

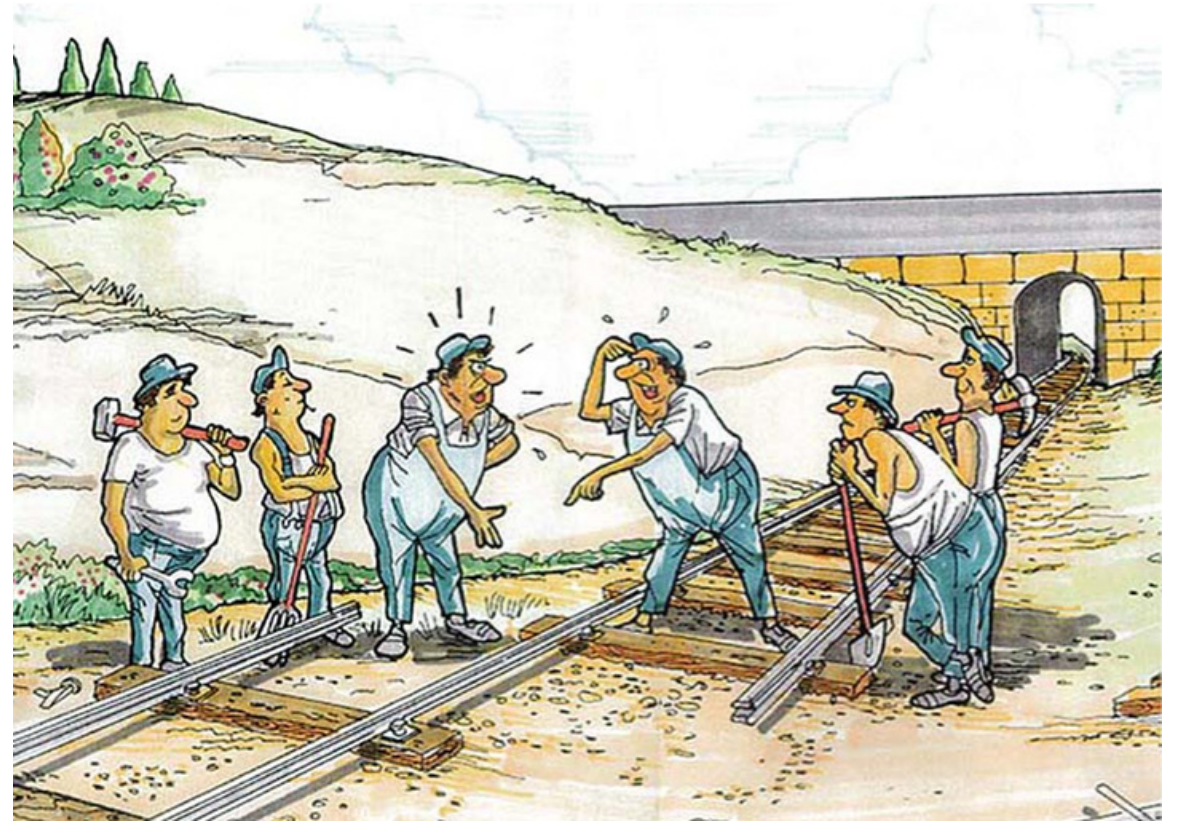
# Developing or Updating your PARKINSON ACTION PLAN

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Associate Professor of Neurology  
Assistant Dean of Student Affairs  
School of Medicine and Health Sciences  
The George Washington University



March 2020



*What now?*

Derailed by the COVID Pandemic

# Parkinson's Action Plan

1. Seeing Movement Disorders Specialist
2. Understanding PD medications
3. Exercising regularly
4. Engaging with rehabilitative therapies (physical, occupational, speech therapy)
5. Building community - Connecting with others impacted by PD
6. Recognizing importance of speaking louder
7. Future financial planning
8. Developing hospitalization plan
9. Seeking mental health support when you need it



## PARKINSON'S SCORECARD

Place a check in the box next to each statement if you agree

I am seeing a Movement Disorder Specialist.

I understand the medicines I am taking and am comfortable with them, including dosages.

I have spoken with my physician about the benefits of physical therapy.

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I have made efforts to meet others with Parkinson's to learn from their experiences.

I know the importance of speaking louder and do so.

I have spoken with a financial planner about how having a chronic disease may impact my financial situation.

I have a plan in place if I am hospitalized, to minimize the risks I may face if I am admitted.

I am aware of how to seek help in the event that my mental health changes.

What's your score?

Total # of check marks

### Score Results

**9+** You have a plan to fight PD, are executing it and well-positioned to help others take steps to fight the disease

**6-8** You are well on your way to effectively fight PD

**4-5** You have made a great start to fight PD and can target your efforts to fight even harder

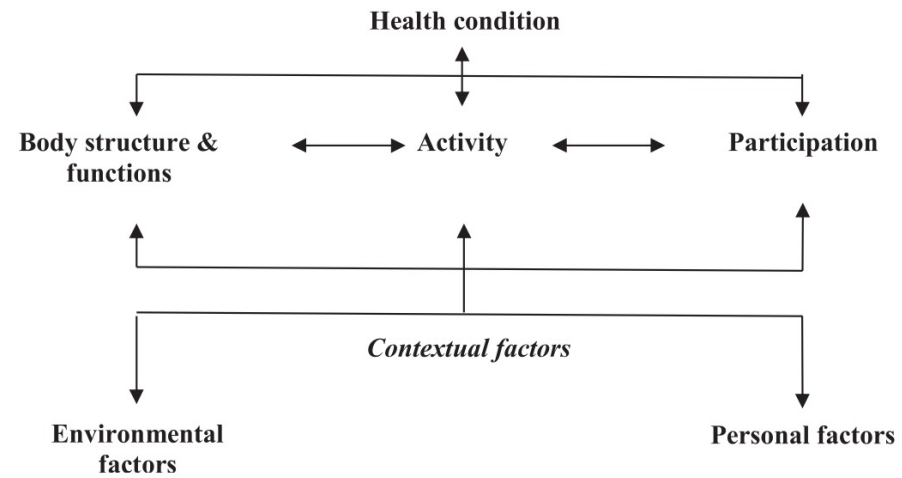
**< 4** You would benefit from focusing more on your fight with PD

Curious about these questions—visit: [www.parkinsonfoundation.org/scorecard](http://www.parkinsonfoundation.org/scorecard)

The Parkinson's Scorecard is a project of the Parkinson Foundation of the National Capital Area (PFNCA), a non-profit organization that helps people live well with Parkinson's. Learn more about PFNCA and/or make a donation at [pfnca.org](http://pfnca.org).

# Why do this?

## *Wellness in PD is multi-factorial*



INTERNATIONAL JOURNAL OF NEUROSCIENCE, 2017 VOL. 127, NO. 10, 930–943

# 1. Having a movement disorders neurologist – and a care team

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**What's your score?**  Total # of check marks

Why do I  
need to see a  
movement  
disorders  
neurologist?



