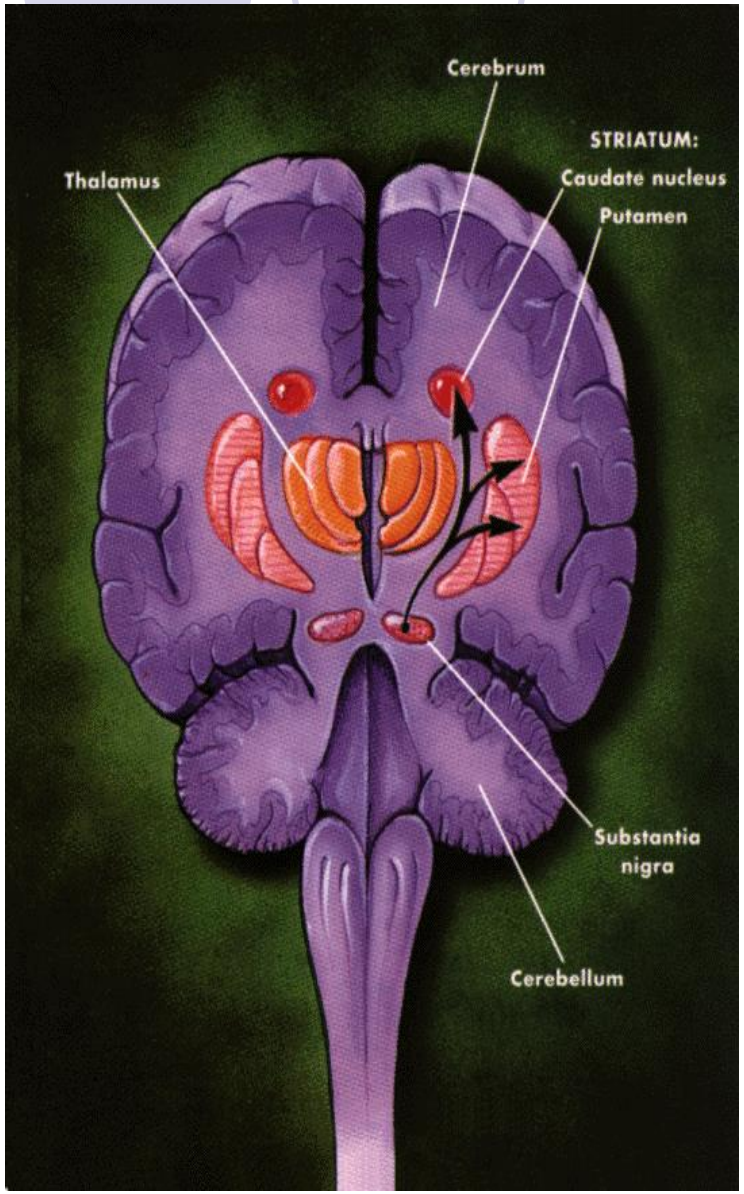
