

TIME MATTERS



TOOLS AND RESOURCES TO ASSIST IN
GETTING PARKINSON MEDICATIONS ON TIME

Including the
Personal Parkinson's Profile

apda AMERICAN
PARKINSON DISEASE
ASSOCIATION

GREATER ST. LOUIS CHAPTER

Strength in optimism. Hope in progress.

TIME MATTERS

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AMERICAN PARKINSON DISEASE ASSOCIATION

Vision/Mission Statement: Every day, we provide the support, education, and research that will help everyone impacted by Parkinson disease live life to the fullest.

The American Parkinson Disease Association (APDA) was founded in 1961. It is the largest grassroots organization in the US, and have a nationwide network of Chapters, Information and Referral (I&R) Centers, and support groups.

The APDA – Greater St. Louis Chapter, located in Chesterfield, MO, is one of the largest chapters in the United States. It serves as a central location where people with Parkinson disease (PD), care partners, medical professionals, students and other interested individuals can receive the latest information, including free printed material, medical and support system referrals, quarterly newsletters, exercise classes, support groups, educational programs and much more. It also funds the APDA Center for Advanced Parkinson Disease Research at Washington University in St. Louis, School of Medicine.

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The APDA – Greater St. Louis Chapter has formed a committee to develop a medication advocacy program to help people with PD, their family members/care partners and medical professionals to work together in ensuring that people with PD receive the correct medication at the exact prescribed times each day, regardless of where they are (home, rehab, hospital, etc.).

This book was created as a tool to keep all of an individual's current information in one, easily accessible place to be used by people with Parkinson's and anyone involved in their care. It may be taken to any care setting to provide helpful information to the healthcare team. There is a digital copy of the PPP available on the included USB flash drive so that you can update and print your personal information as needed.



WHY DOES MEDICATION TIMING MATTER?

The APDA - Greater St. Louis Chapter has received consistent feedback from our constituents that people with PD often do not receive their medications on time when hospitalized or staying in a long-term care setting. Healthcare staff may not be educated or aware of the following:

- Complexity of Parkinson's symptoms, including non-motor symptoms
- Importance of not missing a single dose
- Time sensitive nature of PD medications
- Possible negative drug-interactions when taking PD medications

Missing doses or being late with PD medications can cause significant negative symptoms, including the inability to move well and complete self-care tasks as they normally would. This can be quite frustrating for the person with PD, the family, and healthcare providers.

Consequently, the APDA – Greater St. Louis Chapter formed a Parkinson's Medication Advocacy Committee in 2015 with the goal to help people with Parkinson's, their care partners and family in avoiding or resolving any concerns they may have with getting the correct medications on time, every time.

The APDA would like to thank the following people for contributing to the Time Matters book.

Contributing author: Dr. Rebecca Gilbert, MD, PhD, APDA Vice President and Chief Scientific Officer

Parkinson's medication advocacy committee: Dee Jay Hubbard, (Chair) ~ Debbie Guyer, MA ~ Robert Babione ~ Jay Bender ~ Susan Bromberg ~ Lori Gambill ~ Mark Hizer ~ Carol Krieger ~ Hedva Levy, PharmD, BCPS, BCGP ~ Rich Schumacher ~ Marilyn Warren ~ Sharon Wells ~ Lynda Wiens

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HOW CAN THIS TIME MATTERS BOOK HELP?

The best course of action is to be informed and to be prepared – both for planned and unplanned admissions to hospitals or other care settings. To simplify things, this book includes a number of tools to help patients, care partners and healthcare workers.

- The *Personal Parkinson's Profile (PPP)* keeps essential medical information about the individual with PD in an organized and easily-accessible format
- *Planning Ahead* to help prepare for planned and unplanned admissions
- *Medication Information* about common Parkinson medications and medications to avoid or give with caution
- *Additional Resources* and information that may be relevant for hospital stays and/or living in a long-term care facility

HOW DO YOU USE THIS BOOK?

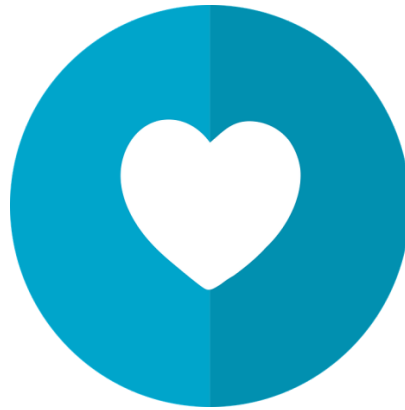
1. Look through the information in this book. Keep an eye out for these helpful tips:

Items in these blue boxes are especially important for people with Parkinson's and their care partners/family members to know.

Items in these green boxes are especially important for healthcare professionals to know.

2. Complete the Personal Parkinson's Profile (PPP) with all applicable information. This information will change over time, so we have provided a USB drive with blank forms that can be completed, saved and shared electronically or printed for convenience.
3. Share this book with family and care partners, especially anyone who may accompany you to medical appointments or who may help you with making medical decisions.
4. Store this book in a secure and convenient location so that it can be easily found in an emergency. Ensure that your family and care partners know where it can be found.
5. Update your information regularly and feel free to add additional documents or information as necessary.
6. Take your Time Matters book with you to medical appointments and bring it along for any planned or unplanned admissions to a healthcare facility.

Please note: *Any medical information provided is solely for the purpose of providing information and is not intended as medical advice. Our healthcare professionals cannot recommend specific treatments or make a diagnosis. We encourage you to direct any specific questions to your personal healthcare providers.*



I have Parkinson Disease
This is my

Personal Parkinson's Profile (PPP)

Name: _____

PERSONAL PARKINSON'S PROFILE (PPP)

The following is a set of detailed information about me and my journey with Parkinson's. It is in an organized, easily accessible format that will be available whenever it is needed. This PPP can be used by me, my family, and my healthcare team to help ensure that accurate, updated information is shared with everyone involved in my care.