Extensive knowledge  
and experience treating  
Parkinson's

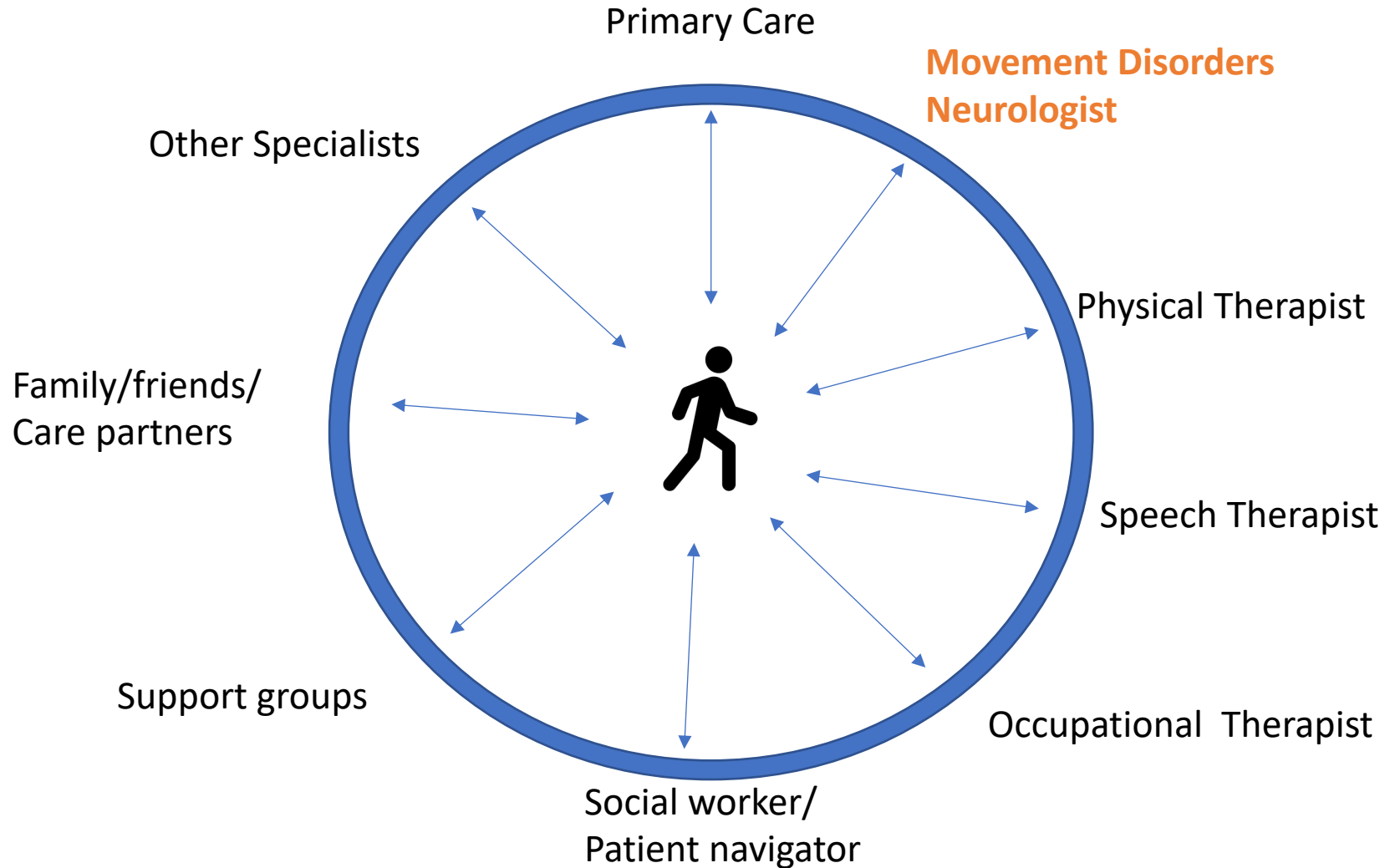


Knowledge of latest treatments and on-  
going clinical research



Connected to relevant allied health  
professionals, resources and information

# Building a Care Team





[Home](#) [About Us](#) [How We Help](#) [Ways To Give](#) [Contact Us](#)

You are here: [Home](#) / [Medical Advisory Board](#)

## Medical Advisory Board

PFNCA's work is guided by its Medical Advisory Board, which consists of leading physicians specializing in Parkinson's Disease. These physicians volunteer their time to ensure that PFNCA programs are providing evidence-based support for patients. They also volunteer as speakers at various PFNCA educational programs.

