

Optimizing Clinical Communication in Parkinson's Disease:

*Strategies for improving communication
between you and your neurologist*

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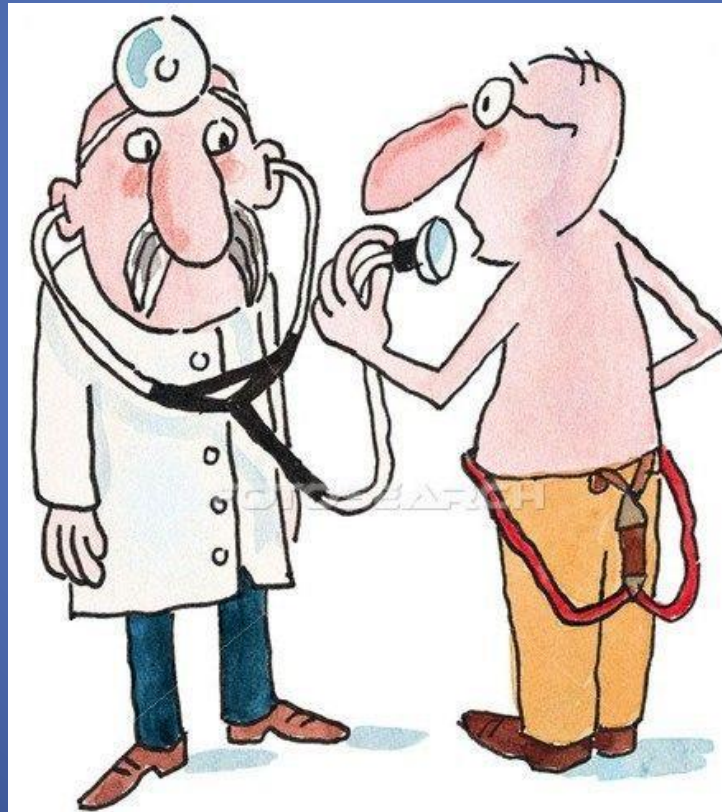
Learning Objectives

At the end of this presentation you should be able to:

1. Identify the common motor and non-motor symptoms of Parkinson's disease
2. Recognize the relationship between the timing of medications and the fluctuation of symptoms
3. List five strategies for improving communication with your neurologist

Managing Parkinson's disease can be challenging.

But you and your doctor can work together to improve your care by



communicating effectively.

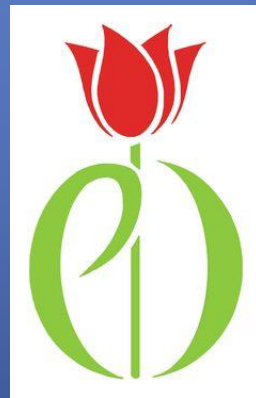
How can I communicate with my doctor?

Today we will discuss some strategies to improve communication with your doctor:

1. Pre-visit: Educate yourself about PD!
2. How to prepare for your visit?
3. What to do at the visit?
4. What to do *after* the visit?
5. What to do if there is an emergency?

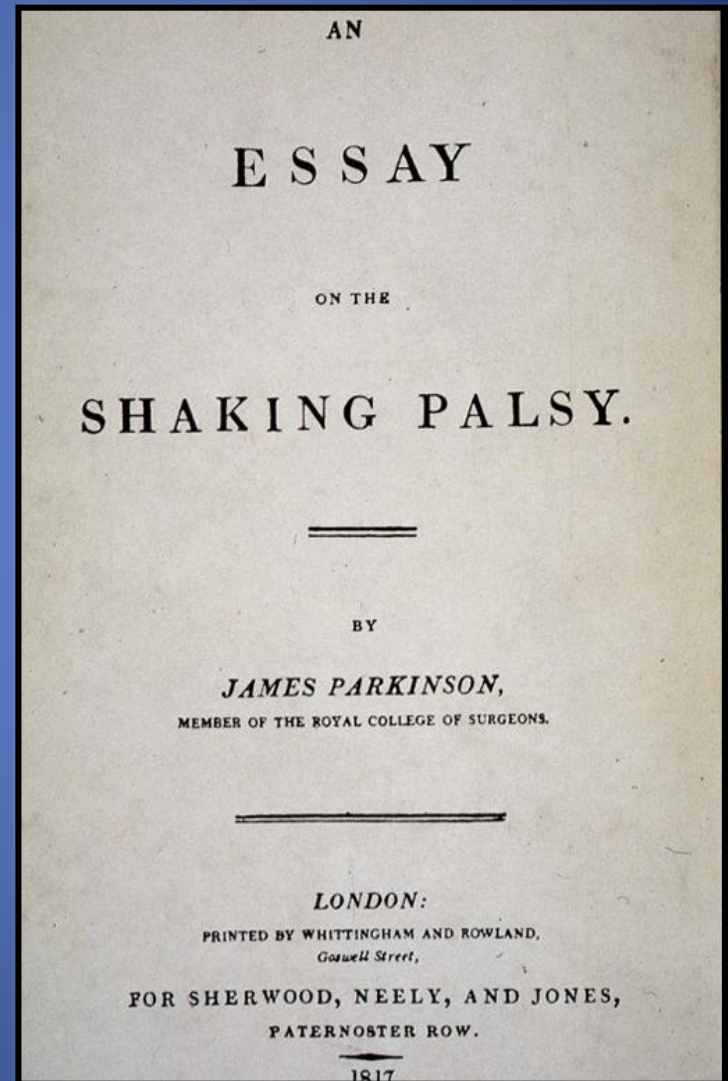
First things first!

1. Learn about Parkinson's disease



What is Parkinson's Disease (PD)?