This Personal Parkinson's Profile (PPP) Includes:

- Basic information about me
- Emergency contacts
- Detailed description of my PD symptoms
- A list of what makes my PD symptoms worse
- A list of daily activities I may need help with
- A list of all my current medications with dosage, time given and reason
- Information about other PD Treatments I may have
- Other health information about me
- Information about my healthcare team
- My insurance information
- My legal information
- Additional documents I chose to include in my PPP

The PPP is your most valuable tool for pre-surgery, planned admission to a hospital, rehabilitation center, assisted living facility or nursing home. There is a digital copy available on the included USB flash drive so that you can update and print your PPP as needed.

Remember to:

- Keep it updated and readily accessible.
- Make sure other family members/care partners know about it and know where it is kept.
- Bring the Time Matters book with you to medical appointments, urgent care visits, planned and unplanned admissions.

ABOUT ME

My name: _____

My birthday: _____

My address: _____

My phone numbers: Home: _____

Cell: _____

Work: _____

My e-mail: _____

Height: _____ Weight: _____

Blood Type: _____

Emergency contact #1:

Name: _____

Phone number (Home/Cell/Work): _____

Relationship to me: _____

Emergency contact #2:

Name: _____

Phone number (Home/Cell/Work): _____

Relationship to me: _____

MY CHARACTERISTICS OF PD

Check all that apply

- ☐ Anxiety
- ☐ Apathy (decreased motivation and interest)
- ☐ Bradykinesia (slowness of movement)
- ☐ Confusion (difficulty thinking clearly)
- ☐ Constipation
- ☐ Delusions (false beliefs; beliefs that are irrational)
- ☐ Dementia
- ☐ Depression
- ☐ Difficulty initiating activity (slow startup)
- ☐ Difficulty swallowing
- ☐ Difficulty walking
- ☐ Dizziness when changing positions (orthostatic hypotension; i.e. when changing from sitting to standing, lying to sitting, lying to standing)
- ☐ Drooling/excessive saliva
- ☐ Dyskinesia (sudden involuntary movements; *can be a result of medication*)
- ☐ Dystonia (muscle spasms)
- ☐ Fatigue
- ☐ Freezing of gait (inability to move, especially when turning corners, going through doorways or small spaces, when feeling rushed)
- ☐ Frequent falls
- ☐ Hallucinations (seeing and/or hearing things that are not there)
- ☐ Imbalance
- ☐ Impulse disorders (i.e. compulsive gambling, compulsive shopping)
- ☐ Loss of smell
- ☐ Masked face (lack of facial expression)
- ☐ Pain
- ☐ Paranoia
- ☐ Poor temperature regulation
- ☐ Rigidity/Stiffness (especially of muscles in arms, legs or trunk)
- ☐ Sexual dysfunction
- ☐ Sleep problems (insomnia and/or acting out dreams, etc.)
- ☐ Slow reaction to verbal commands
- ☐ Small/illegible handwriting
- ☐ Speech problems (reduced volume, slurred speech)
- ☐ Stooped posture
- ☐ Tremor (shaking at rest)
- ☐ Urinary dysfunction (i.e. incontinence)
- ☐ Wearing off of medication (when meds do not work as usual – time between doses)

NOTE: You can use the **APDA Healthcare Communication Graph** to easily track and communicate your symptoms with your healthcare provider.

This is found at <https://www.apdaparkinson.org/what-is-parkinsons/symptoms/>

THIS CAN MAKE MY PARKINSON'S SYMPTOMS WORSE:

- Not getting my medications on time
(Even 15 minutes late can cause me to become extremely slow, rigid, imbalanced, increased tremor and increase all other PD symptoms I checked on the previous page)
- Taking medication contraindicated for PD
- Stress and anxiety
- Need for rest
- Lack of exercise or physical activity
- Infection (especially urinary tract infections)

THIS CAN DECREASE MY PARKINSON'S MEDICATION EFFECTIVENESS:

- Taking medications with iron or an iron supplement (only if I take it at the same time, otherwise iron is ok)
- In some people (20%), protein decreases absorption and effect of PD medications. This may become more common with advancing PD. In this case, I should take my medication on an empty stomach to avoid the interaction.
If I have nausea, however, I should take medications with a carbohydrate (such as crackers, pretzels, etc.)
- Constipation can decrease the effectiveness of my medications

I MAY NEED HELP WITH THESE DAILY ACTIVITIES:

Check all that apply

- ☐ Bathing/showering
- ☐ Cleaning
- ☐ Cooking
- ☐ Dressing
- ☐ Driving a car
- ☐ Eating
- ☐ Getting in/out of bed
- ☐ Getting up from a chair
- ☐ Grooming/hygiene
- ☐ Hearing
- ☐ Moving from bed to chair
- ☐ Remembering things
- ☐ Speaking
- ☐ Stair climbing
- ☐ Taking medications
- ☐ Toileting
- ☐ Turning in bed
- ☐ Walking
- ☐ Writing
- ☐ Other:

IS GETTING MY PD MEDICATIONS ON TIME REALLY THAT IMPORTANT?

YES! The dosage and timing of medication is extremely important to help minimize my symptoms and decrease or eliminate my “off” or down times. In a health care environment, missing a dose or having it delayed can cause me to require extra care, which ends up costing extra time and resources as well as decreasing my quality of life. **I must be given my medications exactly as prescribed by my doctor!** *I realize that there are a lot of people who need medicine, but please prioritize the timing of my Parkinson’s medications if possible.*

INFORMATION ABOUT MY PHARMACY:

Name: _____

Phone number: _____

Address: _____

MY NEUROLOGIST/ MOVEMENT DISORDER SPECIALIST:

Name: _____

Phone number: _____

Hospital Association: _____

Address: _____

I TAKE THESE MEDICATIONS:

Medication	Dosage	Times Given	Purpose/ Prescribing Physician

OTHER PARKINSON DISEASE TREATMENTS I MAY HAVE

☐ Deep Brain Stimulation (DBS)