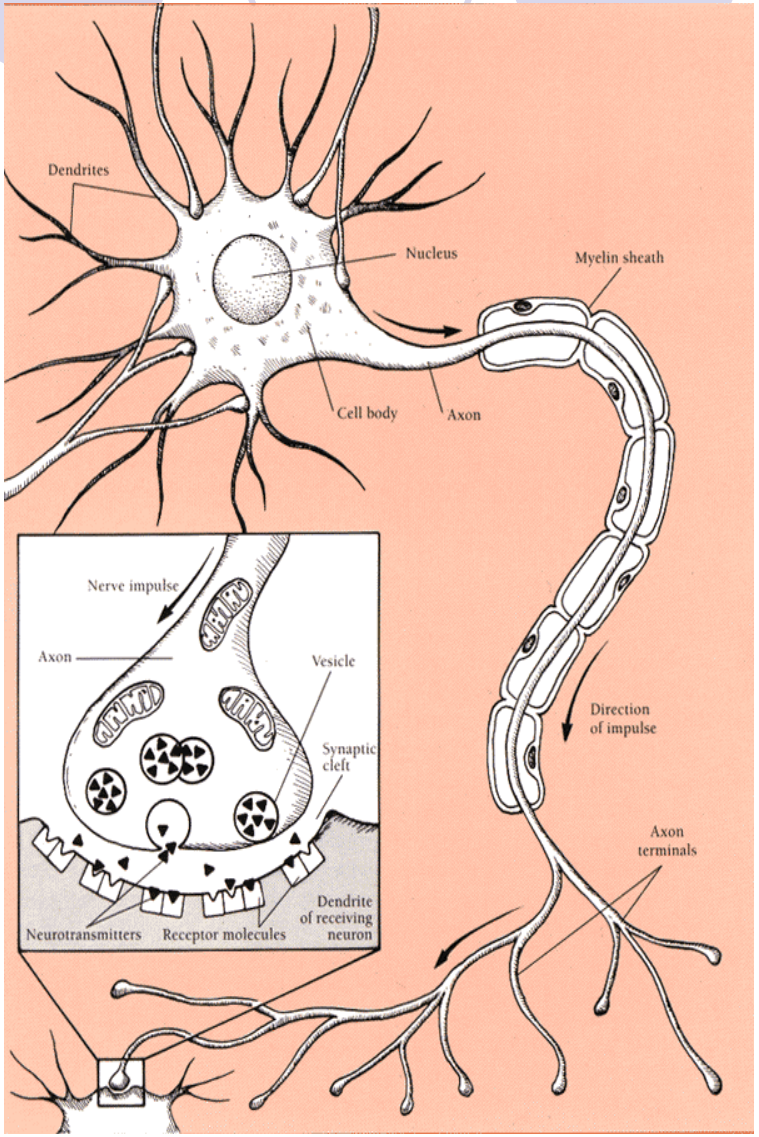
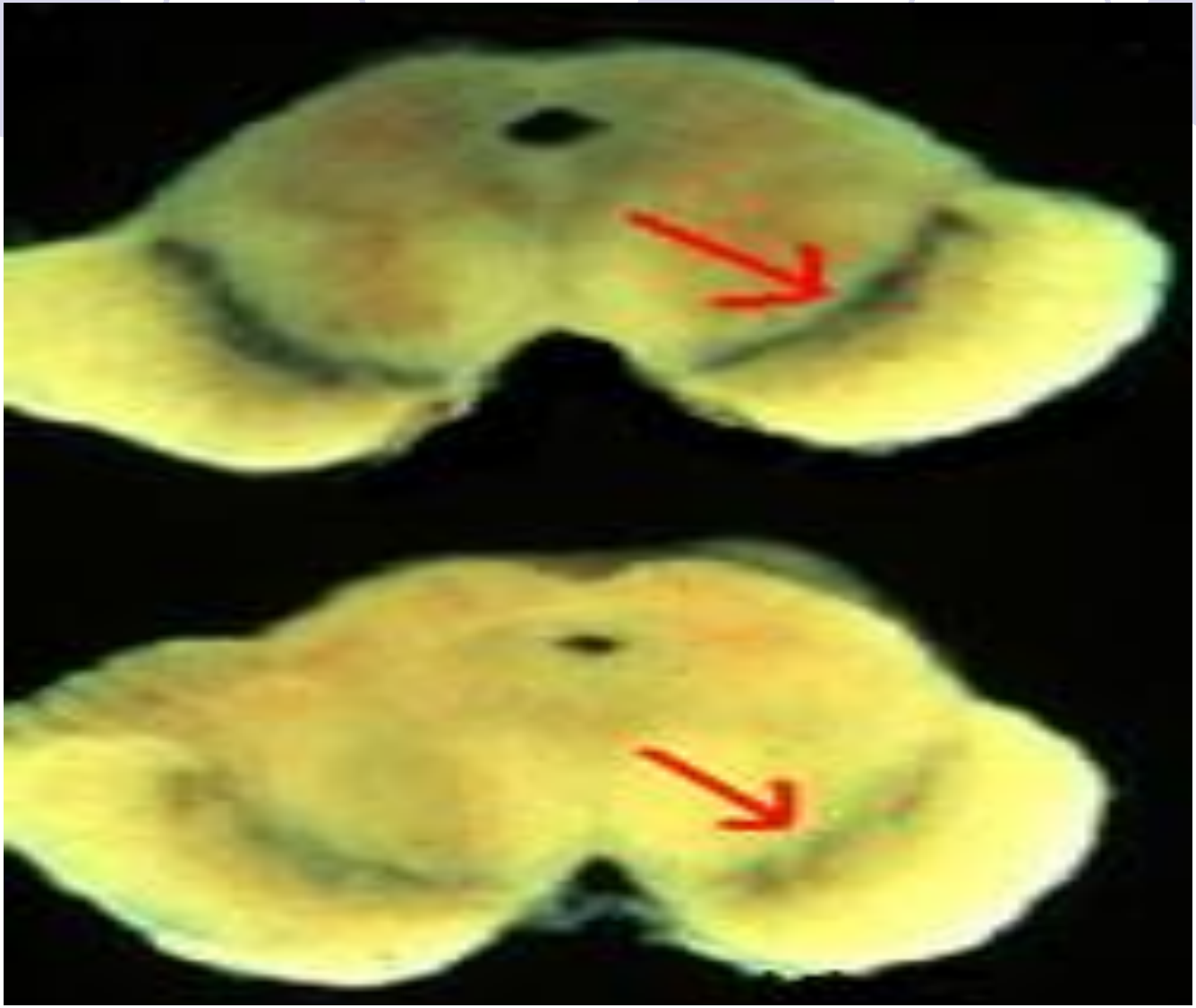
# What is Parkinson's Disease?