## Members



**Dr. Pritha Ghosh,**  
Chair  
George Washington  
University



**Dr. Nicole Dietz**  
Neurology Center of  
Fairfax



**Dr. Stephen Grill**  
Parkinson's and  
Movement Disorders  
Center of Maryland



**Dr. Aviva Ellenstein**  
George Washington  
University



**Dr. Drew Falconer**  
INOVA



**Dr. Debra Ehrlich**  
National Institute of  
Neurological Disorders  
and Stroke



**Dr. Howard Weiss**



**Dr. Christopher  
Kalhorn**  
Georgetown University



**Dr. Zachary Levine**  
National Capital  
Neurosurgery



**Dr. Codrin Lungu**  
National Institutes of  
Health



**Dr. Karl Maki**  
Annapolis Neurology  
Associates



**Dr. Zoltan Mari**  
Cleveland Clinic



**Dr. Justin Martello**  
Christiana Care  
Neurology Specialists



**Dr. Kelly Mills**  
Johns Hopkins University



**Dr. Fernando Pagan**  
Georgetown University



**Dr. Gregory Pontone**  
Johns Hopkins University



**Dr. Sean Rogers**  
INOVA



**Dr. Joseph Savitt**  
University of Maryland



**Dr. Linda Sigmund**

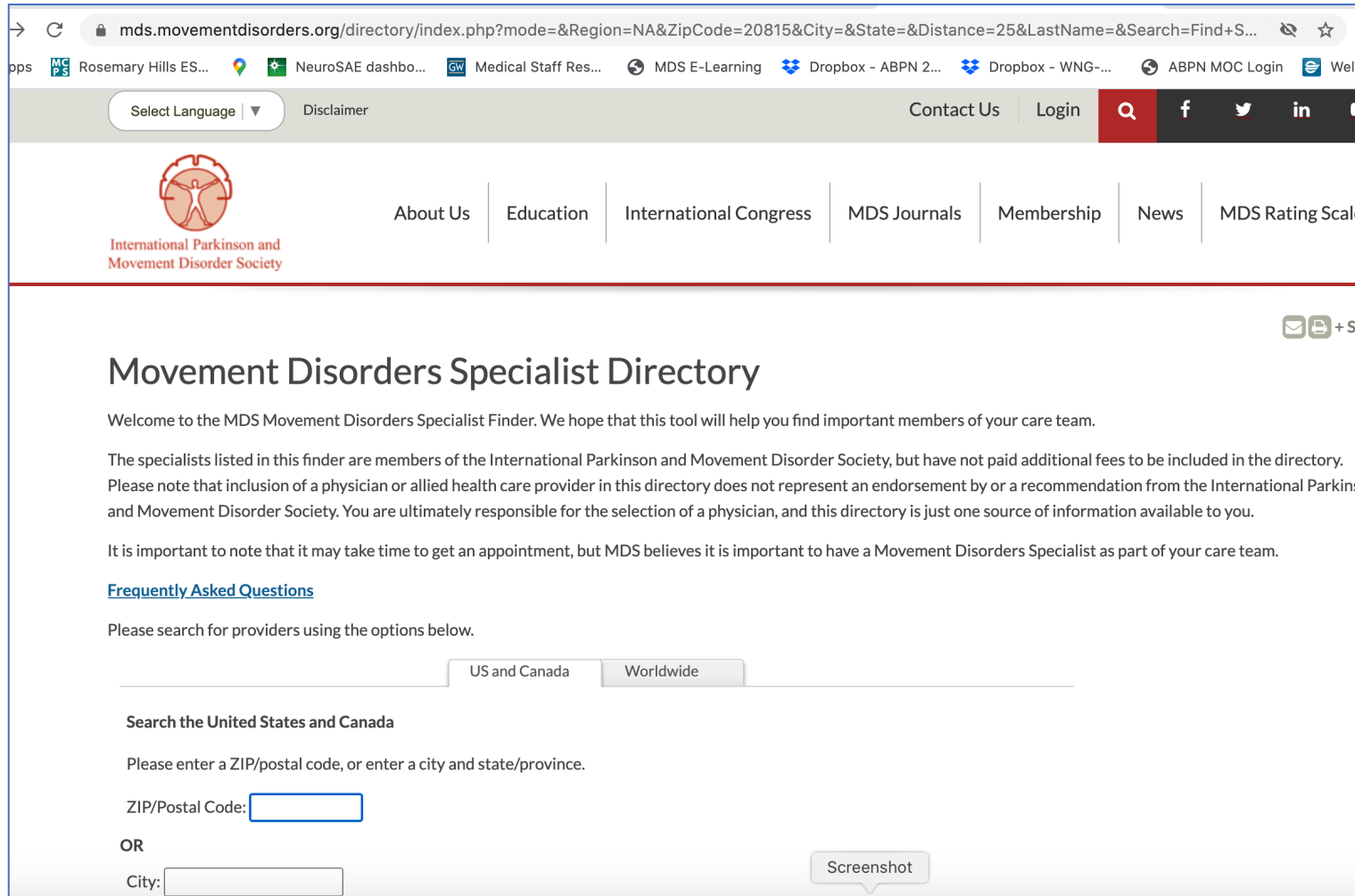


**Dr. Randy  
Stephenson**  
The Neurology Center of  
Fairfax






# Where can I find a Movement disorders specialist?



The screenshot shows the homepage of the MDS Movement Disorders Specialist Directory. The browser address bar displays the URL: `mds.movementdisorders.org/directory/index.php?mode=&Region=NA&ZipCode=20815&City=&State=&Distance=25&LastName=&Search=Find+S...`. The website header includes a navigation menu with links for "About Us", "Education", "International Congress", "MDS Journals", "Membership", "News", and "MDS Rating Scale". The main content area features the title "Movement Disorders Specialist Directory" and a welcome message: "Welcome to the MDS Movement Disorders Specialist Finder. We hope that this tool will help you find important members of your care team." Below this, there is a disclaimer: "The specialists listed in this finder are members of the International Parkinson and Movement Disorder Society, but have not paid additional fees to be included in the directory. Please note that inclusion of a physician or allied health care provider in this directory does not represent an endorsement by or a recommendation from the International Parkinson and Movement Disorder Society. You are ultimately responsible for the selection of a physician, and this directory is just one source of information available to you." A link for "Frequently Asked Questions" is provided. The search section prompts the user to "Please search for providers using the options below." and offers two search options: "US and Canada" (selected) and "Worldwide". Under "Search the United States and Canada", the user is asked to "Please enter a ZIP/postal code, or enter a city and state/province." There are input fields for "ZIP/Postal Code:" and "City:". A "Screenshot" button is visible in the bottom right corner of the page.

→ ↻ `mds.movementdisorders.org/directory/index.php?mode=&Region=NA&ZipCode=20815&City=&State=&Distance=25&LastName=&Search=Find+S...`

Select Language | Disclaimer | Contact Us | Login | 🔍 | f | t | in |

  
International Parkinson and Movement Disorder Society

About Us | Education | International Congress | MDS Journals | Membership | News | MDS Rating Scale

📧 📄 + S

## Movement Disorders Specialist Directory

Welcome to the MDS Movement Disorders Specialist Finder. We hope that this tool will help you find important members of your care team.

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It is important to note that it may take time to get an appointment, but MDS believes it is important to have a Movement Disorders Specialist as part of your care team.

[Frequently Asked Questions](#)

Please search for providers using the options below.

US and Canada | Worldwide

**Search the United States and Canada**

Please enter a ZIP/postal code, or enter a city and state/province.

ZIP/Postal Code:

OR

City:

Screenshot

# Where can I find a Movement disorders specialist or other resources?

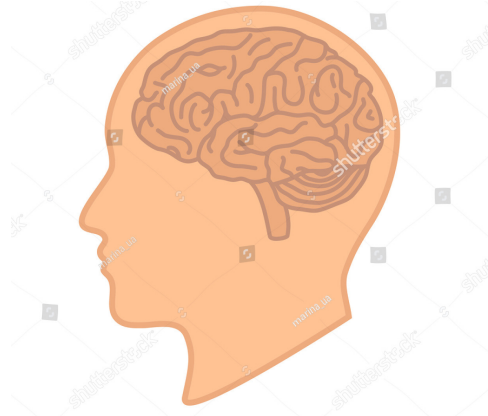
- Directory of Movement Disorder specialists:  
<https://mds.movementdisorders.org/directory/>
- Telemedicine Movement Specialists for those in New York state: <https://www.pdcny.org/>
- American Parkinson Disease Association (APDA) local resource finder:  
<https://www.apdaparkinson.org/community/>
- Physical/Speech/Occupational therapists trained to work with people with Parkinson's: [www.lsvtglobal.com](http://www.lsvtglobal.com)

## 2. Understanding your medications – when, why and how to take them

**PARKINSON'S SCORECARD**

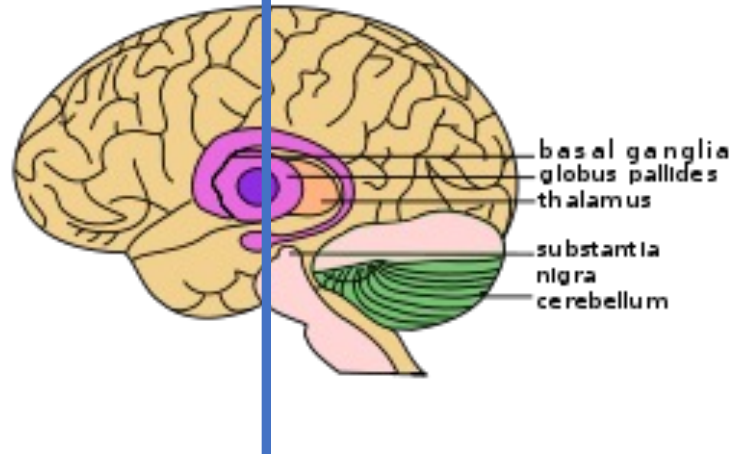
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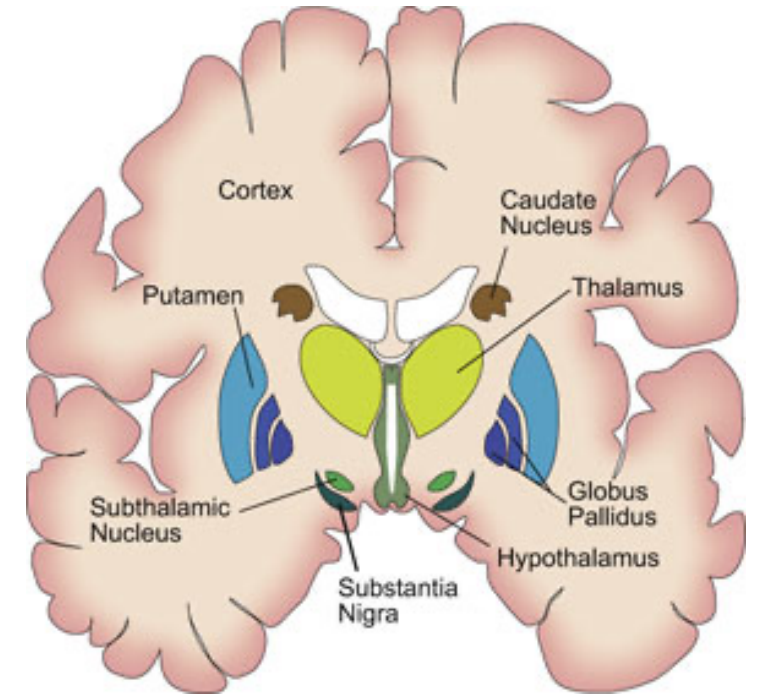


<https://www.shutterstock.com/image-vector/human-brain-head-profile-view-cartoon-640495282>

