Six Steps to Optimum Care

TAKE ACTION AT HOME

The best way to avoid medication-related problems and other complications during a hospital stay is to prepare beforehand. Here's what you can do.

STEP 1 Prepare Your Aware in Care Kit

Make sure the contents provided with your kit are completed and up to date.

☐ **Medication Form.** Write down all of your prescriptions and over-the-counter medications for Parkinson's and any other medical conditions. If writing by hand is difficult, this form can also be completed online at Parkinson.org/AwareInCare. Make five copies of the "Medication Form" and put the original form in the kit. When your prescriptions change, be sure to fill out a new form, then make copies and replace the outdated ones in your kit.

☐ **Fill out the Medical Alert Card.** This card includes vital information about treating people with Parkinson's disease, including medications that are not safe for Parkinson's patients. Complete the back of the "Medical Alert Card." Put the card in your wallet.

In addition to what is provided, add these key items to your kit:

☐ **Emergency Contact List.** This should include names, phone numbers, emails and addresses of your primary care physician, Parkinson's doctor, other specialists (if applicable), your care partner and close family members. Put a copy of this list in your Aware in Care kit. Review and update the list every six months.

☐ **Health Care Proxy Card.** If you become incapacitated and unable to express yourself, who do you want to carry out your wishes? Work with a lawyer to create a Health Care Proxy Form that complies with your state guidelines to identify the individual(s) authorized to make medical decisions for you. Consider various scenarios such as end-of-life care and hospice. Keep a copy of your signed Health Care Proxy Form in your kit.

☐ **Parkinson's Medications.** Keep an extra supply of all your current medications in your Aware in Care kit. That way, if you have a medical emergency, you can pick up the bag and leave in a hurry, knowing you have everything you need. Make sure all medications are stored in their original bottles and your name is marked on each label. Then check that the dose written on the label matches what you are actually taking.

Once your kit is fully stocked, take these steps to stay prepared:

☐ **ID Bracelet.** Wear this bracelet on your wrist at all times. The front of the bracelet alerts medical professionals to the fact that you have Parkinson's disease and also refers them to the wallet card for more information. The back of the bracelet has the toll-free Parkinson's Foundation Helpline number, 1-800-4PD-INFO (473-4636). Encourage hospital staff to call the number if they have questions about Parkinson's disease.

☐ **Keep your Aware in Care kit handy.** Tell your care partner where you store the kit in case they need to get it in a hurry.

☐ **Share with your loved ones.** Ask your care partner and family to review the kit and this booklet with you so that they can help you educate the hospital staff.

STEP 2 Find a Good Hospital

Get to know the hospitals in your community before you need one. Map out where you will go if an emergency requires you to go to the hospital. It is your right as a patient to ask questions, so call ahead and ask:

- Do you have a neurologist available for patient consultation in the hospital?
- Do you stock a wide range of Parkinson's medications in the pharmacy?
- What is your rule on Parkinson's patients taking their own medications?
- How do you accommodate requests for medications at specific times during the day?
- How do you accommodate special dietary requests?
- Do you have staff trained in Parkinson's disease management?
- Do you provide outpatient care for Parkinson's patients?

WHEN YOU ARE IN THE HOSPITAL

Whether your hospital visit is planned or urgent, make sure these vital steps are never left out. Here is how to get the most from your care team.

STEP 3 Be Vocal

- **Request a consultation with a neurologist.** Provide the neurologist with a copy of your Medication Form and discuss your medical condition. Make sure the neurologist is consulted on all medication and treatment decisions during your entire hospital stay.
- **Ask your Parkinson's doctor to contact the doctor in charge of your care in the hospital.** He or she should provide detailed information about your medical condition and medications.
- **Share your knowledge about Parkinson's disease with the nurse(s) and doctor(s) in charge of your care during your stay.** Use the "Parkinson's Disease Fact Sheet for Nurses" in your kit to share vital information about your needs as a person with Parkinson's. If you ever run out, call our Helpline to request another pack.
- **Each time you are asked about the medications you take, provide a copy of the Medication Form.** You may have to supply this information multiple times. Although this can be frustrating, it is critical that you hand each person that asks a complete list of your medications. Also explain to every new person you meet that you need your medications delivered on time, every time to control your Parkinson's symptoms.
- **If you brought your medications with you in their original bottles to the hospital, let your nurses and doctors know**. Ask if all of your medications are available in the hospital pharmacy. If not, find out what the hospital's policy is for using your own supply during your hospital stay. Some hospitals will allow this.