- A chronic, progressive neurodegenerative disorder
- The second most common neurodegenerative disorder



Motor symptoms of PD

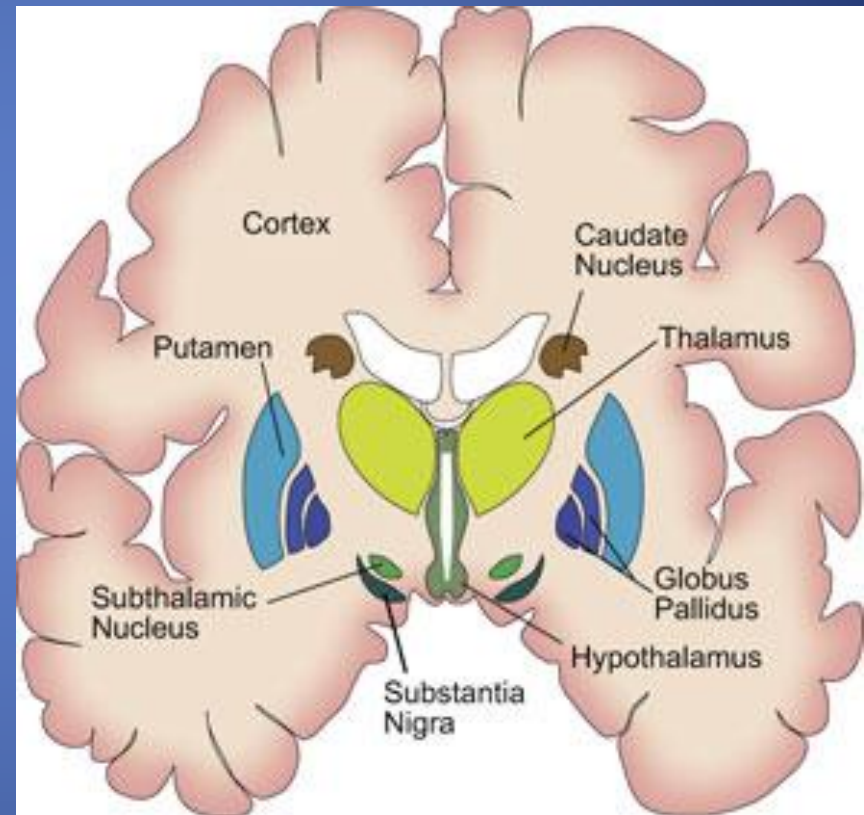
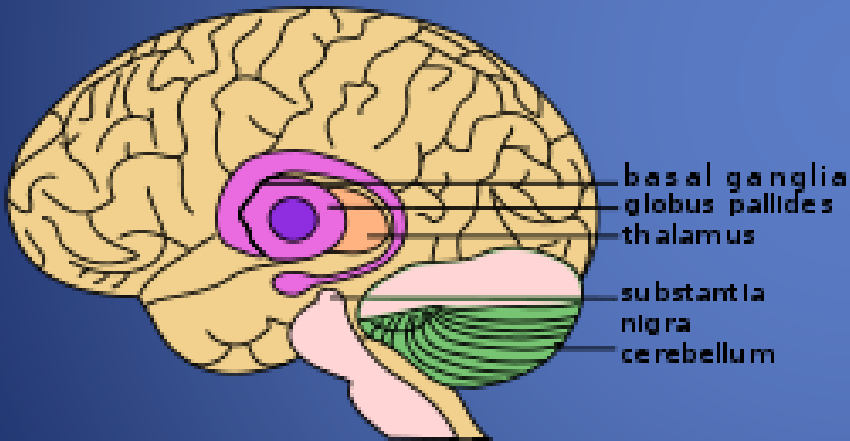
Cardinal MOTOR features:

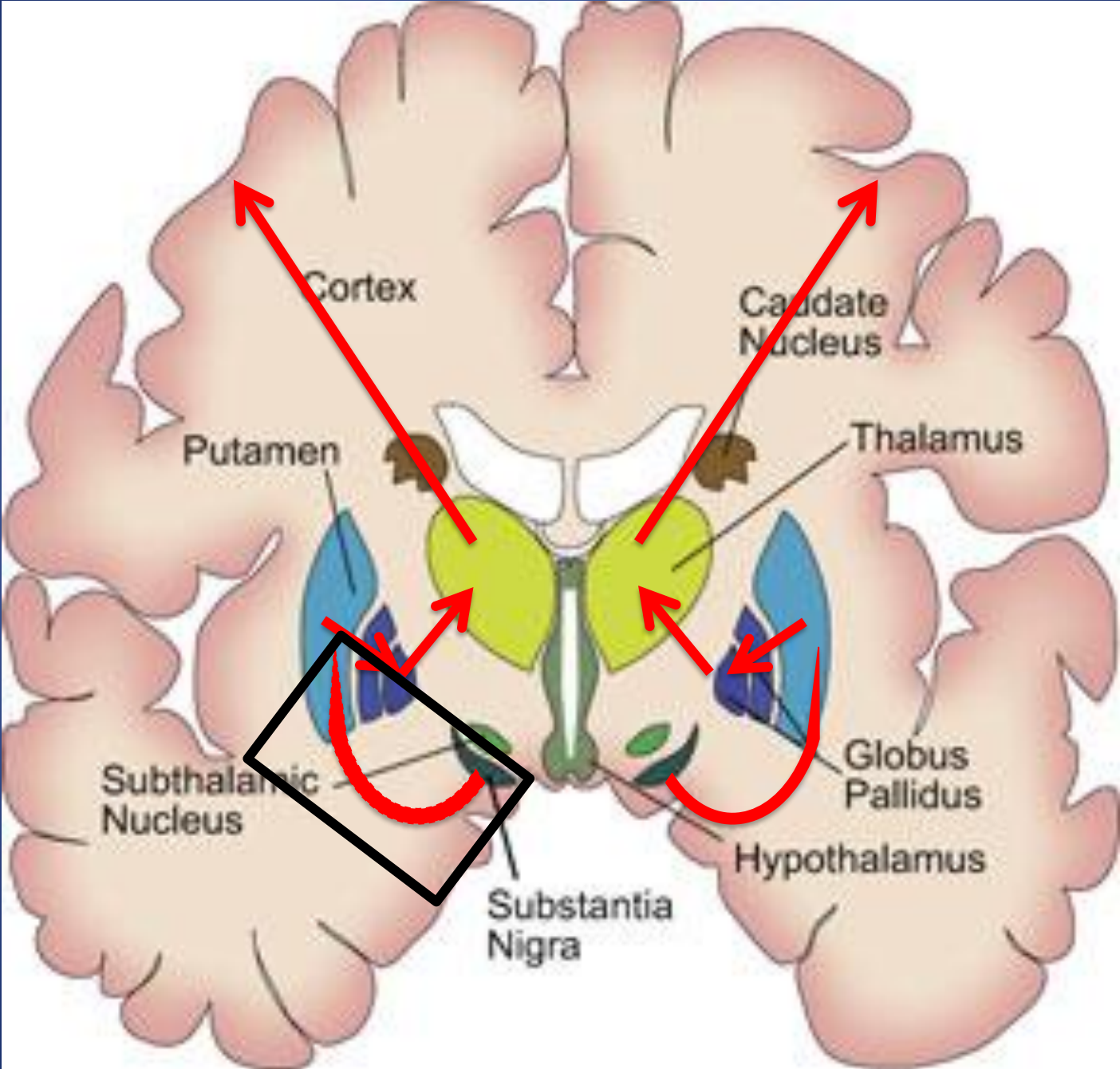
- 1) Rest tremor
- 2) Bradykinesia (slowness of movement)
- 3) Rigidity (stiffness)
- 4) Gait and balance disturbance