### Basal Ganglia and Related Structures of the Brain



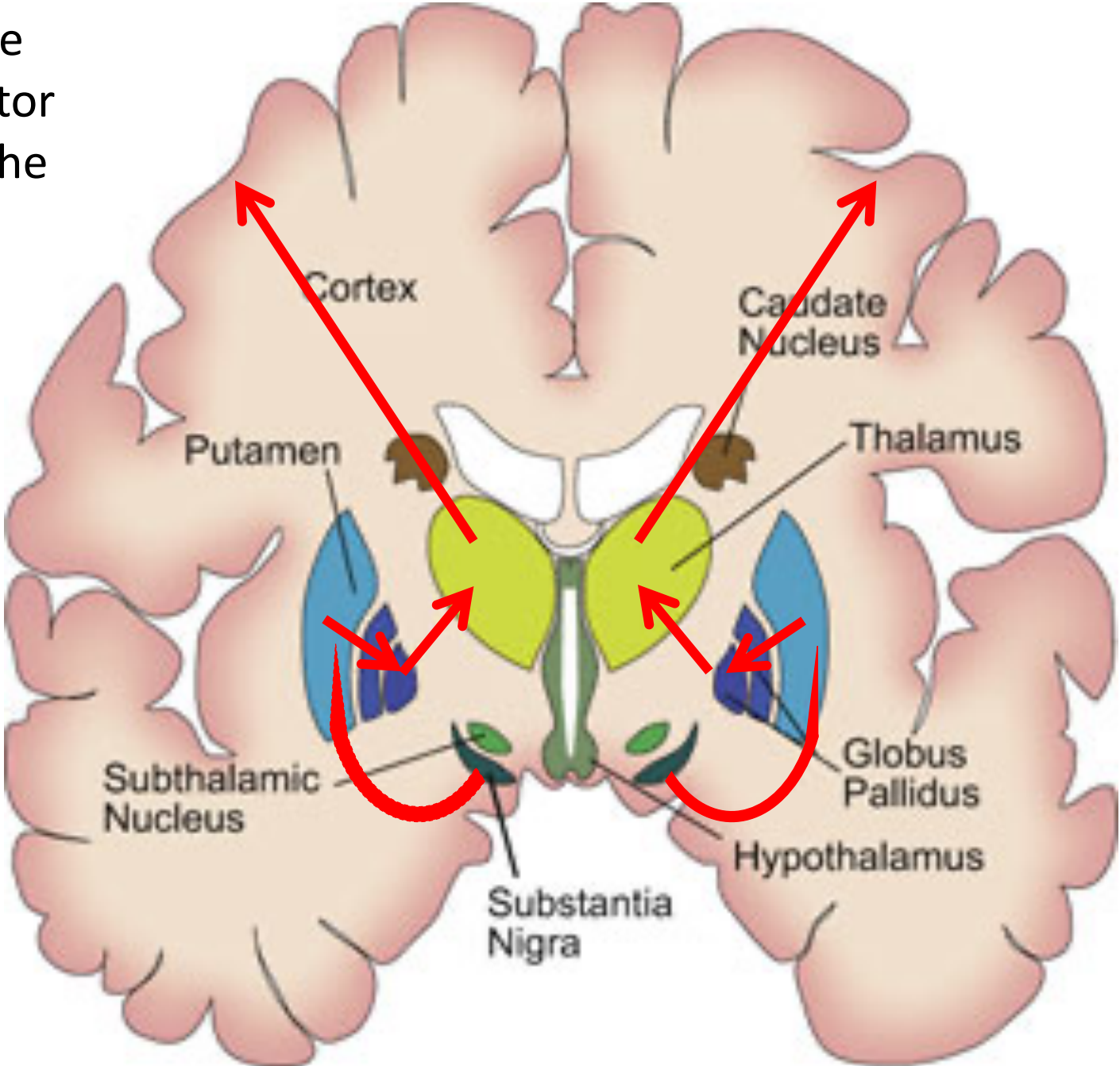
[http://upload.wikimedia.org/wikipedia/commons/thumb/1/1b/Basal\\_Ganglia\\_and\\_Related\\_Structures.svg/250px-Basal\\_Ganglia\\_and\\_Related\\_Structures.svg.png](http://upload.wikimedia.org/wikipedia/commons/thumb/1/1b/Basal_Ganglia_and_Related_Structures.svg/250px-Basal_Ganglia_and_Related_Structures.svg.png)



[http://www.dana.org/uploadedImages/Images/Spotlight\\_Images/BW\\_JanFeb07\\_basal\\_ganglia\\_spot.jpg](http://www.dana.org/uploadedImages/Images/Spotlight_Images/BW_JanFeb07_basal_ganglia_spot.jpg)

# What causes the motor symptoms of PD?

A lack of dopamine in the brain's "motor circuitry" causes the movement symptoms of PD



Your body needs dopamine  
to move the way your car  
needs gasoline to move



# So how do we treat this?

CARE TEAM



[This Photo](#) by Unknown Author is licensed under [CC BY-NC](#)

MEDICATION  
(and sometimes surgery)



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EXERCISE



NY Times Jan 23, 2017

# Medications for Motor symptoms: Most replete dopamine

## Carbidopa-Levodopa

- Sinemet, Sinemet CR, Rytary, Parcopa, Duopa, Inbrija

## Dopamine Agonists

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

## COMT Inhibitors

- Entacaopone, Comtan, Stalevo, Tolcapone, Tasmar

## MAO-b Inhibitors

- Azilect, Rasagiline, Selegiline, Eldepryl, Zelapar, Safinimide

## Anti-Cholinergics

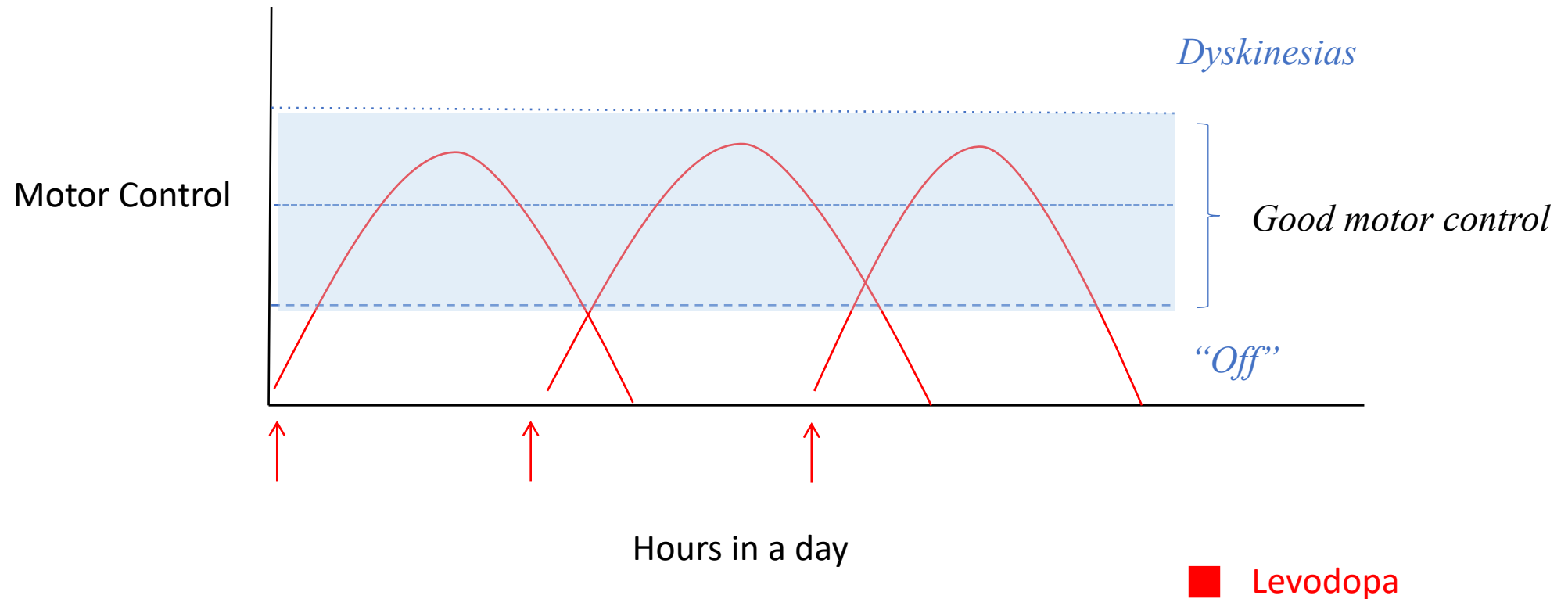
- Not dopaminergic! Used for tremor only
- Artane, trihyexiphenidyl