- **Be Persistent!** It can be difficult to let others know what you need, but it's critical to give clear direction upon your arrival. Talk with the nurses and doctors who are taking care of you in the hospital about your symptoms and how you feel.

  Say, for example, "My voice is low and I often lack facial expressions due to Parkinson's, but this doesn't mean I'm ignoring you or I don't understand." Or, "I need time to answer your questions." If you experience "on-off" fluctuations, explain that you may need help with basic tasks at times.

- **If the length of your hospital stay is longer than one day, you will probably encounter new staff each day.** Assume that each person you meet has little experience with Parkinson's disease and likely does not understand your symptoms, the importance of getting you your medications on time, every time or the medications you should avoid.

- **The best way to share information is to present each member of your care team with an "Parkinson's Disease Fact Sheet for Nurses."** When you hand one to a new person, you might say, "Hi, my name is _____, and I have Parkinson's disease. I want to share some of the key information about Parkinson's. Most important, I need my medications on time, every time, to ensure my symptoms are well-controlled. I can answer any questions you might have and there is a Parkinson's Helpline you might want to call 1-800-4PD-INFO (473-4636). Thank you for helping me."

- Most people you meet will appreciate your efforts to share your knowledge about Parkinson's. However, if you feel your nurse or doctor isn't listening to you, it is important to take action. If you have trouble speaking, ask your care partner, friend or family member to speak up for you. Here are some ways to keep your care on track.

  - **Ask to speak to the nurse in charge of the unit or floor.** Explain to him or her that you have Parkinson's. Share the information in your kit. Talk about your symptoms and how you feel.

- **Tell the nurses to come back 30 minutes after giving you your medication.** They might not understand how much the drugs affect your ability to move until they see it for themselves.
- **Call your Parkinson's doctor.** Tell him or her about your concerns and ask if he or she will call the doctor in charge of your care in the hospital.
- **Ask to see a patient advocate.** Many hospitals have a patient advocate or patient representative department. These professionals are available to help patients navigate through the hospital system and to coordinate care when necessary.

STEP 4 Get Moving

— **Soon after your medical procedure, it is vital that you get out of bed and start moving, if possible.** Even if you are unable to get out of bed, there are exercises you can do that will help speed your recovery.

— **You should ask for physical, occupational or speech therapy, depending on your symptoms and needs.** During your stay, take the opportunity to have an experienced professional show you how to build your physical skills and strength. Ask your doctor if you qualify to receive physical therapy at home after you are discharged.

STEP 5 Stay on Top of Your Care

It is essential to pay attention to the medications, treatments and tests you get throughout your stay.

— Never agree to any treatment that you are not certain about. Talk openly about all concerns. For example, if you have a deep brain stimulator, make sure the doctors and nurses know. Before getting an MRI or any diagnostic test, tell your doctor, nurse and MRI technician that there are specific protocols to follow.

— Know which medications are safe. Before taking any medications, double check the list found in the back of this booklet and on your "Medical Alert Card." If you have questions, ask to speak to your doctor.

Dietary considerations:

- Gastrointestinal, digestion and constipation issues are common in people with Parkinson's. For example, eating protein may impact medication absorption. Some people with Parkinson's find that taking their Parkinson's medications an hour before mealtime is most effective.
- If you have issues with swallowing and drooling, request modifications to the food you receive and avoid foods that contribute to drooling (such as sweets). Also, if you take medication for constipation at home, list this on your "Medication Form" so that you will continue to receive stool softeners while you are in the hospital.
- Consider asking for a nutrition consultation. Tell the nutritionist what works best for you, and make sure he or she communicates these special needs to the doctors and nurses who are caring for you.