Other Common Motor features: Masked face, soft voice, flexed posture, small handwriting, shuffling walk, decreased arm swing when walking

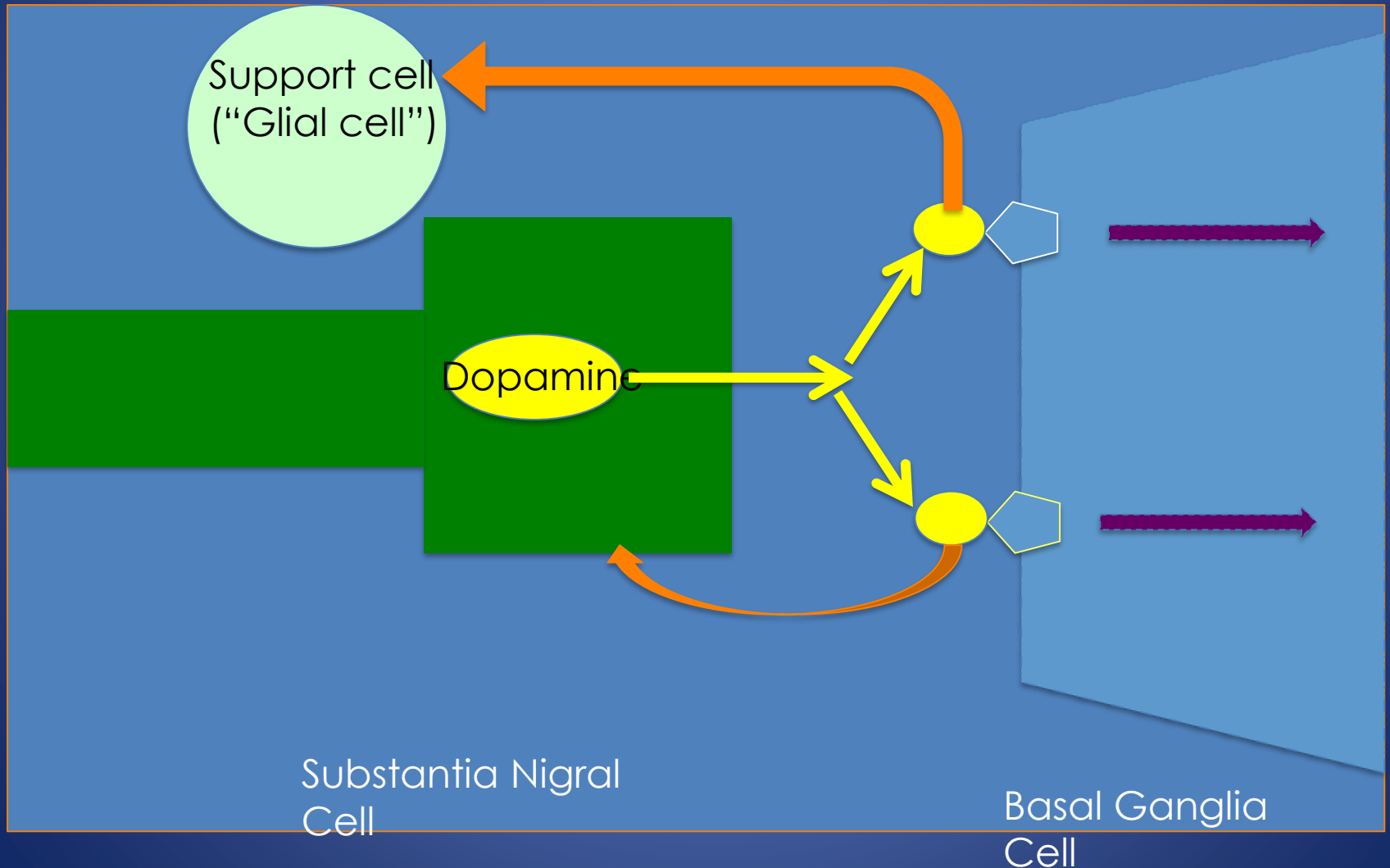
What causes the motor symptoms of PD?