## Other

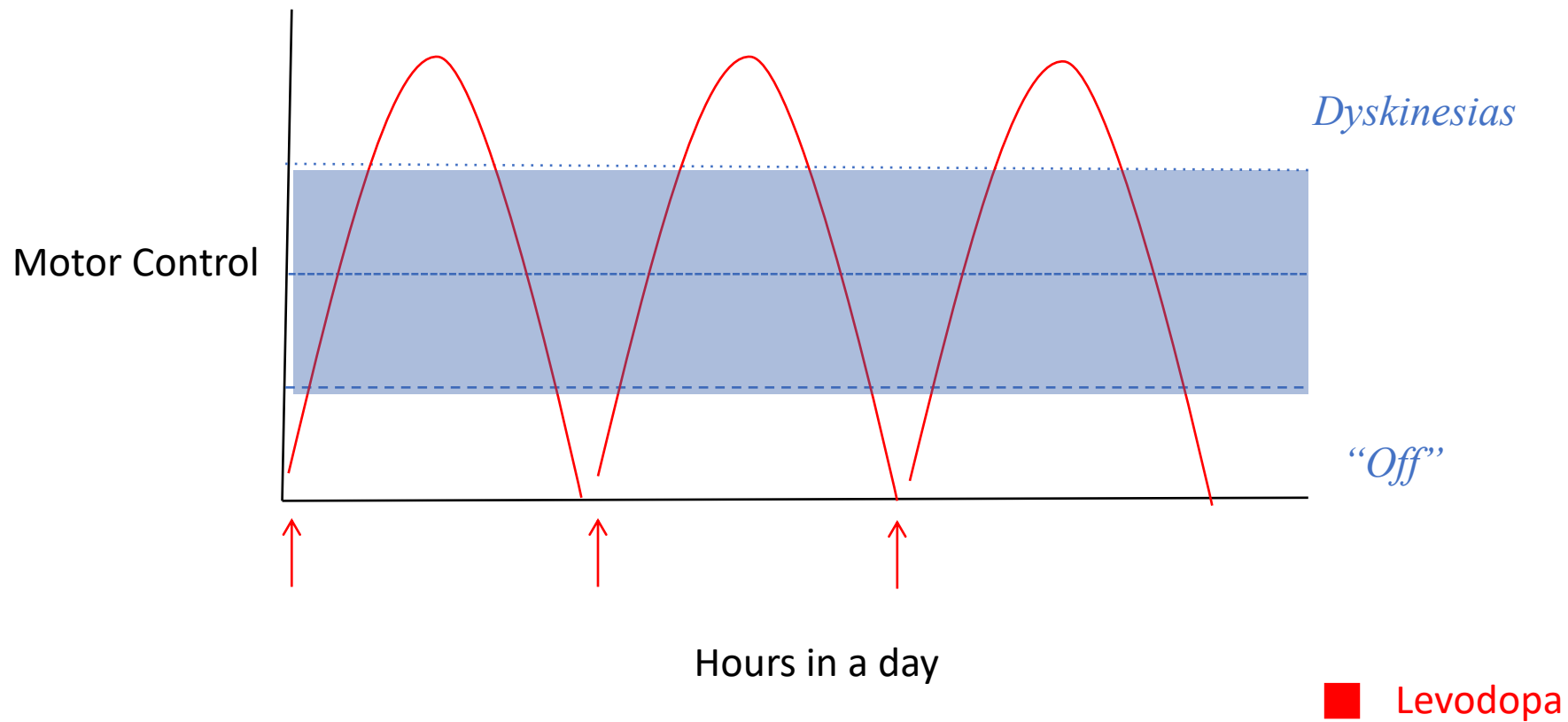
- Amantadine - Not dopaminergic! (Used for dyskinesia)
- Istradefylline – Non-dopaminergic (Adenosine A2A receptor antagonist)



# The medications work to maintain brain dopamine levels in the “zone of good motor control”



Over time, it can be difficult to stay in the “zone of good motor control”



# Motor or Non-Motor Complications = Common symptoms that fluctuate with medications

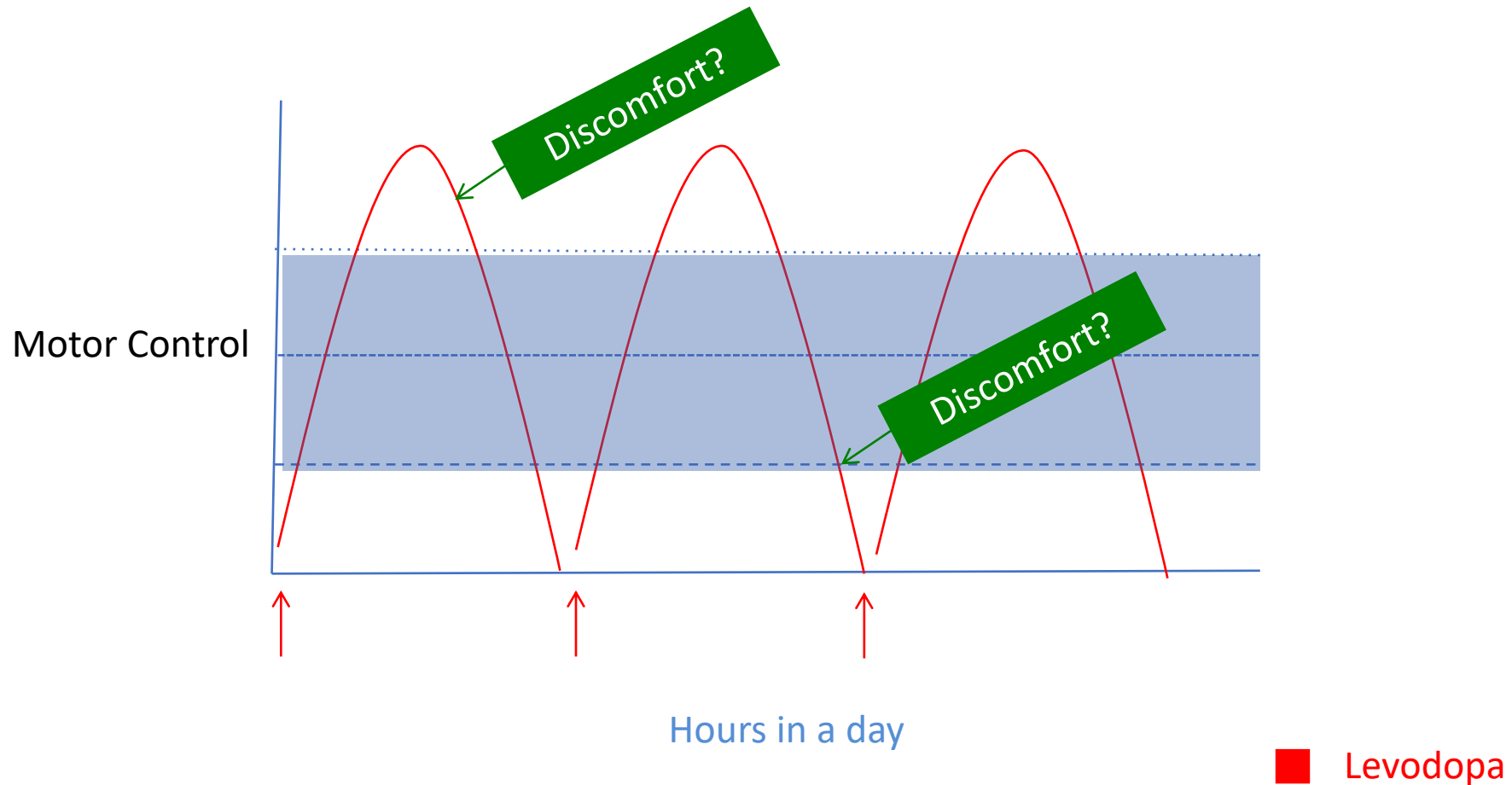
- Dyskinesias (excessive movements)
- Wearing off (tremor, gait freezing, slowness emerge)
- Anxiety attacks
- Nausea
- Pain

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**

Are these bothersome symptoms related to the timing of your PD medications?