- A surgical procedure to help treat tremors, rigidity, stiffness, slowed movement, walking problems
- Does not slow down the disease or restore sick and dying nerve cells, but offers symptomatic benefits
- A thin electrode is implanted into the brain, targeting motor circuits that are not functioning properly.
- Small electrical pulses from a device similar to a cardiac pacemaker are then used to stimulate a small brain region and block the signals that cause some Parkinson's symptoms.
- 3 components:
 - Lead (implanted in brain), extension (wire under skin of head, neck and shoulder), neurostimulator ("battery pack" – implanted under the skin near the collarbone)
- DBS can be effective in treating:
 - Slowness or lack of movement (bradykinesia and akinesia)
 - Stiffness of muscles (rigidity)
 - Shaking of the limbs (tremor)
 - Gait problems that remain responsive to levodopa
 - Mild balance problems that remain responsive to levodopa
 - Motor fluctuation (variations in level of motor symptoms & their control by medication)
 - Dyskinesia
 - Dystonia (painful abnormal muscle activation causing toe curling or twisting of hand or feet)
 - Nighttime motor symptoms that emerge due to lack of frequent medication doses
- DBS typically does NOT improve:
 - Speech problems or Swallowing problems
 - Cognitive problems (thinking, memory) or Mood problems (depression, anxiety)
 - Freezing of gait or other movement that occurs when medications are working at their best
 - Moderate or greater balance problems
 - Bladder, bowel, or sexual dysfunction
- **Precautions:**
 - **X-rays, EKG and CAT scans are permitted and safe for use**
 - **DBS neurologist or neurosurgeon must be consulted if an MRI of any body part is necessary**
 - **Have DBS turned off for surgery that may involve electrocautery**

For additional and updated information on DBS, please visit <https://www.apdaparkinson.org/what-is-parkinsons/treatment-medication/deep-brain-stimulation/>

My DBS Specialist:

Name: _____

Phone Number: _____

OTHER PARKINSON DISEASE TREATMENTS I MAY HAVE

☐ **Duodopa Pump (Duopa)**

- Duopa is a gel suspension of carbidopa/levodopa used to treat advanced Parkinson disease.
- Typically prescribed to people who experience motor fluctuations with oral medications and contains 2 medicines: carbidopa and levodopa
- Duopa gel is delivered directly into the small intestine with a surgically implanted pump via a tube
- The procedure involves making a small hole (stoma) in the stomach wall to place a gastro-jejunostomy tube (PEG-J) in an area of the small intestine called the jejunum.
- The medication is delivered continuously into the intestine over 16 hours through the tube, by a small portable pump, which is worn or carried
- If you notice any redness, swelling, and/or pain around the stoma, please contact your neurologist or GI doctor immediately
- Most common side effects:
 - Swelling of legs and feet
 - Nausea
 - High blood pressure (hypertension)
 - Depression
 - Mouth and throat pain
- Other possible serious side effects:
 - Falling asleep during normal daily activities
 - Low blood pressure when you sit or stand up quickly (orthostatic hypotension)
 - Hallucinations
 - Compulsive urges (gambling, compulsive eating, compulsive shopping, increased sex drive)
 - Depression and suicide
 - Dyskinesia (uncontrolled sudden movements)
 - Neuropathy (progressive weakness or numbness or loss of sensation in the fingers or feet)
 - Heart attack or other heart problems
 - Abnormal blood tests
 - Glaucoma (worsening of the increased pressure in the eyes)

My Duodopa Pump (Duopa) Specialist:

- Name: _____
- Phone Number: _____

OTHER HEALTH ISSUES I MAY HAVE:

My non-Parkinson disease health issues:

My drug allergies:

My dietary needs/restrictions:

MY IMMUNIZATIONS:

Date Given	Vaccine Type

MY HEALTHCARE TEAM:

	Name & Description	Phone Number
My Primary Care Physician		
My Neurologist		
My Movement Disorder Specialist		
My Dentist		
Other Specialist: _____		
Other Specialist: _____		
Other Specialist: _____		
Other Healthcare Provider: _____		
Other Healthcare Provider: _____		

INSURANCE INFORMATION:

	Provider	Policy Number	Phone Number
Primary Insurance			
Secondary Insurance			
Dental Insurance			
Pharmacy			
Other Insurance (i.e. Vision/ Long-term care)			
Other Insurance (i.e. Vision/ Long-term care)			
Other Insurance (i.e. Vision/ Long-term care)			

LEGAL INFORMATION:

- ☐ I have an Advanced Directive (Living Will; *see the following pages for copy*)
- ☐ I have a Healthcare Power of Attorney (*see the following pages for copy*)
- ☐ I have a DNR (Do Not Resuscitate; *see the following pages for copy*)

	Name & Description	Phone Number
My Attorney		
My Financial Planner		
Other Important Contact (i.e. Caregiver, Home Health Provider, etc.)		
Other Important Contact: _____		
Other Important Contact: _____		
Other Important Contact: _____		

ADDITIONAL DOCUMENTS

Place copies of any additional documents you may want to have on hand for an emergency or planned admission in this section here, behind this page. This may include an advanced directive (living will), Healthcare Power of Attorney or DNR (Do Not Resuscitate).

You may also wish to include copies of your insurance cards or other documents.