Basal Ganglia and Related Structures of the Brain

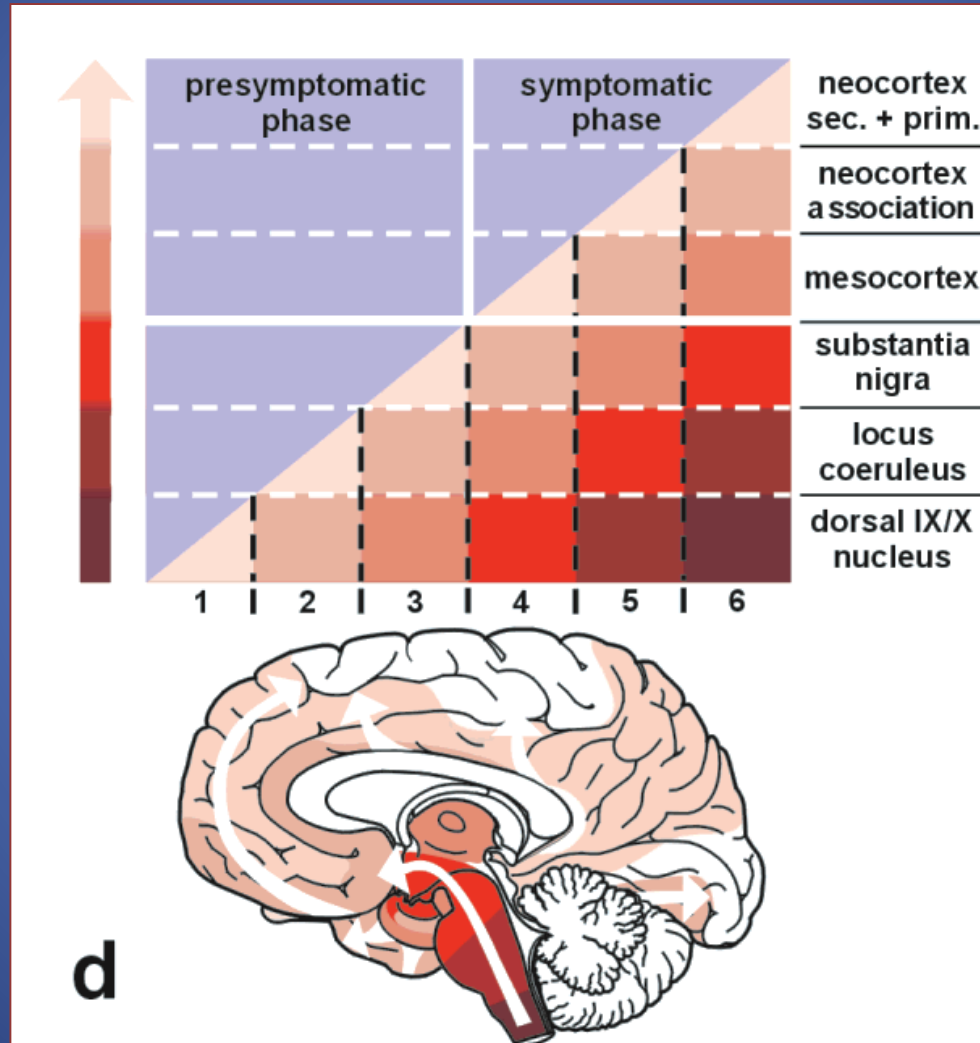




Cells from the Substantia Nigra supply dopamine



Parkinson's can affect other parts of the nervous system



Non-motor Features of PD

Gastrointestinal:

Constipation

Drooling

Swallow problems

Nausea/vomiting

Autonomic problems

Orthostatic hypotension

Urinary dysfunction

Sexual dysfunction

Excessive sweating

Sensory

Pain

Tingling

Smell loss

Neuropsychiatric symptoms

Depression

Anxiety

Hallucinations

Delusions

Cognitive decline

Dementia

Sleep problems

Insomnia

REM behavior disorder

Excessive sleepiness

Medications for Motor symptoms

Carbidopa-Levodopa

- Sinemet, Sinemet CR, Rytary, Parcopa, Duopa

Dopamine Agonists

- Pramipexole, Mirapex, Ropinirole, Requip, Rotigine, Neupro, Apomorphine

COMT Inhibitors

- Entacapone, Comtan, Stalevo, Tolcapone, Tasmara

MAO-b Inhibitors

- Azilect, Rasagiline, Selegiline, Eldepryl, Zelapar

Anti-Cholinergics

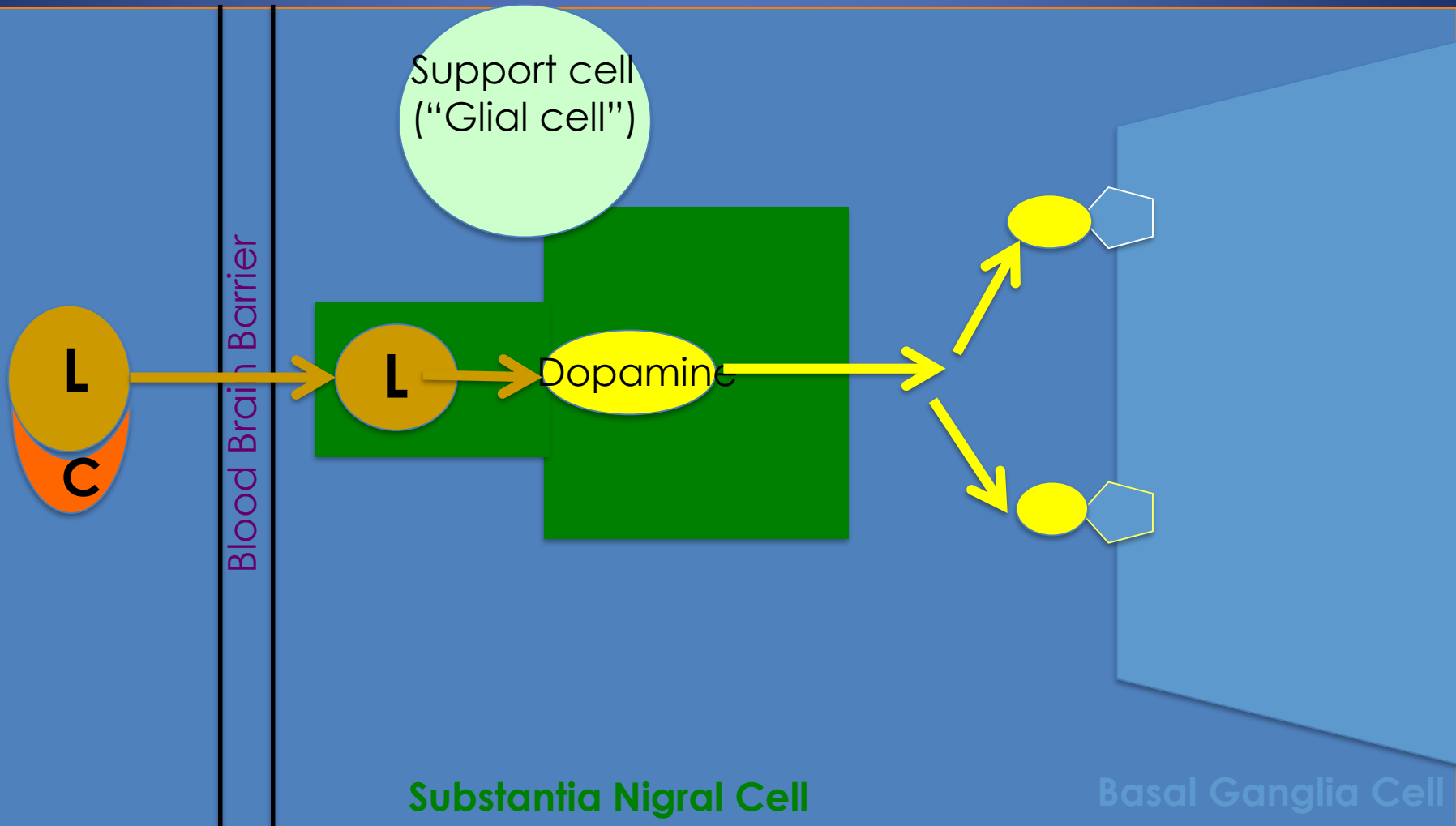
- Not dopaminergic! Used for tremor only
- Artane, trihexyphenidyl