# Sample PD Symptoms Diary

<b>Medications</b>																		
<b>Dyskinesia</b>																		
<b>Freezing</b>																		
<b>OFFs</b>																		
<b>Falls</b>																		
<b>Time</b>	<b>A M</b> 6	<b>7</b>	<b>8</b>	<b>9</b>	<b>10</b>	<b>11</b>	<b>P M</b> 12	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>	<b>9</b>	<b>10</b>	<b>11</b>

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

# Non-motor Features of PD

<b>Gastrointestinal:</b> Constipation Drooling Swallow problems Nausea/vomiting	<b>Autonomic problems</b> Orthostatic hypotension Urinary dysfunction Sexual dysfunction Excessive sweating
<b>Sensory</b> Pain Tingling Smell loss	<b>Neuropsychiatric symptoms</b> Depression Anxiety Hallucinations Delusions Cognitive decline Dementia
<b>Sleep problems</b> Insomnia REM behavior disorder Excessive sleepiness	

# Managing non-motor symptoms

*Symptomatic therapy...for example:*

<b>Non-motor Symptom</b>	<b>Treatments</b>
Depression/anxiety	Antidepressants, anti-anxiety medications, counseling
Balance or walking problems	Physical therapy
REM sleep disorder	Clonazepam, melatonin, sleep doctor consultation
Orthostatic blood pressure	Compression stockings, salt tabs, hydration, medications, cardiology consultation

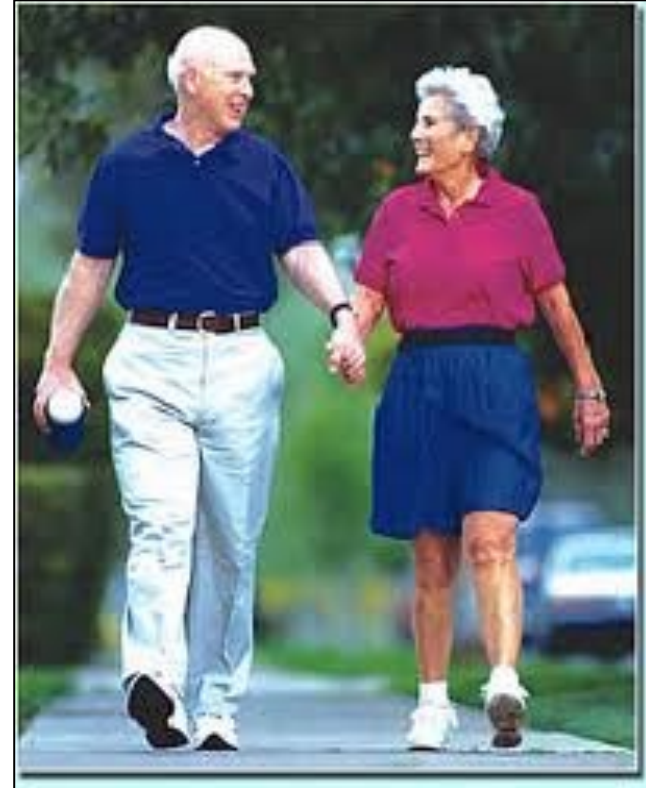


### 3. Exercise – a critical “medicine” for PD

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# 3. Exercise – A critical “medicine” for PD

- General health: Improves heart health, bone/muscle strength, digestion, circulation
- Improves cognition and connections in the brain
- Improves motor symptoms
- Neuroprotective?

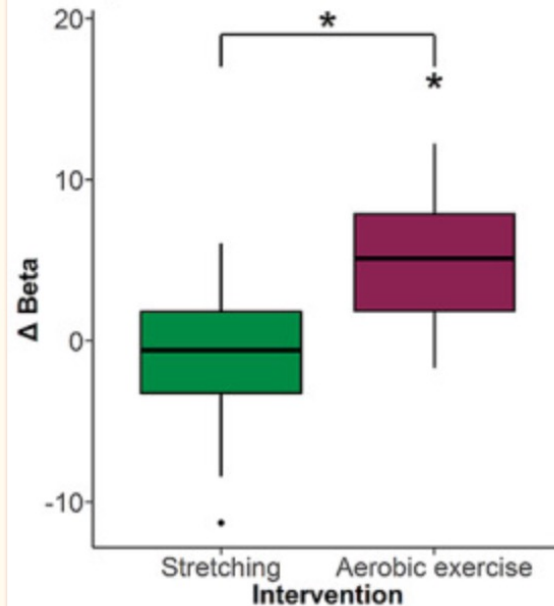


# Exercise

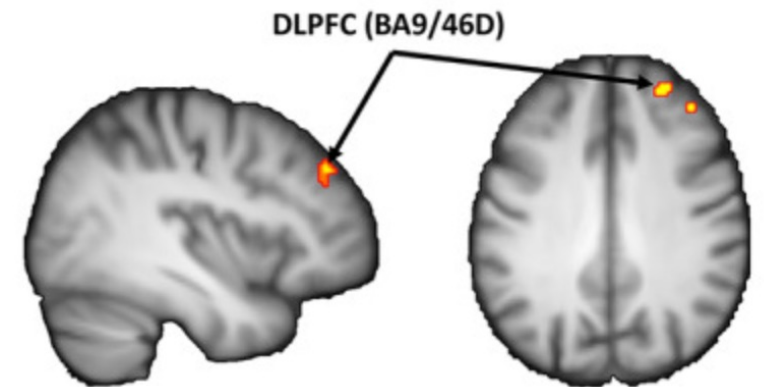
- **Changes brain FUNCTION:** Associated with better connections between different parts of the brain
- **Changes brain STRUCTURE:** Less atrophy (shrinkage) of brain tissue
- **Changes BEHAVIOR:** Better motor function (MDS-UPDRS III)

## B Effects of aerobic exercise on connectivity between dorsolateral prefrontal cortex and right frontoparietal network

Change in DLPFC – RFPN connectivity



■ RFPN: Exercise>Stretching, T2>T1  
( $p < .05$ , fwe-corrected)



X = 10 Y = -24 Z = -18

# Exercise - What is recommended?

- 
- **20-30 min moderate intensity aerobic activity**
    - Walking, cycling, boxing, jogging, dancing
  - ***Stretching, strength training is also helpful to prevent injury***
  - Be aware of potential fall risks
  - Engage physical therapist in helping to design exercise program



# 4. Rehabilitative therapies – A key part of promoting wellness in PD

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**Rehabilitative Therapies include:**

- Physical therapy (PT)
- Occupational therapy (OT)
- Speech therapy

# 4. Benefits of Rehabilitative Therapies

## Physical Therapy

- Focuses on mobility
  - Walking, balance, posture, transfers,
  - GOAL: Maintaining independence, improving fitness, enhancing quality of movements
- Approach:
  - Exercise
  - Practice

## Occupational Therapy

- Focuses on enabling performance and engagement in meaningful activities
  - Self-care
  - Functional mobility
  - Work tasks
  - Shopping, cooking
  - Engaging in leisure activities (going to a restaurant)
- Approach:
  - Develops movement and cognitive strategies.
  - Adapts environment

## 4. Benefits of Rehabilitative Therapies – example

Ms. H is 67 years old who has had PD for 7 years. She lives with her partner in a 2-bedroom house and loves to cook.