Planning Ahead

- In Case of an ER Visit
- In Case of a Planned Admission
- Planning for Surgery
- What To Do When Medications Are Not Given On Time

IN CASE OF AN EMERGENCY ROOM VISIT:

- Make sure you **take this Time Matters book** along so your information can be correctly and easily shared with hospital personnel. This will save time and help ensure that your medication schedule is not interrupted, as well as help you remember essential health information while communicating with your healthcare team.
- Make sure you take your medications with you in case you have an extended wait

Remember, EMT and emergency room personnel may not be specifically trained to treat individuals with Parkinson's. Be prepared to be assertive and help educate them so they can understand the issues and how to help. One helpful document (referenced on pages 33-34) would be “**Medications to be avoided or used with caution in Parkinson's Disease**” and the most current version can be found at <https://www.apdaparkinson.org/what-is-parkinsons/treatment-medication/medication/meds-to-avoid-your-copy/>

PLANNING FOR SURGERY:

It's important to discuss the following things with the surgeon, nurse and/or anesthesiologist before surgery is planned:

- Pre-operative medication dosing instructions:
 - Some surgeons allow taking meds with sips of water the morning of the surgery. Contact your surgeon to discuss that.
 - If you are taking MAO-B Inhibitors, you may want to stop 1-2 weeks prior to surgery if indicated. Consult your physician.
- Restart PD medications post-surgery (except MAO-B Inhibitors) as soon as possible.
 - Discuss with surgeon.
 - Your neurologist may want you to wait 1-2 weeks after your hospitalization before restarting MAO-B Inhibitor, consult your physician.
- Be aware that people with Parkinson's may have a lower threshold to analgesics (sedation/pain medications) and could experience hallucinations, delusions, or confusion.
 - However, this is not a contraindication (reason to avoid their administration entirely, but should be used with caution).
 - Acetaminophen (Tylenol), Ibuprofen (Motrin) or Naproxen (Aleve) are sometimes reasonable alternatives and as soon as tolerated, these medicines should be given instead of narcotic pain medications.

Make sure that your medical care team is aware of the medications that should not be given to people with Parkinson disease.

Use the document (referenced on page 33-34) “**Medications to be avoided or used with caution in Parkinson's Disease**”. The most current version can be found at

<https://www.apdaparkinson.org/what-is-parkinsons/treatment-medication/medication/meds-to-avoid-your-copy/>

IN CASE OF A PLANNED ADMISSION TO A HOSPITAL, REHABILITATION CENTER, ASSISTED LIVING FACILITY OR NURSING HOME:

People with Parkinson disease can suffer great complications if their medications have been adjusted or changed. Stopping medications abruptly, receiving incorrect medication and/or not getting medications on time can all lead to complications.

The rules governing when medications are given allow one hour's leeway on either side of the scheduled administration time. Hospital staff are so overworked that it is difficult for even the best-intentioned staff to give all the medications on the optimal schedule.

It is important to maintain constant communication with the hospital staff.

- They want you to receive excellent care as much as you do. They just may not be well informed about Parkinson disease.
- They are teachable. Help them in a positive and non-hostile way, and do not accuse the staff of being incompetent and uncaring.

Suggestions for hospital stays and medication:

Adapted from "Making the Connection Between Brain and Behavior: Coping with Parkinson's Disease" by Joseph H. Friedman, MD and Southwest Parkinson News, Fall 2016

- If possible, get a letter from your Parkinson's doctor (neurologist or Movement Disorder Specialist) explaining the need for your PD medications to be given on time, every time, based on your home schedule.
- Always give the specific times you take your medications, not the number of doses per day. Be sure that the drug schedule used at home (with time and dose) is understood and copied into the hospital orders.
- Discuss with your nurse what happens to you if you don't get your medications on time. Also talk with them about how you and/or your care partner can help make sure you get your medications on time.
- Don't take or give medications on your own.
- Some medication changes can be accepted but it is best for hospital staff to check in with your neurologist/Movement Disorder Specialist.

- In some cases, people may be taking medicines not stocked in the hospital pharmacy.
 - If your medication is non-formulary, talk with the hospital staff and/or the hospital pharmacy about their policies and procedures for medications from home.
 - If an experimental drug is being used, take the medications in their original bottles along with the instructions to the hospital to ensure that doses are not missed.
- To prevent deconditioning, physical therapy (PT) and occupational therapy (OT) are helpful while in hospital.
 - Talk to your nurse and therapist about scheduling your PT/OT sessions when you are ON, so you will get optimal benefit from your session.
 - A rehabilitation stay after a hospital visit would also be helpful

Other things to keep in mind:

- Confusion can be a significant problem for people with PD who are hospitalized.
 - May be caused by stress, changes in environment, strangers, continuous noise/lights
 - May present as delirious state with disorientation, misperceptions or hallucinations
- People with PD whose symptoms fluctuate (“on” and “off” periods) are often poorly understood in the hospital.
 - The staff could think the person is trying to be “babied” when he turns “off”, asking for help in dressing or eating when he had been sauntering down the corridor unassisted only a few minutes earlier.
 - Occasionally dyskinesia, the writhing movements caused by levodopa medication or oversensitivity, are thought to be attention-getting tricks rather than involuntary and unwanted movements.

WHAT TO DO WHEN MEDICATIONS ARE NOT GIVEN ON TIME:

1

- Be vocal about your medication needs to nurses
- Be prepared to share information about Parkinson's during each phase of a stay at a hospital, rehab center, extended care facility or nursing home
- Be assertive and persistent with your healthcare team, not aggressive

2

- Ask to speak with the charge nurse for the unit or floor
- Explain that you have Parkinson's and tell them about your symptoms, how you feel and the importance of getting your medication on time

3

- Speak with the facility's pharmacist.
- Discuss your medications with them and ask what you can do together to help get them on time.

4

- Call your Parkinson's doctor (neurologist or Movement Disorder Specialist) and ask them to call the doctor overseeing your care at the hospital or facility

5

- Ask to speak to a patient care advocate
- Many hospitals have a patient advocate or patient representative department
- These advocates are available to help you navigate the hospital system and coordinate care when necessary.

6

- If you are at a nursing home, request support from a long-term care ombudsman. Ombudsmen are volunteers who serve residents of nursing homes and residential care facilities to offer support and advocacy.
- St. Louis area VOYCEconnect helpline: [314.919.2403](tel:314.919.2403)
- Missouri State Office of Long-Term Care Ombudsman Program: [800.309.3282](tel:800.309.3282)
- Illinois State Department on Aging Senior Helpline: [800.252.8966](tel:800.252.8966)

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- If none of these suggestions get results, call the APDA-Greater St. Louis Chapter at [636.778.3377](tel:636.778.3377) and ask to speak with the coordinator of the Medication Advocacy Program to get additional support.