Amantadine

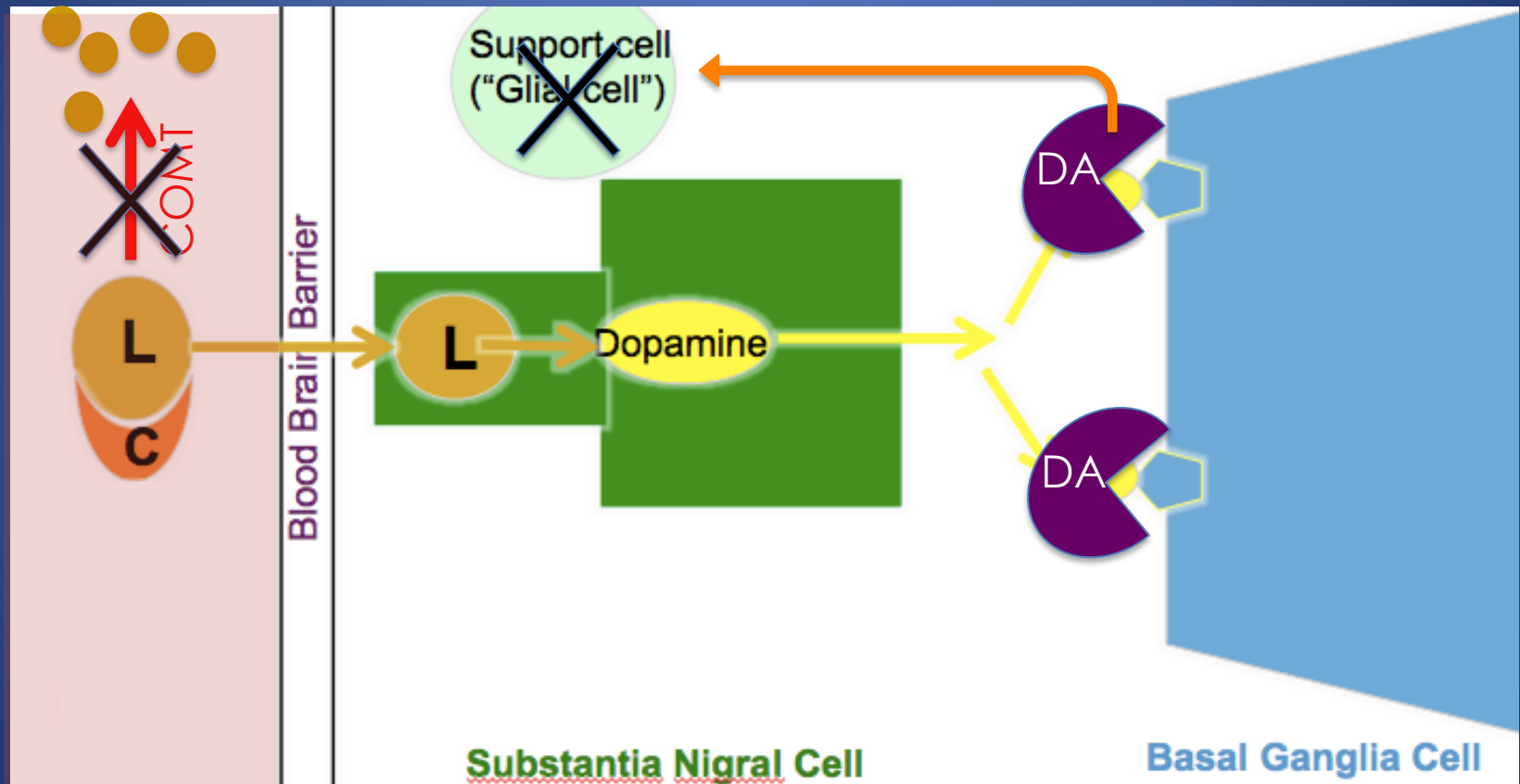
- Not dopaminergic! (Used for dyskinesia)

Levodopa:

Replaces dopamine in the brain



Most other medications enhance dopamine or mimic it's actions



Dopamine management throughout the course of Parkinson's disease

Disease Progression



- MAO-B inhibitor
- Dopamine agonist
- LD
- Amantadine

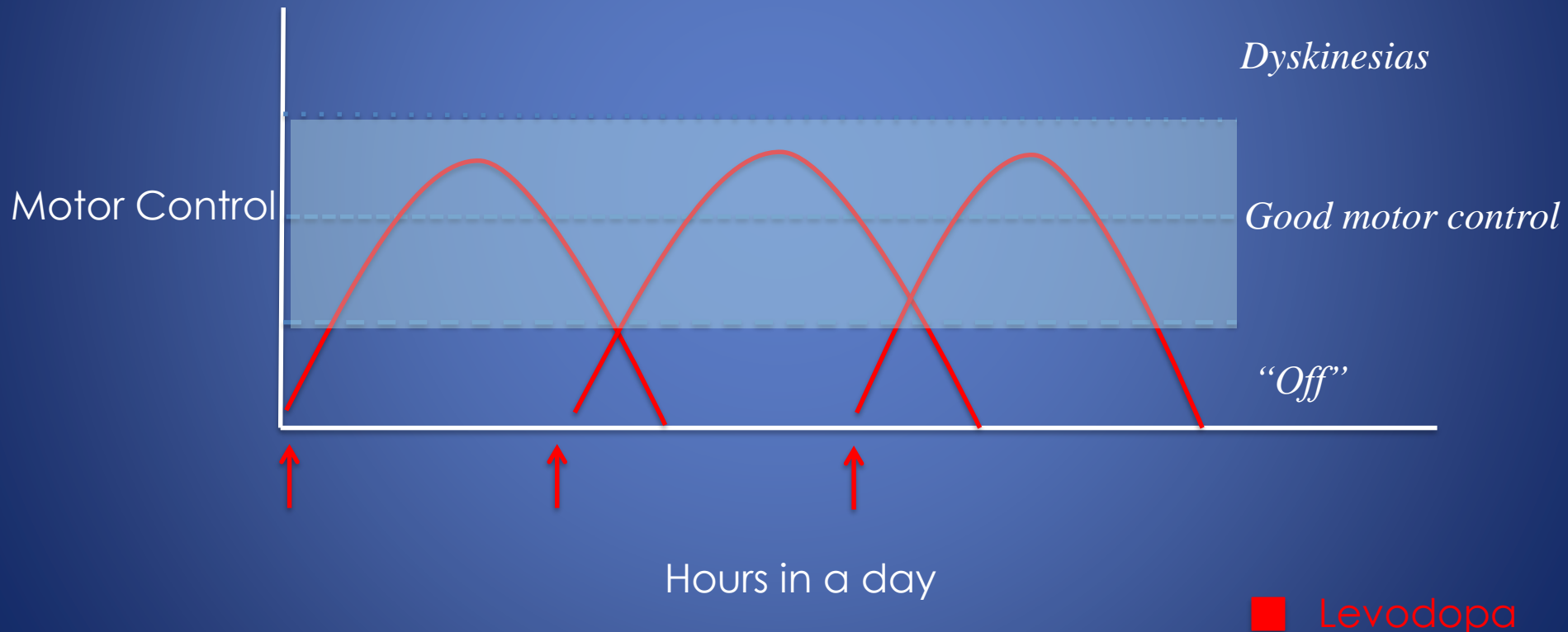
- MAO-B inhibitor
- Dopamine agonist
- LD
- COMT inhibitor
- Amantadine