Discharge plan and instructions:

- At the end of your stay, your doctor and nurse should provide you with a set of instructions to follow when you get home. Make sure you and your care partner understand the plan and never hesitate to ask questions if something is not clear.

STEP 6 Follow Up and Provide Feedback

- **Contact your Parkinson's doctor and your primary care physician and give them a progress report.** If possible, fax or mail them a copy of your discharge instructions.
- **Find out what follow-up care you will need and what things you can do at home to help control and improve your condition.** Based on your situation, ask whether you could benefit from medication equipment or additional care such as physical therapy or home care, if these have not already been set up by the hospital.

Parkinson's Foundation

Patient Name: ______________________________________

DOB: ______________________________________

______________________ lives with Parkinson's disease, placing them into a high-risk group for developing serious complications from COVID-19. Though their immune system is not compromised, they are more prone to pneumonias and infections, and **infections can cause sudden changes in behavior and motor function, increasing their risk of complications significantly.** Below are some recommendations that will help to keep his/her Parkinson symptoms stable and reduce unnecessary complications.

- (S)he requires his/her Parkinson medications on time, **based on the specific time (s)he takes them at home**. This schedule allows his/her Parkinson symptoms to remain under control. Their current medication schedule is stapled to this letter. If nurses are unable to distribute medications based on their specific schedule (NOT allowing for an hour window before or after the prescribed times) we recommend giving the patient and/or their care partner the authorization to self-administer medications while in the hospital. A strict adherence to the medication schedule is imperative to avoid unnecessary complications and an extended hospitalization.
- While we recognize that there may be some situations that require isolation of the patient, we must stress the importance of having a care partner present as an advocate whenever possible.
- Should delirium occur, **avoid haloperidol (Haldol) and most neuroleptics. Neuroleptics that are considered safe for Parkinson disease are** pimavanserin (Nuplazid), Seroquel (quetiapine) and Clozaril (clozapine).
- Prochlorperazine (Compazine), metoclopramide (Reglan), promethazine (Phenergan) and droperidol (Inapsine) are contraindicated for use in Parkinson Disease. Should an anti-emetic be required, safe alternatives are Tigan (trimethobenzamide) and Zofran (ondansetron).
- If surgery becomes necessary, please allow him/her to take their Parkinson medications as close to the time of surgery as possible, with a sip of water, unless it is unsafe to do so. They should resume their Parkinson medication as soon after surgery as is safe.
- Ambulate as soon as is safe and consider a physical therapy evaluation prior to discharge.
- People with Parkinson Disease are prone to constipation. A good bowel regimen will be most beneficial in preventing constipation and optimizing absorption of medication.
- Should (s)he require a nasogastric tube, carbidopa/levodopa 25/100 immediate release tablets can be crushed and administered via the tube.
- A swallow evaluation may be indicated should dysphagia develop.
- Selective MAO B inhibitors, such as rasagiline (Azilect), selegiline (l-deprenyl, Eldepryl), and selegiline HCL oral disintegrating (Zelapar) are contraindicated with meperidine (Demerol) and tramadol (Rybix, Ryzolt, Ultram), among other commonly prescribed medications. It may be appropriate to hold the MAO B inhibitor for 2 weeks prior to surgery to avoid any potential interactions, and resume when pain is under control. But if surgery is imminent, please use alternative medications for pain and check with the pharmacy for other potential drug interactions.
- Under no circumstances should his/her Parkinson's medications be changed without consulting my office. If medications are not available in your pharmacy, we encourage the use of the his/her home supply. A sudden change of medications (including substitution), or stoppage of medications could cause serious harm to the patient.
- (S)he has been provided with an Aware in Care Kit by the Parkinson's Foundation, which contains all of this information and more to share with the surgical team**. We recommend that you use this throughout his/her stay in the hospital to keep all care providers informed about his/her needs.** Thank you for helping to provide a complication free hospitalization and a rapid recovery.