Medications Approved for the Treatment of Parkinson Disease

Updated May 2018

Mechanism of action	Generic name	Trade name®	Common side effects*
DOPA Decarboxylase inhibitor/DA precursor	Carbidopa/Levodopa	Sinemet	Nausea, dizziness, orthostatic hypotension, anxiety, dyskinesia, confusion, hallucinations, somnolence
	Carbidopa/Levodopa (controlled release)	Sinemet CR	
	Carbidopa/Levodopa (orally disintegrating)	Parcopa	
	Carbidopa/Levodopa (extended release capsules)	Rytary	
	Carbidopa/Levodopa (enteral suspension)	Duopa	
COMT inhibitor, inhibits breakdown of levodopa	Entacapone	Comtan	Same as carbidopa/levodopa. In addition: diarrhea, discoloration of body fluids. Tasmar can cause elevated liver function enzymes.
	Tolcapone	Tasmar	
DOPA decarboxylase inhibitor/DA precursor/ COMT Inhibitor	Carbidopa/Levodopa Entacapone	Stalevo	Same as carbidopa/levodopa and COMT inhibitor
DA agonist	Pramipexole	Mirapex	Nausea, dizziness, orthostatic hypotension, swelling of ankles, dyskinesia, hallucinations, confusion, somnolence, sleep attacks, impulse control disorders Neupro can lead to a skin reaction at the patch site
	Pramipexole (extended release)	Mirapex ER	
	Ropinirole	Requip	
	Ropinirole (extended release)	Requip XL	
	Apomorphine (injection)	Apokyn	
	Rotigotine (transdermal patch)	Neupro	

COMT = catechol-o-methyltransferase

DA = dopamine

DOPA = dopamine

MAO-B = monoamine oxidase B

NMDA = n-methyl-d-aspartate

**The most common side effects are listed. Additional side effects, should be discussed with your health care provider.*

The updated version of this document can be found at:

<https://www.apdaparkinson.org/what-is-parkinsons/treatment-medication/medication/>

Medications Approved for Treatment of Parkinson Disease (continued)

Mechanism of action	Generic name	Trade name®	Common side effects*
MAO-B inhibitor, inhibits breakdown of dopamine	Selegiline	Eldepryl	Selegiline can cause insomnia Dizziness, nausea, gastrointestinal upset, dyskinesia, hallucinations, confusion, headache Note possible drug interactions Safinamide exerts its effects through other mechanisms of action as well
	Selegiline (orally disintegrating)	Zelapar	
	Rasagiline	Azilect	
	Safinamide	Xadago	
Mixed mechanisms, including NMDA antagonism	Amantadine	Symmetrel	Hallucinations, leg swelling, dizziness, mottled skin (livedo reticularis), confusion, dry mouth and eyes, constipation, dizziness, orthostatic hypotension, somnolence
	Amantadine (extended release)	Gocovri	
Anticholinergic	Trihexyphenidyl	Artane	Dry mouth and eyes, constipation, urinary retention, memory impairment, confusion, depression, hallucinations
	Benzotropine	Cogentin	

COMT = catechol-o-methyltransferase

DA = dopamine

DOPA = dopamine

MAO-B = monoamine oxidase B

NMDA = n-methyl-d-aspartate

**The most common side effects are listed. Additional side effects, should be discussed with your health care provider.*

The updated version of this document can be found at:

<https://www.apdaparkinson.org/what-is-parkinsons/treatment-medication/medication/>

Reminders for your healthcare team:

- Before making changes to any Parkinson's medications, contact the prescribing neurologist or Movement Disorder Specialist
 - This includes adding new medications, discontinuing a current medication, changing dosages, changing or adjusting times given, substitutions, etc.
- If you have any concerns or questions about the Parkinson's medications, or if you are considering making changes to the Parkinson's drug therapy, please continue to follow the exact instructions as prescribed until you have discussed it with the prescribing neurologist or Movement Disorder Specialist.

Medications to be Avoided or Used With Caution in All People with Parkinson Disease

Medication Type	Medication Name	Brand Name	Mechanism of Action
Typical Antipsychotics	Chlorpromazine Fluphenazine Haloperidol Loxapine Thioridazine Thiothixene Trifluoperazine Pimozide Perphenazine	Thorazine® Prolixin® Haldol® Loxitane® Mellaril® Navane® Stelazine® Orap® Trilafon®	Block D2 (dopamine) receptors in the brain, which can worsen Parkinson's symptoms
Atypical Antipsychotics	Risperidone Olanzapine Ziprasidone Aripiprazole Lurasidone Paliperidone Iloperidone Brexpiprazole Cariprazine Asenapine	Risperdal® Zyprexa® Geodon® Abilify® Latuda® Invega® Fanapt® Rexulti® Vraylar® Saphris®	Block dopamine receptors, but dissociate from the receptor more quickly than typical antipsychotics. They also tend to block serotonin receptors in addition to dopamine receptors. The result is less parkinsonism than that caused by the typical antipsychotics.
Antiemetics (used to treat nausea or vomiting)	Chlorpromazine Droperidol Metoclopramide Prochlorperazine Promethazine	Thorazine® Inapsine® Reglan® Compazine® Phenergan®	Block D2 (dopamine) receptors in the brain, which can worsen Parkinson's symptoms
Drugs to treat hyperkinetic movements such as chorea and tardive dyskinesia	Tetrabenazine Deutetrabenazine Valbenazine	Xenazine® Austedo® Ingrezza®	Decrease dopamine stores
Antihypertensives	Reserpine	Serpalan	Decreases dopamine stores
	Methyldopa	Aldomet®	Inhibits an enzyme which converts L-dopa into dopamine in the brain
Antidepressants	Phenelzine Tranylcypromine Isocarboxazid	Nardil® Parnate® Marplan®	Block monoamine oxidase non-selectively. If taken in combination with certain classes of PD meds, these medications could result in dangerous increases in blood pressure and agitation
	Amoxapine	Asendin®	Although classified as a tricyclic anti-depressant, it can also block dopamine receptors

Note: If an anti-psychotic that blocks dopamine receptors needs to be used, atypical anti-psychotics are better choices than typical antipsychotics. Clozapine (Clozaril®) and Quetiapine (Seroquel®) are dopamine blockers with the least risk of worsening Parkinson symptoms. Pimavanserin (Nuplazid®) is a serotonin inverse agonist and was approved specifically for use as an anti-psychotic in patients with Parkinson's disease.