- **Problem:** She is having more difficulty cooking – feels overwhelmed, takes much longer to do this and feels exhausted by the end
- **OT Analysis:** When she cooks, she has gait freezing in the crowded kitchen, difficulty multi-tasking and working under time pressure
- **PT analysis:** Gait freezing occurs in narrow spaces. She responds well to shifting weight from left to right and to musical cues
- **GOAL:** Within 6 weeks, she will cook a simple two-person meal, of no more than two pots, four days a week without feeling exhausted

# 4. Benefits of Rehabilitative Therapies – example

Ms. H is 67 years old who has had PD for 7 years. She lives with her partner in a 2-bedroom house and loves to cook.

- **OT interventions:**

- Structured planning strategy to simplify, reduce time pressure and reduce multi-tasking
- High stool to sit on for cutting vegetables to reduce multi-tasking (maintaining balance while cutting)
- Discuss simple re-organization of the kitchen to create more open space (ie. move kitchen table to the side, reranging cupboards for easy access and fewer turns)
- Talk with partner about avoiding introducing extra tasks or conversation while she cooks

- **PT Interventions:**

- Strengthen compensatory strategies for dealing with gait freezing
- Strengthen balance reflexes
- Using these strategies in the kitchen (ie. listening to specific music in the kitchen)



## 4. Benefits of Rehabilitative Therapies



**Speech Therapy** – Improving communication and safety

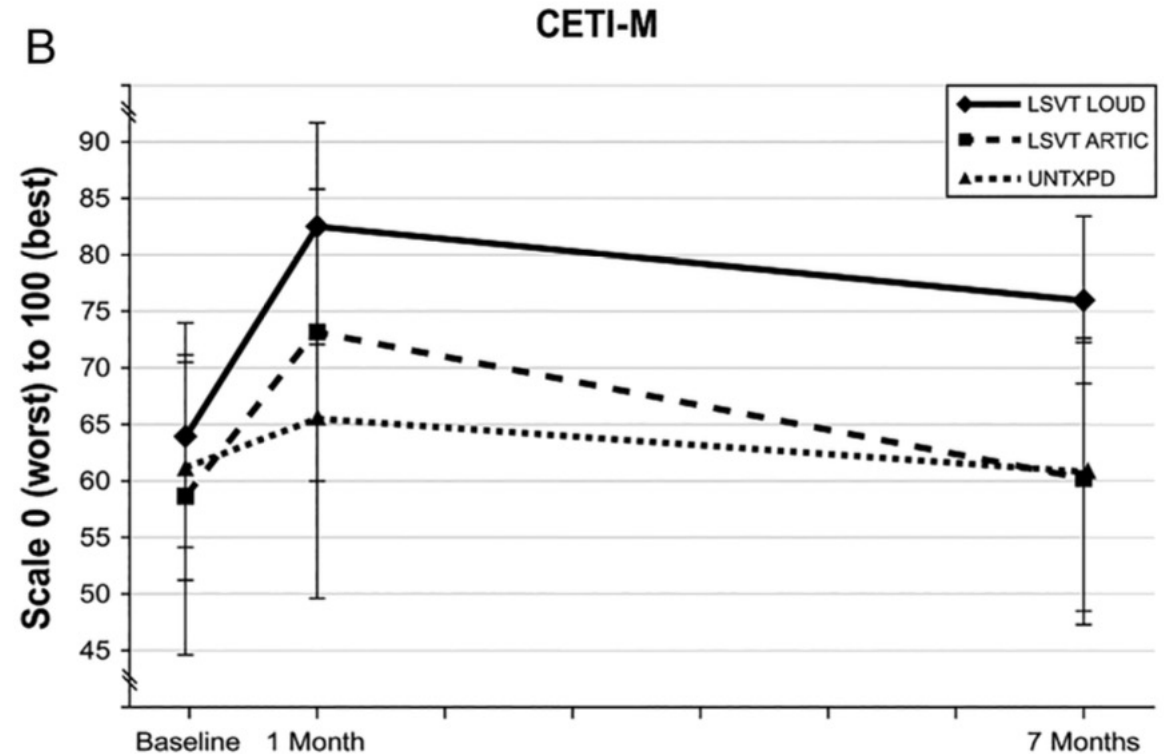
- Can focus on speaking loudly, clearly (LSVT – “Lee Silverman Voice Technique”)
- Can focus on organizing thoughts and ideas (cognitive therapy)
- Can focus on safe swallowing

# 5. Speaking up – Practice is key!

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## 5. SPEAKING UP – practice is *key*

- Speech and communication is key to staying connected to your loved ones, community and the world around you.
- Practice is key – if you don't use it, you lose it!



# 6. Community and Support – Connecting with others impacted by PD

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## 6. Community and Support – Learning from and leaning on others

*“Parkinson’s group exercise classes and support groups have been a lifesaver in some ways...Sure, they have the physical benefit. But they also provide the solidarity and esprit de corps --the feeling of belonging-- that keeps you motivated...”*

-- Reflections from a local person fighting Parkinson’s disease



PARKINSON FOUNDATION  
OF THE NATIONAL CAPITAL AREA

# 7. Financial Planning with a chronic condition

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# 7. Financial Planning with a chronic condition

- **Considerations:**

- Organizing your accounts and records
- Keeping account numbers and passwords in a safe place that you share with a trusted family member or friend
- Discussing with loved ones your long-term wishes if/when you need more support
- Reviewing finances with trusted companions and/or a financial planner to help support your long-term plan



# 8. Hospital Plan – plan for the unexpected

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I have a plan in place if I am hospitalized, to minimize the risks I may face if I am admitted. <input type="checkbox"/>	I am aware of how to seek help in the event that my mental health changes. <input type="checkbox"/>
<b>What's your score?</b>	<input type="text"/> Total # of check marks



# 8. Hospital Plan – plan for the unexpected

## Aware in Care Kit



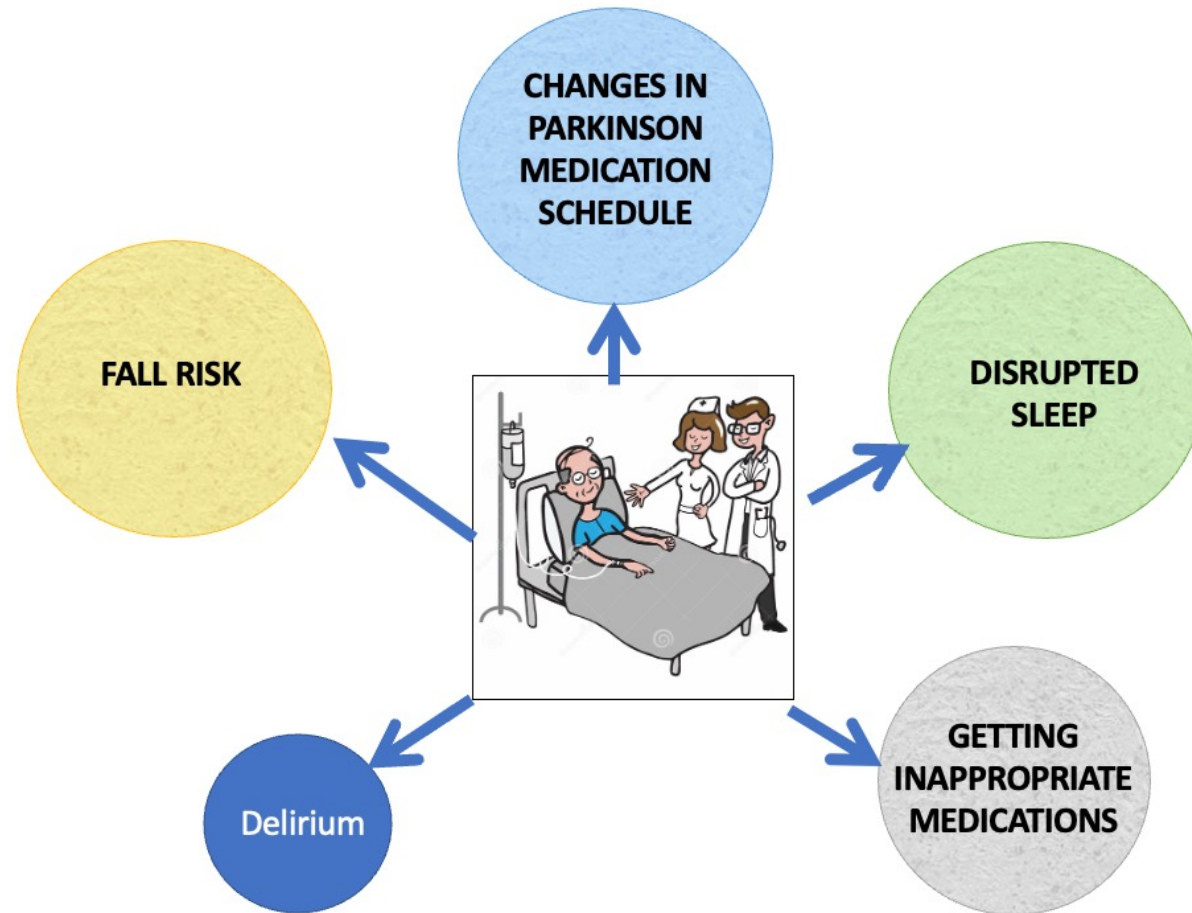
- Hospital fact sheet
- Medication form
- List of medications to avoid
- Doctor's letter/information
- Medical Alert Card