Should you have additional questions or concerns, please don't hesitate to contact us.

Doctor's Signature ______________________________ Phone: ____________________

Doctor's Printed Name: ___________________________ Email: ____________________

PARKINSON'S DISEASE

Medication Form

Complete this form, make copies and keep them in your Aware in Care kit. At the hospital, share your completed Medication Form when you are asked to provide a list of medications. Fill out a new form when your prescriptions change and keep an updated version in your kit.

YOUR NAME	DATE FORM COMPLETED

Important names and numbers

CARE PARTNER	RELATIONSHIP	PHONE/FAX
PARKINSON'S DOCTOR OR NEUROLOGIST		PHONE/FAX
PRIMARY CARE PHYSICIAN		PHONE/FAX
PHARMACY		PHONE/FAX

Basic Information

I was diagnosed with Parkinson's disease in ____________ (year).

I also have the following conditions (check box):

○ COPD
○ Depression
○ Diabetes
○ Heart Disease
○ Hypertension
○ Melanoma
○ Osteoarthritis
○ Other: ____________________

Medication List

List all medications you are taking for Parkinson's and other conditions, including over-the-counter medications and supplements.

MEDICATION	DOSAGE	FREQUENCY/TIMING	CONDITION TREATED	STARTED

IF YOU NEED ADDITIONAL SPACE FOR MORE MEDICATIONS, USE PAGE 3

FORM CONTINUES ON BACK

Form can also be completed online at Parkinson.org/AwareInCare

The Parkinson's Foundation **Aware In Care** campaign aims to help people with Parkinson's get the best care possible during a hospital stay. For more information please visit **Parkinson.org/AwareInCare** or call **1-800-4PD-INFO (473-4636)**.

Aware in Care
Parkinson's Foundation

Special Considerations

If any of the following are checked, please consult the Special Considerations of the Hospital Action Plan booklet in the Aware in Care Kit for more information.

○ **I have a deep brain stimulation device.**

Notes: ______________________________

○ **I have a Duopa Pump.**

Notes: ______________________________

○ **I have trouble swallowing.**

Notes: ______________________________

○ **I have special dietary needs.**

Notes: ______________________________

○ **I get dizzy or feel faint.**

Notes: ______________________________

○ **I have balance issues.**

Notes: ______________________________

○ **I Parkinson's disease-related dementia.**

Notes: ______________________________

○ **I experience hallucinations or delusions as part of my Parkinson's.**

Notes: ______________________________

○ **I feel disoriented or confused today in a way that is not normal for my Parkinson's.**

Notes: ______________________________

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Medication List

CONTINUED FROM PAGE 1

List all medications you are taking for Parkinson's and other conditions, including over-the-counter medications and supplements.

MEDICATION	DOSAGE	FREQUENCY/TIMING	CONDITION TREATED	STARTED

PARKINSON'S DISEASE

Fact Sheet for Nurses

Parkinson's disease is a progressive, incurable neurological disorder associated with a loss of dopamine-generating cells in the brain that results in a complex array of symptoms. It is primarily associated with progressive loss of motor control, but there are many more non-motor symptoms. Parkinson's impacts an estimated one million people in the United States.