- 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



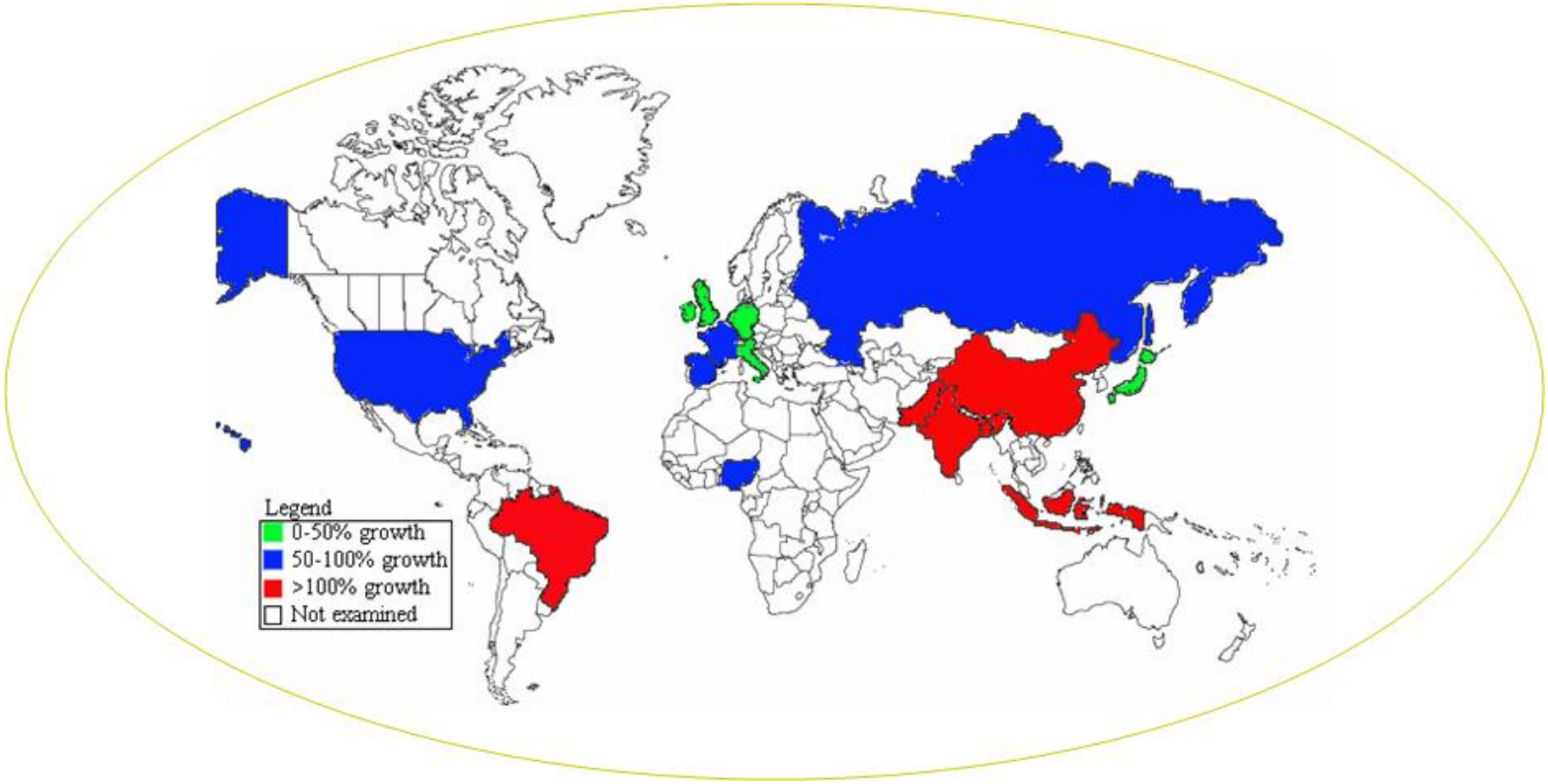


# Incidence of Parkinson's Disease

- Parkinson's Disease affects about **1,000,000** Americans
- **50,000-60,000** Americans are diagnosed each year
- Average age of onset is **55-65 years of age**
- **5-10%** of patients are **under** the age of **40**
- Present worldwide in all races and socioeconomic groups
- Slightly higher incidence in men

# 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***



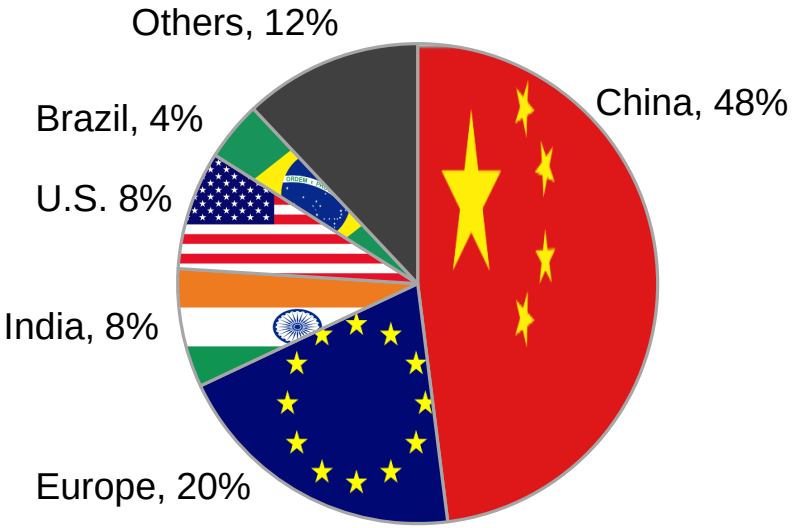

*Among individuals over 50 in the world's ten most and Western Europe's five most populous nations