### Important Medical Information for Health Care Professionals

- To avoid serious side effects, Parkinson's patients need their medication **on time, every time** – do not skip or postpone doses.
- Do not stop levodopa therapy abruptly.
- If an antipsychotic is necessary, use quetiapine (Seroquel®) or clozapine (Clozaril®).
- **Special Alert:** Drugs such as benzodiazepines, muscle relaxants, bladder control medications and other medications used for sleep and pain may lead to confusion, hallucinations and other symptoms.

Turn this card over for a list of contraindicated medications & important considerations if the patient has a brain device & needs a MRI/EKG/EEG.

# 8. Hospital Plan – Why can it be so complicated?



## 8. Hospital Plan – how to optimize your care

### 1. BRING MEDICATION LIST(s):

- Home medication list and schedule,
- List of medications to avoid (if possible)

### 2. ADVOCATE for getting medications as close to home schedule as possible

### 3. ASK the team to take appropriate precautions to prevent falls and confusion

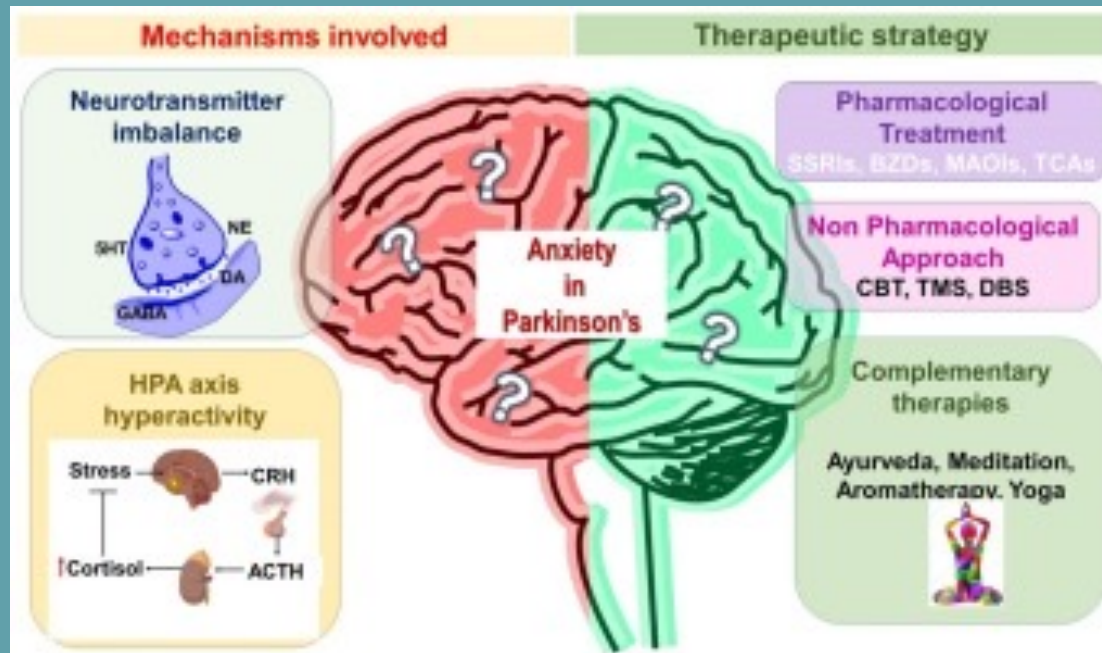
# 9. Seeking Mental Health Support when you need it

<b>PARKINSON'S SCORECARD</b>	
<b>Place a check in the box next to each statement if you agree</b> <input checked="" type="checkbox"/>	
I am seeing a Movement Disorder Specialist. <input type="checkbox"/>	I understand the medicines I am taking and am comfortable with them, including dosages. <input type="checkbox"/>
I have spoken with my physician about the benefits of physical therapy. <input type="checkbox"/>	I have spoken with my physician about the benefits of Speech therapy. <input type="checkbox"/>
I understand the importance of exercising regularly and do so. <input type="checkbox"/>	I have made efforts to meet others with Parkinson's to learn from their experiences. <input type="checkbox"/>
I know the importance of speaking louder and do so. <input type="checkbox"/>	I have spoken with a financial planner about how having a chronic disease may impact my financial situation. <input type="checkbox"/>
I have a plan in place if I am hospitalized to minimize the risks I may face if I am admitted. <input type="checkbox"/>	I am aware of how to seek help in the event that my mental health changes. <input type="checkbox"/>
<b>What's your score?</b>	Total # of check marks

# 9. Seeking Mental Health Support when you need it

## Why?

- Mental Health is affected by the stress of *having* a chronic conditions
- Mental health can be affected by the biology of Parkinson's
- **Mental health impacts your life!**
  - Increased irritability
  - Poor sleep
  - Stress on relationships
  - Affects memory and ability to think clearly



**Bottom line: Getting mental health support can be a game changer**

# 9. Seeking Mental Health Support when you need it

## Strategies:

- Lean on others – loved ones, PD community (support groups), greater community
- Talk to your doctor
- Consider seeing a therapist
- Stay active
- Eat healthy
- Practice mindfulness *and self-compassion*
- Take your medications on time



# Summary

- Working toward wellness is an on-going process with many facets
- It's never too late to get back on track!
- Take it one step at a time to work toward your goals.
- Use the tools, resources and community around you to help you on your journey.



## PARKINSON'S SCORECARD

Place a check in the box next to each statement if you agree

I am seeing a Movement Disorder Specialist.

I understand the medicines I am taking and am comfortable with them, including dosages.

I have spoken with my physician about the benefits of physical therapy.

I have spoken with my physician about the benefits of Speech therapy.

I understand the importance of exercising regularly and do so.

I have made efforts to meet others with Parkinson's to learn from their experiences.

I know the importance of speaking louder and do so.

I have spoken with a financial planner about how having a chronic disease may impact my financial situation.

I have a plan in place if I am hospitalized, to minimize the risks I may face if I am admitted.

I am aware of how to seek help in the event that my mental health changes.

What's your score?

Total # of check marks

### Score Results

**9+** You have a plan to fight PD, are executing it and well-positioned to help others take steps to fight the disease

**6-8** You are well on your way to effectively fight PD

**4-5** You have made a great start to fight PD and can target your efforts to fight even harder

**< 4** You would benefit from focusing more on your fight with PD

# THANK YOU