© Revised and Updated by Rebecca Gilbert, MD, PhD, APDA Vice President, Chief Scientific Officer – March 2018

The information contained in this supplement is solely for the information of the reader. It should not be used for treatment purposes, but rather for discussion with the patient's own physician.

The most current version of this document can be found at:
https://d2icp22po6iej.cloudfront.net/wp-content/uploads/2018/05/APDA-Meds_to_Avoid.pdf

Medications to be Avoided or Used With Caution
in Combination with Selegiline HCL (Eldepryl®, Deprenyl®, Zelapan®),
Rasagiline (Azilect®) and Safinamide (Xadago®)

Medication Type	Medication Name	Brand Name
Narcotics/Analgesics	Meperidine Tramadol Methadone Propoxyphene	Demerol® Ultram® Dolophine® Darvon®
Antidepressants	St. John's Wort	Several Brands
Muscle Relaxants	Cyclobenzaprine	Flexeril®
Cough Suppressants	Dextromethorphan	Robitussin® products, other brands — found as an ingredient in various cough and cold medications
Decongestants/Stimulants	Pseudoephedrine Phenylephrine Ephedrine	Sudafed® products, other brands — found as an ingredient in various cold and allergy medications
Other medications that inhibit Monoamine oxidase	Linezolid (antibiotic) Phenelzine Tranylcypromine Isocarboxazid	Zyvox® Nardil® Parnate® Marplan®

Note: Additional medications are cautioned against in people taking Monoamine oxidase inhibitors (MAOI), including other opioids (beyond what is mentioned in the chart above), most classes of antidepressants and other stimulants (beyond what is mentioned in the chart above). However, there are patients who have successfully taken these medications in combination. Please discuss these medications with your neurologist. Antidepressants that are also MAOIs are absolutely contraindicated.

Medication Reminder

- This medication list is not intended to be complete and additional brand names may be found for each medication. Every patient is different and you may need to take one of these medications despite caution against it.
- Please discuss your particular situation with your physician and do not stop any medication that you are currently taking without first seeking advice from your physician. Most medications should be tapered off and not stopped suddenly.
- Although you may not be taking these medications at home, one of these medications may be introduced while hospitalized. **If a hospitalization is planned, please have your neurologist contact your treating physician in the hospital to advise which medications should be avoided.**



Additional Resources

- About Parkinson disease
- Tips for managing PD well
- Urinary Tract Infections (UTIs)
- Orthostatic Hypotension (nOH)
- Parkinson's Disease Psychosis (PDP)
- Choosing a Long-Term Care Facility
- Helpful Terms

ABOUT PARKINSON DISEASE

Parkinson disease (PD) is a chronic, degenerative neurological disorder that affects one in 100 people over the age of 60. PD was first characterized in 1817 by an English physician, James Parkinson.

Parkinson disease is a disorder of the central nervous system that results from the loss of cells in various parts of the brain, including a region called the substantia nigra. The cells in the substantia nigra produce dopamine, a chemical messenger responsible for transmitting signals within the brain that allow for coordination of movement.

Loss of dopamine causes neurons to fire without normal control, leaving people with PD less able to direct or control their movement. PD is one of several diseases categorized by clinicians as a movement disorder.

The exact cause of Parkinson disease is unknown, although research points to a combination of genetic and environmental factors. Parkinson disease impacts approximately one million people in the United States, and more than five million worldwide. At the present time, there is no cure.

There are many common motor and non-motor symptoms of Parkinson disease. However, these will vary from person to person. They can also change over time, and may or may not appear in each person. Medications can manage many of the motor and non-motor symptoms of Parkinson disease. Listed below are some of the most common symptoms. This is not an exhaustive list.

Motor Symptoms May Include:

- Tremor
- Rigidity
- Slow Movement
- Balance Problems
- Walking/Gait Problems

Non-Motor Symptoms May Include:

- Sleep Problems
- Depression and Anxiety
- Fatigue
- Urinary and Gastrointestinal Issues
- Voice and Swallowing Issues
- Cognitive issues

For additional and updated information about *Parkinson's Disease*, please visit
<https://www.apdaparkinson.org/what-is-parkinsons/>

For a list of *educational supplements* on numerous topics, please visit
<https://www.apdaparkinson.org/resources-support/download-publications/>

TIPS FOR MANAGING WELL

Assemble a Team

Your care “team” cannot just include doctors and nurses, it must also include other health professionals such as speech, physical and occupational therapists that can help you live better with PD. Many people with PD find that these therapies can give them symptom relief, ease pain and enhance their lives.

Exercise

While the precise role exercise plays in delaying the progression of the disease and its symptoms is still being researched, studies consistently report that those with PD who exercise regularly do better than those who do not. Many experts recommend intense exercise outside of your normal comfort zone for maximum benefit, but studies also show benefits from less intense activities like walking, tango dancing and tai chi. As always, consult your doctor before beginning any exercise program.

Eat Right

There is no agreement on any special diet or supplements for PD, but most experts agree that a healthy diet with plenty of water is important. Healthy eating can help keep your bones strong, decreasing the likelihood of a fracture if you fall. It also helps you fight constipation, which is common with PD.

Sleep

We all know how critical a good night’s sleep is to our health and well-being. However, for those with PD, sleep becomes even more important as the body needs more time to restore and repair itself. Sleep disorders are common in PD, but get your rest when you can!