Source: Neurology 2007;68:384-6

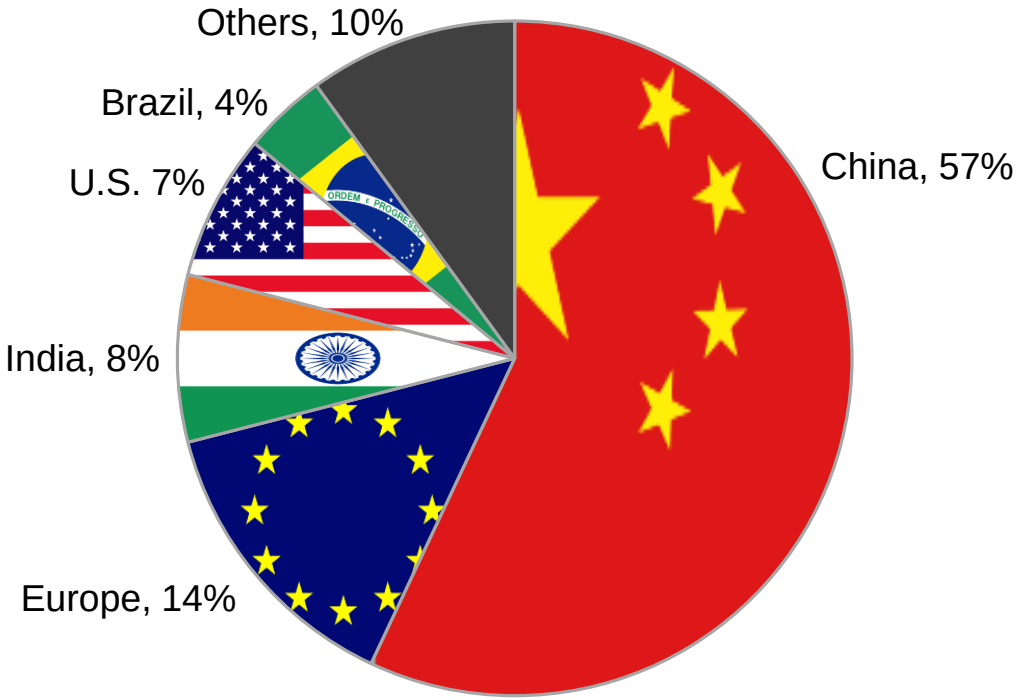
# The burden affects the whole world

**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

# Early (Prodromal) Symptoms

Some of these non-motor symptoms appear before the first sign of Parkinson's disease develops

- REM Sleep Behavior Disorder
- Loss of sense of smell
- Constipation
- Mood Disorders
  - Anxiety
  - Depression


Better understanding of these can improve earlier diagnosis/intervention

# During/After PD Diagnosis

**Dysautonomia**

- Constipation
- Urinary Urgency/Frequency
- Heat Intolerance
- Increased Perspiration
- Orthostasis/Low Blood Pressure
- Sexual Functional Problems
- Decreased Smell Ability
- Altered Taste

**Sleep Abnormalities**

- REM Sleep Behavioral Disorder
- Insomnia
- Excessive Daytime Sleepiness
- Restless Leg Syndrome

**Mood Changes**

- Depression
- Anxiety
- Impulse Control Disorder

**Cognitive Issues**

- Bradyphrenia (Slowness of thinking)
- Short Term Memory Loss
- Difficulty Multitasking

**Other Symptoms**

- Fatigue
- Speech Difficulties
- Pain
- Double Vision
- Micrographia (Small Handwriting)

# Later Stage PD Symptoms

**Dysautonomia**

- Swallowing Dysfunction
- Excessive Salivation/Drooling
- Urinary Incontinence
- Constipation with Bowel Obstruction

**Mood/Cognitive Changes**

- Dementia
- Psychosis (Hallucinations and Delusions)
- Apathy

**Sleep Disorders**

- Excessive Daytime Sleepiness
- Inability to return to sleep
- Frequent Night Awakening