- MAO-B inhibitor
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- Apomorphine
- Amantadine

Many therapeutic agents may be required over the course of the patient's disease to optimize patient function.

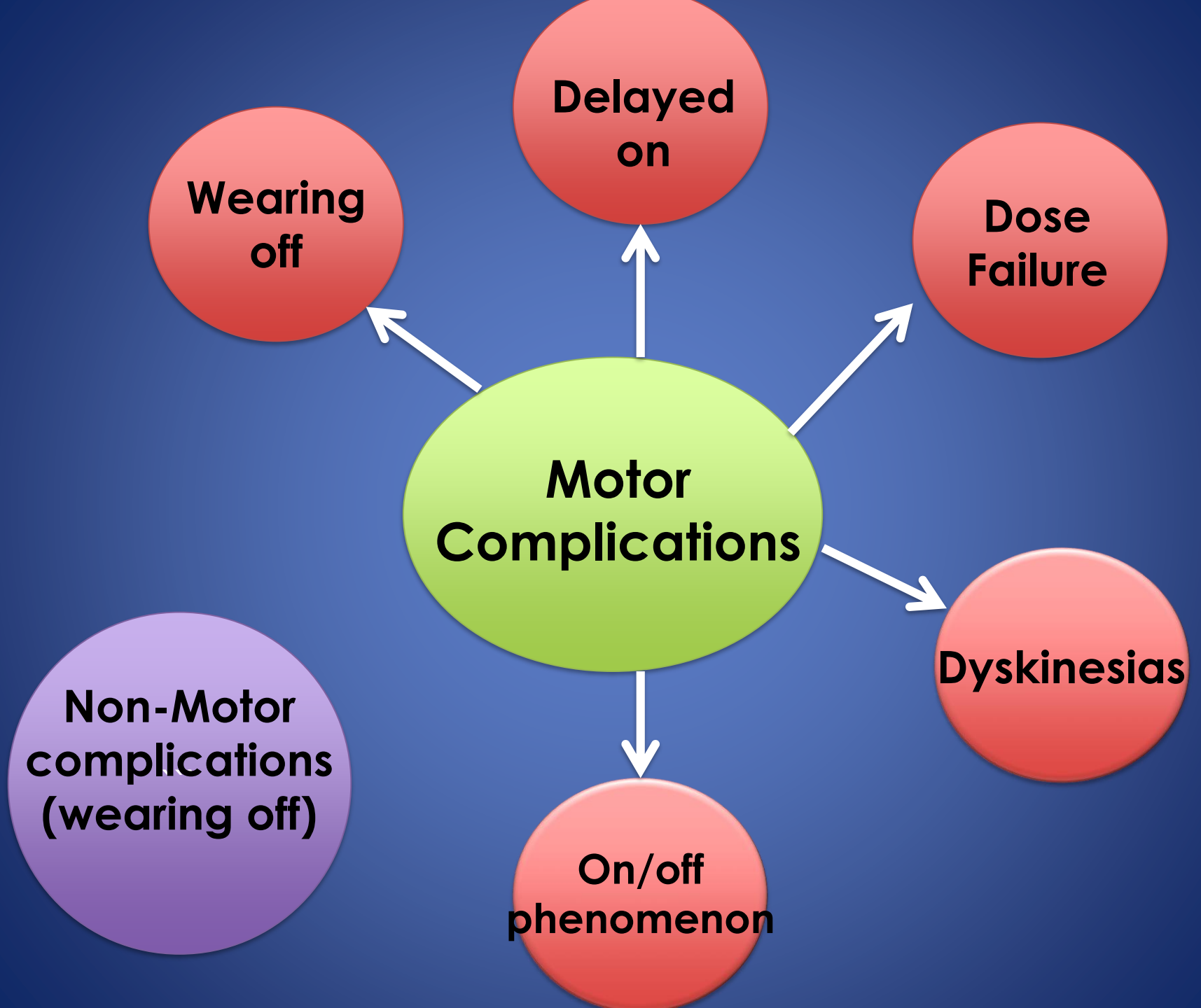
Managing dopamine levels is critical to successfully treating PD.

The medications work to maintain brain dopamine levels



Motor Complications





Common Signs of Wearing Off

Nonmotor

Abdominal discomfort
Akathisia (restlessness)
Anxiety
Cloudy mind
Drenching sweats
Drooling
Shortness of breath
Trouble swallowing
Fatigue
Mood changes
Numbness or tingling
Pain or tightening

Motor

Tremor
Bradykinesia
Muscle cramping
Trouble getting out of chair
Reduced dexterity
Stiffness
Balance problems
Weakness
Gait freezing

To determine if you are having motor or non-motor complications...