Sign up for Clinical Trials

By participating in clinical trials, you play a more active role in your own healthcare and can gain access to new PD treatments before they become widely available. Many clinical trials for potentially valuable new therapies and treatments are developed at great cost but are never completed because of a shortage of willing participants. If you are interested in clinical trials, your doctors can help you make an informed decision.

Become an Advocate

You become a PD advocate whenever you become involved in activities intended to improve the lives of people living with PD. Whether you choose to raise awareness, fundraise, donate, volunteer, or find your own unique way of lending support, the work of every PD advocate strengthens the voice of the entire PD community.

Join a Support Group

The APDA offers many programs for people with PD and caregivers. These programs help families with day-to-day issues, provide a forum for gathering about PD and serve as a place to make new friends who share similar experiences. For many people with PD, their support group is a gateway into the world of PD advocacy, education, and services available in the community.

To find an APDA support group, please visit our website: apdaparkinson.org/greaterstlouis

Plan for the Future

PD can require you to plan for the costs of medication, insurance and other health care related needs. You may also have employment concerns. Financial planning information and tools are available online and from financial and estate planners, elder law attorneys and disability consultants.

For additional and updated information about managing Parkinson’s Disease, please visit <https://www.apdaparkinson.org/resources-support/living-with-parkinsons-disease/>

URINARY TRACT INFECTION (UTI)

People with PD are prone to urinary tract infections (UTIs). When the bladder is full, it alerts the brain through nerve cells and the brain uses additional nerve cells to tell the muscles to relax and allow the urine to be expelled. A person with PD may not have enough muscle control to completely empty their bladder, causing a perfect breeding ground for bacteria. Incontinence may also contribute to frequent UTIs.

- Typical signs/symptoms are:
 - Cloudy urine
 - Bloody urine
 - Strong/foul-smelling urine
 - Frequent or urgent need to urinate
 - Pain/burning with urination
 - Pressure in the lower pelvis
 - Low-grade fever
 - Night sweats, shaking or chills
- Other possible symptoms (behavioral):
 - Confusion or delirious state
 - Agitation or restlessness
 - Hallucinations or delusions
 - Other behavioral changes
 - Agitation
 - Refusal to take PD medications
 - Refusal to eat
 - Poor motor skills, dizziness and falls
- **Many people with PD and UTIs do not present with urinary symptoms but may present only with cognitive decline, psychosis or increased motor symptoms of PD.**

NEUROGENIC ORTHOSTATIC HYPOTENSION (nOH)

Neurogenic orthostatic hypotension (nOH) is a sharp drop in blood pressure that happens when a person changes position (such as sitting to standing, lying to sitting), causing dizziness or even loss of consciousness. This condition can put people with PD at risk of fainting, losing balance and falling.

- Symptoms of nOH include:
 - Lightheadedness or dizziness
 - Weakness
 - Difficulty thinking
 - Headache
 - Fainting or feeling faint
 - Trembling
 - Nausea
 - Cold hands and feet
 - Chest pain
 - Pain in back of neck when standing
- Both Parkinson's itself and the medications that are used to treat it can contribute to nOH
- Additional causes include diuretics, cardiac disease, dehydration, fever and anemia
- Behaviors and circumstances that can make nOH worse:
 - Dehydration
 - Exposure to heat
 - Fever
 - Prolonged standing
 - Vigorous exercise
 - Drinking alcohol
 - Certain times of day (especially early morning)
 - Straining while going to the bathroom
 - Changing the position of the body (e.g. standing up)
 - Meals high in carbohydrates
- Tips for avoiding neurogenic orthostatic hypotension
 - Drink lots of water and other fluids
 - After consulting with your doctor, increase your salt intake
 - Exercise gently and regularly – avoid long periods of inactivity
 - Eat small, frequent meals
 - Reduce alcohol intake
 - Avoid hot drinks and hot foods
 - Review all medications with your doctor as some can make this much worse
- If you experience dizziness in the morning:
 - Raise the head of the bed by 4 inches
 - Drink a cold glass of water 30 minutes before getting up
 - Do exercises before getting up that contract the leg or feet muscles
 - Shift slowly from lying to sitting and then standing
 - Use compression garments, such as antigravity stockings
- In some cases, medications to raise blood pressure can be prescribed, but non-pharmaceutical approaches are tried first

PARKINSON'S DISEASE PSYCHOSIS (PDP)

Dr. Rebecca Gilbert, MD, PhD

What is Parkinson's disease psychosis?

- Parkinson's disease psychosis is a non-motor symptom of Parkinson's disease that causes patients to experience hallucinations and/or delusions. More than half of all patients with Parkinson's disease eventually develop symptoms over the course of their disease.¹
- Diagnosing and treating this condition can be complex. The condition relates to both neurology (the branch of medicine that deals with the nervous system) and psychiatry (the branch of medicine that is focused on mental and behavioral health). For this reason, Parkinson's disease psychosis is considered a neuropsychiatric condition, since it deals with mental health symptoms (hallucinations and delusions) caused by a disease of the nervous system (Parkinson's disease).

What causes Parkinson's disease psychosis?

Currently, there is not a clear understanding of the exact cause of Parkinson's disease psychosis, although certain brain chemicals and receptors (e.g. dopamine and serotonin) are believed to play a role. In general, the condition is believed to be caused by either one of the following:

Side effect of dopamine therapy:

- Although an exact causal relationship has not been established, some believe that this condition may be a side effect of dopaminergic therapy (dopamine drugs are the most common treatment for Parkinson's disease).² Dopaminergic therapy increases dopamine levels, helping improve motor symptoms in patients with Parkinson's disease. However, increasing dopamine levels can also cause chemical and physical changes in the brain that inadvertently lead to symptoms such as hallucinations or delusions.

Natural outcome of the disease:

- This condition can be triggered by changes in the brain that occur regardless of taking dopamine enhancing medication. Some of these changes occur naturally as Parkinson's disease progresses.²

Who's at risk for Parkinson's psychosis?