Critical Clinical Care Considerations

- **To avoid serious side effects, Parkinson's patients need their medications on time, every time — do not skip or postpone doses.**
- **Do not substitute Parkinson's medications or stop levodopa therapy abruptly. Doing so may cause a life-threatening condition called neuroleptic malignant syndrome (NMS).**
- **Write down the exact times of day medications are to be administered so that doses are given on the same schedule the patient follows at home.**
- **Resume medications immediately following procedures, unless vomiting or severely incapacitated.**
- **If an antipsychotic is necessary, use pimavanserin (Nuplazid), quetiapine (Seroquel) or clozapine (Clozaril). DO NOT use haloperidol (Haldol).**
- **Be alert for symptoms of dysphagia (trouble swallowing) and risk of pneumonia. Consult with SLP is recommended.**
- **Ambulate as soon as medically safe. Patients may require assistance. Consult with PT is recommended.**

Medications That May Be Contraindicated in Parkinson's Disease

MEDICAL PURPOSE	SAFE MEDICATIONS		MEDICATIONS TO AVOID
Antipsychotics	**pimavanserin** (Nuplazid, FDA approved to treat Parkinson's disease psychosis) **quetiapine** (Seroquel) **clozapine** (Clozaril)		avoid **all other typical and atypical antipsychotics**
Pain Medication	**most are safe to use**, but narcotic medications may cause confusion/psychosis and constipation		*if patient is taking MAO-B inhibitor such as selegiline or rasagiline (Azilect), avoid:* **meperidine** (Demerol)
Anesthesia	request a consult with the anesthesiologist, surgeon and Parkinson's doctor to determine best anesthesia given your Parkinson's symptoms and medications		*if patient is taking MAO-B inhibitor such as selegiline or rasagiline (Azilect), avoid:* **meperidine** (Demerol) **tramadol** (Rybix, Ryzolt, Ultram) **droperidol** (Inapsine) **methadone** (Dolophine, Methadose) **cyclobenzaprine** (Amrix, Fexmid, Flexeril) **halothane** (Fluothane)
Nausea/GI Drugs	**domperidone** (Motilium) **trimethobenzamide** (Tigan) **ondansetron** (Zofran) **dolasetron** (Anzemet) **granisetron** (Kytril)		**prochlorperazine** (Compazine) **metoclopramide** (Reglan) **promethazine** (Phenergan) **droperidol** (Inapsine)
Antidepressants	**fluoxetine** (Prozac) **paroxetine** (Paxil) **escitalopram** (Lexapro)	**sertraline** (Zoloft) **citalopram** (Celexa) **venlafaxine** (Effexor)	**amoxapine** (Asendin)

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Aware in Care
Parkinson's Foundation

Common Symptoms of Parkinson's Disease

Motor

- Bradykinesia (slowness of movement)
- Decreased ability to swallow (dysphagia) and drooling
- Freezing—being stuck in place when attempting to walk
- Lack of facial expression
- Low voice volume or muffled speech
- Stiffness/rigidity of the arms, legs or trunk
- Stooped posture
- Tremor or shaking at rest
- Trouble with balance and falls

Non-Motor

- Anxiety
- Cognitive decline and dementia
- Constipation
- Depression
- Hallucinations and psychosis
- Impulse control disorders
- Orthostatic hypotension
- Pain
- Sexual dysfunction
- Sleep disturbances
- Urinary dysfunction

Typical Parkinson's Medications

L-DOPA

carbidopa/levodopa (Sinemet or Sinemet CR)
carbidopa/levodopa oral disintegrating (Parcopa)
carbidopa/levodopa/entacapone (Stalevo)
carbidopa/levodopa extended-release capsules (Rytary)
carbidopa/levodopa enteral solution (Duopa)

DOPAMINE AGONISTS

ropinirole (Requip)
pramipexole (Mirapex)
rotigotine (Neupro)
apomorphine (Apokyn)

MAO-B INHIBITORS

rasagiline (Azilect)
selegiline (l-deprenyl, Eldepryl)
selegiline HCL oral disintegrating (Zelapar)

ANTI-CHOLINERGICS

trihexyphenidyl (formerly Artane)
benztropine (Cogentin)
ethopropazine (Parsitan)

COMT INHIBITORS

entacapone (Comtan)
tolcapone (Tasmar)
carbidopa/levodopa/entacapone (Stalevo) **has L-DOPA in formulation*

OTHER

amantadine (Symadine, Symmetrel)
extended-release amantadine (Gocovri, Osmolex ER)

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.