# Medications

- **MAO-B Inhibitors**
  - Azilect (rasagiline)
  - Eldepryl (selegiline)
- **Dopamine Agonists**
  - Requip (ropinerole) IR and ER
  - Mirapex (pramipexole) IR and ER
  - Neupro Patch
  - Apokyn (apomorphine)
- **Levodopa**
  - Sinemet (carbidopa/levodopa) IR and ER
  - Stalevo (carbidopa/levodopa/entacapone)
  - Parcopa
  - Duopa
  - Rytary
- **Anticholinergics**
  - Artane (trihexyphenidyl)
- **COMT-Inhibitor**
  - Comtan (entacapone)
- **Amantadine**
  - Symmetrel

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

# Therapy

- Physical Therapy
  - LSVT BIG, PWR!, Balance/Gait Training
- Occupational Therapy
  - LSVT BIG, home modification, assistive devices
- Speech Therapy
  - LSVT LOUD, Swallow Evaluation, Cognitive Training

# Surgical Interventions

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

- Deep Brain Stimulation
  - Reversible, adjustable
- Thalamotomy/Pallidotomy
  - Permanent, less frequently done
- Duopa
  - Newest treatment option for levodopa administration

# Healthcare Needs in PD Change Over Time

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

# The Primary Care Physician

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

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

# The Neurologist

- Primary person 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**

# 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"

# 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

# What's in the Kit?


5. Parkinson's Disease Fact Sheet—Share the facts about Parkinson's with hospital staff and ask that a copy be placed in your chart

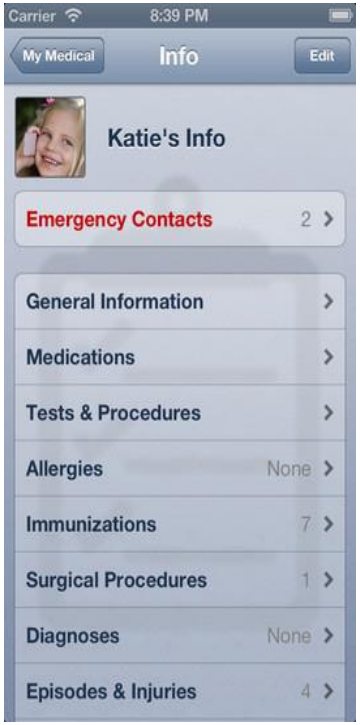

6. I Have Parkinson's Reminder Slips—Share vital information about Parkinson's disease with every member of your care team in the hospital


7. Thank You Card—Present this card to a staff member who provides high quality care


8. Magnet—Use this magnet to display a copy of your Medication Form in your hospital

# Be Organized!

- Keep a medication list that is easy to access and update
- Organize pill containers
- Know your physician's names/contact information – make them easy to locate
- Request copies of your medical records and keep your own file
  - Power of Attorney
  - Advanced Directive
  - Emergency Contacts
- Use technology!
  - Mobile Applications

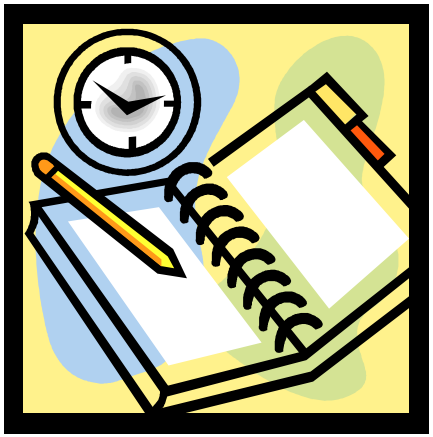



# Ask Questions!

- 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 physician 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 spiral notebook and bring it to visits.



# When Additional Help is Needed

- Caregiver Strain
  - Multidimensional Caregiver Strain Index (MCSI)
- Safety Issues
  - Falls, mobility challenges, balance
- Cognitive Problems
  - Memory causing medication neglect
  - Hallucinations/delusions causing behavioral challenge

# When Additional Help is Needed

- Bring in “care team”
  - Caregivers, family, friends
- Moving is a difficult decision for both parties
- Continuing care retirement community
  - Great option
- Not a “failure” of either party
- Realization that care or other medical issues is beyond what caregiver can provide
- Caregiving role stays the same – level and type changes
  - Advocate/overseer of care

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