- There's no predicting with certainty which patients with Parkinson's disease will go on to develop symptoms like hallucinations or delusions. A number of risk factors – both internal and external- are associated with the condition. Some of these risk factors include: age, duration and severity of Parkinson's disease; and the taking of dopamine therapy.³⁻⁶

What are the symptoms of Parkinson's disease psychosis?

- Two of the most prominent symptoms are hallucinations and delusions.⁷ Hallucinations involve seeing, hearing, experiencing or sensing things that are not really there. Delusions are false beliefs that are not based in reality. In describing symptoms of Parkinson's disease psychosis, patients may use such common terms as: seeing things, paranoia, flashbacks, nightmares, false beliefs, or not being in touch with reality.⁸

Psychosis Medication

Pimavanserin (PEA-ma-VAN-ser-in) (Nuplazid™) is approved to treat hallucinations and delusions that may develop in advanced PD. It can cause swelling of the ankles, constipation and confusion. Those with heart rhythm disturbances should avoid taking this medication.

Why isn't there a greater awareness of Parkinson's disease psychosis?

- It's not uncommon for people with Parkinson's disease psychosis to remain silent about their experiences.^{2,4,9} In fact, only 10% to 20% actually report their symptoms to their physicians.⁴⁻⁹ Work continues to be done to raise awareness of this condition.

How can I get help?

- First and most importantly, if you find yourself experiencing symptoms such as hallucinations or delusions, speak out. It is essential to talk about your full range of Parkinson's disease symptoms with your treatment team. A dialogue among patients, care partners, and physicians is a critical component of the effective management of your condition.

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CHOOSING A LONG TERM CARE FACILITY

Deciding to move to a long term care facility (i.e., nursing home, assisted living, etc.) can be a difficult and overwhelming process. The Centers for Medicare & Medicaid Services recommend the following steps:

1. Find facilities in your area by asking your friends and family, as well as your healthcare team. The APDA can also offer recommendations.
2. Compare the quality of the facilities you're considering using online resources or by contacting your local long term care ombudsman.
3. Visit the facilities you are interested in. You may want to go with a family member or care partner to get their perspective. Bring along questions to ask and visit the facility at different days and times if possible. The APDA-Greater St. Louis Chapter recommends asking the following questions:

- Do you have experience with residents with Parkinson disease?

- If you currently have residents with Parkinson's, how many do you have?

- Is the staff familiar with the importance of Parkinson's medications being given on time?

- What procedures are in place to ensure residents with Parkinson disease get their medications on time?

4. Choose the long term care facility that meets your needs. If more than one meets your needs, use the research you have done to compare them. Trust your gut instinct, and if you didn't like something when you visited, you will likely feel better selecting a different facility.

For additional resources and recommendations on choosing a long term care facility, contact the APDA-Greater St. Louis Chapter or view our online resources at www.apdaparkinson.org/greaterstlouis.

HELPFUL TERMS

Action tremor: A tremor that occurs with intentional movement, for example when pouring a drink

Anticholinergic: A class of drug often used for the management of PD, typically as additional medications to other standard PD therapies; used to reduce the tremor or ease the problems associated with the wearing off of levodopa therapy

Bradykinesia: Slowness of movement

Carbidopa-levodopa: A combination medication commonly used to treat PD; intended to increase dopamine levels in the brain

Care partner: A person, such as a close family member or friend, who supports an individual with a chronic medical condition

Clinical trials: Studies conducted in humans, often involving a drug or another type of treatment

Cognitive: Pertains to thought processes, such as memory, attention, concentration and judgment

COMT inhibitor: A class of drug that blocks catechol-O-methyltransferase (COMT), an enzyme that breaks down dopamine and levodopa; used in PD to prevent the breakdown of levodopa therapy before it reaches the brain

Contraindication: A situation in which a drug, procedure or surgery should not be used because it may be harmful to the person

Dopamine: A brain chemical (neurotransmitter) that enables movement; brain levels of dopamine decrease in certain brain regions in people with Parkinson disease

Dopamine agonist: A class of drugs that bind to dopamine receptors in the brain to mimic the action of dopamine

Dyskinesia: Fragmented or jerky movements of the limbs or torso; often apparent at peak times of levodopa therapy in more advanced PD

Dysphagia: Difficulty swallowing

Dystonia: Involuntary muscle contractions that may cause sustained or repetitive twisting, spasms or cramps

Gait: Pattern of walking

General neurologist: A physician who is trained to diagnose and treat a variety of neurologic disorders

Hypomimia: A reduced or mask-like expression of the face

Internal tremor: Sensation of vibration inside the body

Lewy bodies: Clumps of protein (alpha-synuclein) found in the nerve cells in certain brain regions of people with PD and related conditions

Micrographia: Small handwriting

Motor symptoms: Symptoms that primarily involve movement

Movement disorder: A neurological condition that affects movement

Movement disorder specialist: A neurologist who has undergone specialized training to diagnose and treat movement disorders such as Parkinson disease

Neurogenic Orthostatic Hypotension (nOH): The body's inability to quickly regulate blood pressure, particularly when sitting from a lying position or standing from a sitting position

Non-motor symptoms: Symptoms that do not primarily involve movement

“On-off” phenomenon: Unpredictable swings from mobility to immobility that happen towards the end of a medication dose; usually seen in people with more advanced PD who are treated with levodopa therapy

Parkinsonian syndromes: Movement disorders that are not idiopathic PD but have some overlapping symptoms, such as rigidity and slowness or movement

Primary insomnia: The inability to fall asleep

Resting tremor: A tremor that occurs when a person is at rest; a hallmark of PD

Rigidity: Stiffness of the muscles

Secondary MAO-B inhibitors: Drugs that selectively block the enzyme monoamine oxidase B (MAO-B) in the brain; MAO-B breaks down dopamine

Tremor: An involuntary quivering movement or shake

Urinary frequency: The need to urinate often

Urinary hesitancy: Difficulty initiating a urine stream

Urinary urgency: The feeling that one must urinate right away, even if the bladder is not full

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