1. Take your medications on a consistent schedule

1. Keep a diary of when your bothersome symptoms occur in relation to the timing of your medications

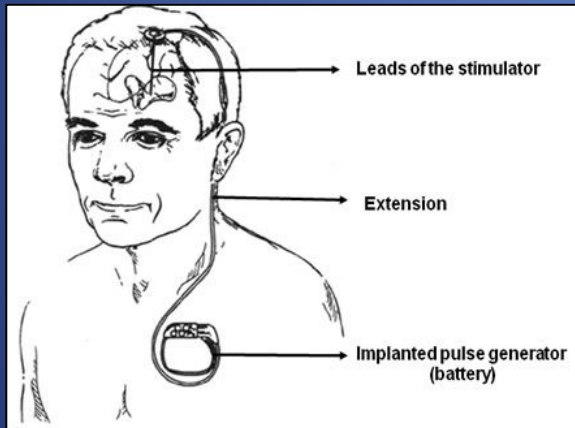
Sample PD Symptoms Diary

Medications																		
Dyskinesia																		
Freezing																		
OFFs																		
Falls																		
Time	AM 6	7	8	9	10	11	PM 12	1	2	3	4	5	6	7	8	9	10	11

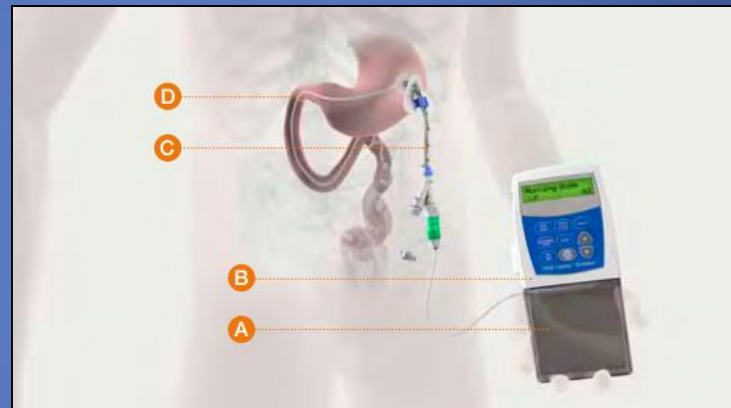
Complete a diary for 3 days and bring to your appointment.

Surgical Therapies for PD

Typically used to treat motor complications or to treat tremor that doesn't respond to medications



Deep Brain Stimulation



Levodopa-Carbidopa
Intestinal Gel (Duopa)

Other:

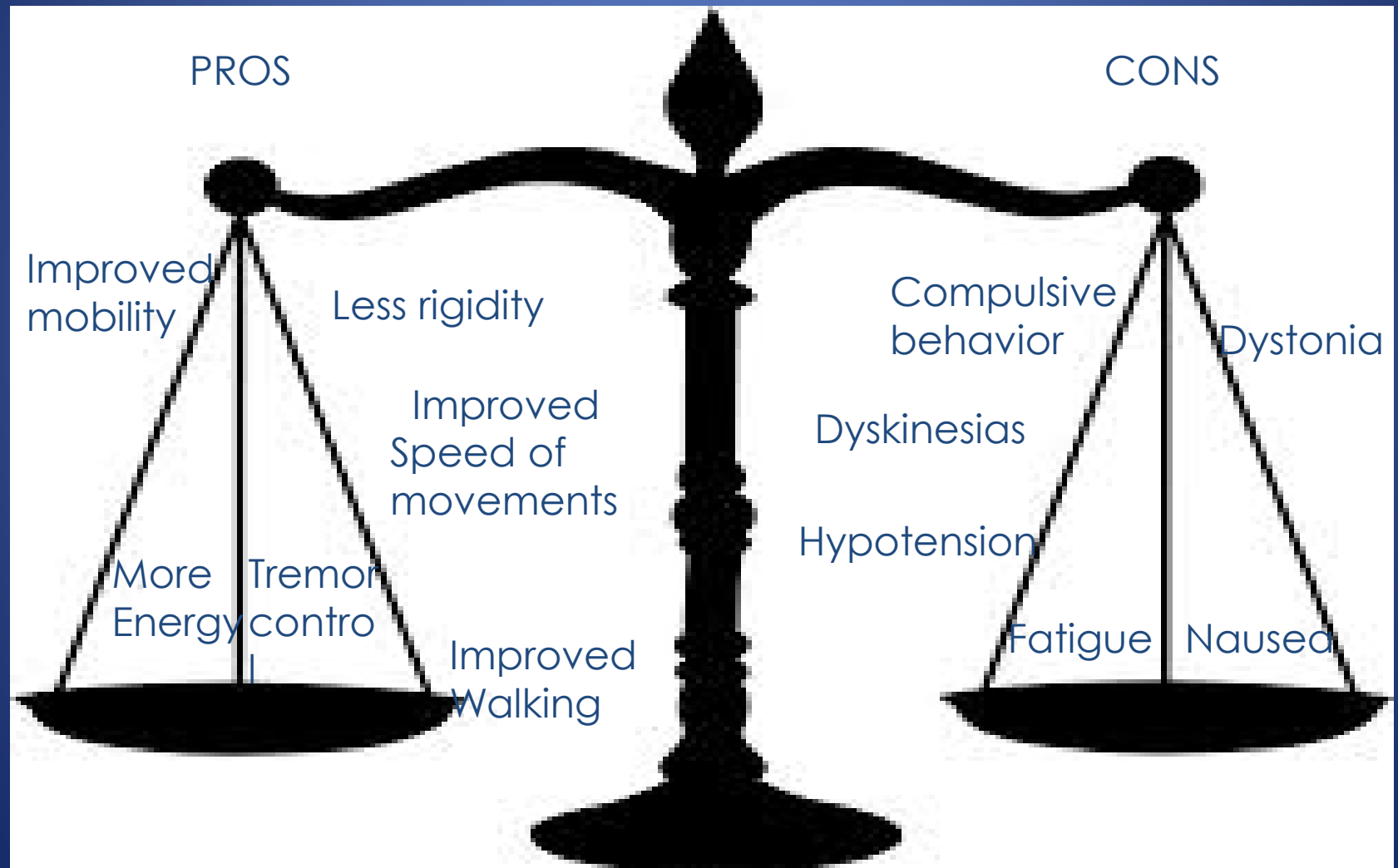
- Pallidotomy
- Thalamotomy

Managing non-motor symptoms

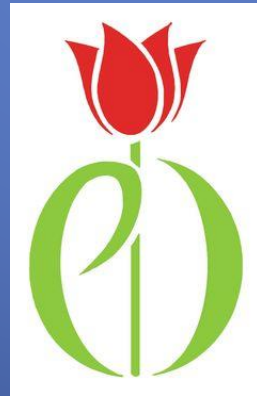
Symptomatic therapy...for example:

Non-motor Symptom	Treatments
Depression/anxiety	Antidepressants, anti-anxiety medications, counseling
Dementia	Memory medications, review of old medications, behavioral strategies
REM sleep disorder	Clonazepam, melatonin
Orthostatic blood pressure	Compression stockings, salt tabs, hydration, medications

Treatment is a balance



2. Prepare for your doctor's visit



Preparing for your visit

1. Write down your symptoms and questions



2. Bring your medications (as a list or the pill bottles)



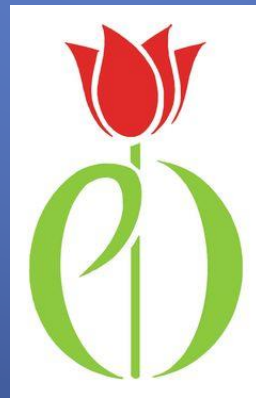
3. Bring your symptom diary (if you are having fluctuations)



4. Bring records of relevant lab work, prior meds tried, imaging or consultations



3. What to do at your visit with the doctor



At your visit...

1. Prioritize concerns

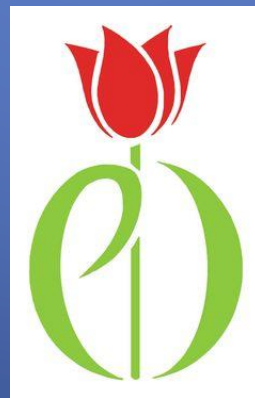
2. Bring a family member, friend or caregiver

3. Bring contact info for other providers in your healthcare team

At your visit...

- Other helpful tips:
 - Try to be on time to your appointment
 - Be prepared if you to wait... bring your next dose of medications

4. What to do after your visit



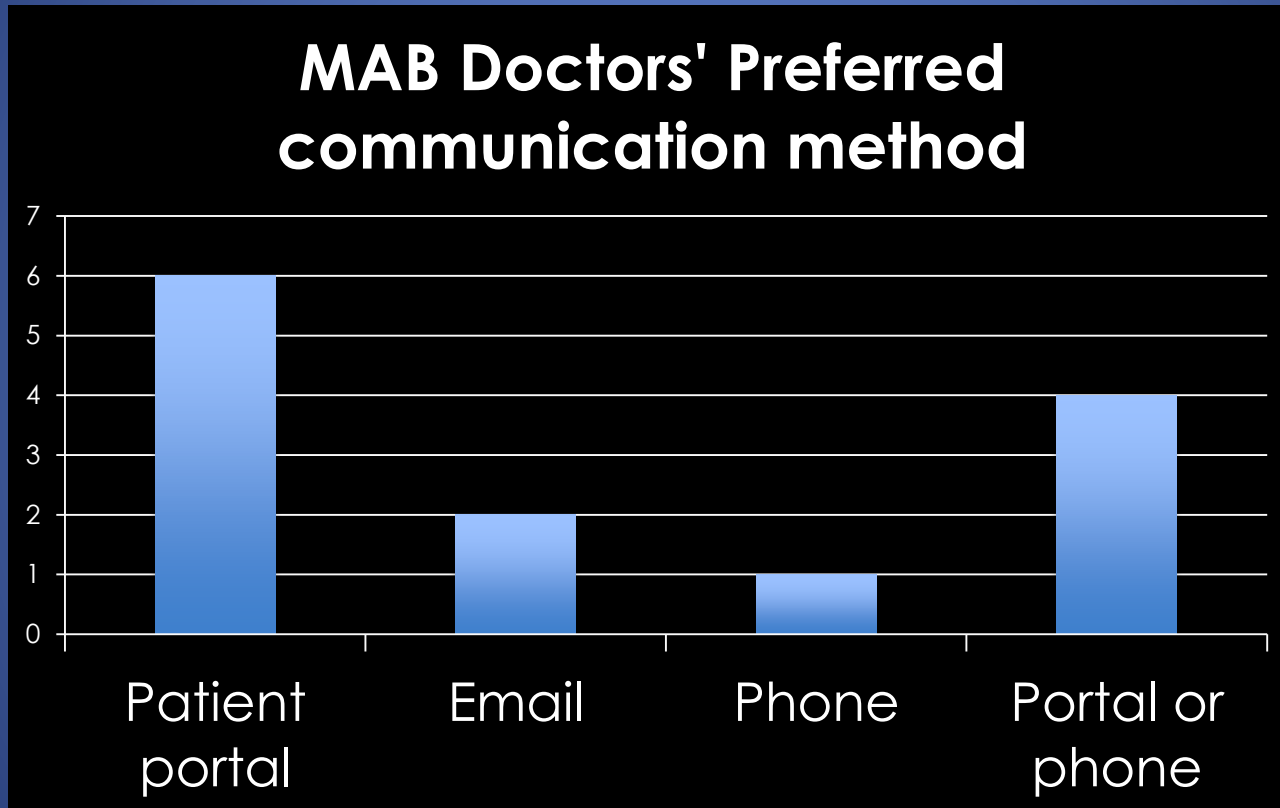
You left your doctor's office, but remembered a few more questions...



How should you get in touch with your doctor?

Answer: It depends on the doctor or practice...

For non-urgent issues...



Expect a 12-72 hour turn around time...

For non-urgent issues like
medication refills...

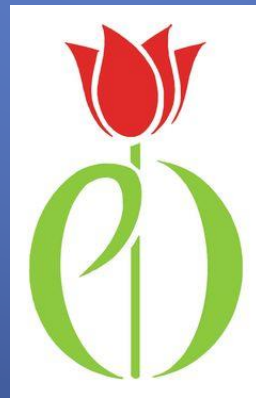
...Please request the refill 10
days before you run out!



Follow up

- If you haven't heard from your doctor in 3-4 days, try calling or messaging them again.
- If you have a lot of questions, it might be a good idea to schedule a follow up appointment and focus just on those questions.

5. What to do in case of an emergency



For truly urgent issues...

- Call 911 or go to your nearest ER
- Call your primary care doctor

A sudden decline in your health is rarely due to Parkinson issues. Typical culprits include infections, medication issues, falls, heart issues, strokes, blood pressure problems, electrolyte problems, etc.

When you are in an emergency...

Leave a message with your neurologist's office. Have the primary care, emergency physician or hospital physician call/page your neurologist or the on-call neurologist (if after hours).

When you are in an emergency...

Things to bring to the ER:



1. Emergency contact list
2. Extra supply of medications in original containers
3. Updated list and schedule of medications
4. Health proxy form
5. Medical alert card
6. If you have DBS, information about your device and the patient programmer

Summary

To improve communication with your doctor

1. Learn about Parkinson's
2. Write down and prioritize your concerns
3. Bring your medications to the visit
4. Keep/bring a diary if your symptoms fluctuate
5. Bring a friend/family member to the visit
6. Ask your doctor for the best method to communicate between visits

THANK YOU!