Consequences of Untimely Medication Administration: As PD medications wear off motor symptoms return which can impact a patient's ability to function. PD patients are at risk for:

- Falls — due to rigidity, postural instability, freezing and bradykinesia
- Aspiration pneumonia — due to dysphagia from impairment in the muscles needed for swallowing
- Incontinence — due to rigidity and bradykinesia which impairs the ability to get to the bathroom
- Skin breakdown — due to the inability to change position freely
- Emotional distress — due to feelings of helplessness, frustration, anxiety, fear, depression, embarrassment

If the patient has deep brain stimulation device (DBS) or uses Duopa Therapy consult the Deep Brain Stimulation (DBS) Precautions post card, Duopa Therapy Precautions post card, and the Special Considerations pages within the Hospital Action Plan.

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MEDICAL ALERT

I have **PARKINSON'S DISEASE**
which could make me move slowly and
have difficulty standing or speaking.

I AM NOT INTOXICATED.
Please call my family or physician for help.

Parkinson's Foundation

1-800-4PD-INFO (473-4636)
www.parkinson.org

Important Medical Information for Healthcare 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 pimavanserin (Nuplazid), 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 and important considerations if the patient has a brain device and needs an MRI/EKG/EEG.

MY NAME

HOME ADDRESS

EMERGENCY CONTACT PHONE

PHYSICIAN PHONE

ALLERGIES/OTHER MEDICAL CONDITIONS

MEDICATIONS THAT MAY BE CONTRAINDICATED IN PARKINSON'S DISEASE

Safe Medications:	Medications to Avoid:
ANTIPSYCHOTICS	
pimavanserin (Nuplazid, FDA approved to treat Parkinson's disease psychosis), quetiapine (Seroquel), clozapine (Clozaril)	avoid all other typical and atypical antipsychotics
PAIN MEDICATION	
most are safe to use, but narcotic medications may cause confusion/ psychosis and constipation	if patient is taking MAO-B inhibitor such as selegiline or rasagiline (Azilect), avoid meperidine (Demerol)
ANESTHESIA	
request a consult with the anesthesiologist, surgeon and Parkinson's doctor to determine best anesthesia given your Parkinson's symptoms and medications	if patient is taking MAO-B inhibitor such as selegiline or rasagiline (Azilect), avoid: meperidine (Demerol), tramadol (Rybix, Ryzolt, Ultram), droperidol (Inapsine), methadone (Dolophine, Methadose), propoxyphene (Darvon, PP-Cap), cyclobenzaprine (Amrix, Fexmid, Flexeril), halothane (Fluothane)
NAUSEA/GI DRUGS	
domperidone (Motilium), trimethobenzamide (Tigan), ondansetron (Zofran), dolasetron (Anzemet), granisetron (Kytril)	prochlormethazine (Compazine), metoclopramide (Reglan), promethazine (Phenergan), droperidol (Inapsine)
ANTIDEPRESSANTS	
fluoxetine (Prozac), sertraline (Zoloft), paroxetine (Paxil), citalopram (Celexa), escitalopram (Lexapro), venlafaxine (Effexor)	amoxapine (Asendin)

Share this with your doctor

If you have a deep brain stimulation device (DBS):

MRI Warning

- MRI should not be performed unless the hospital has MRI experience imaging a DBS device safely.
- MRI should never be done if the pacemaker is placed anywhere other than the chest or abdomen.
- Under certain conditions, some DBS devices are safe for full-body MRI and do not need to be turned off.

In other cases, devices should be turned to 0.0 volts and MRI should not be used to image structures of the body lower than the head, as dangerous heating of the lead could occur.

- Always check with your DBS team before having an MRI to make sure the procedure will be safe for you.

EKG and EEG Warning

- Turn off the DBS device before conducting EKG or EEG.
- Diathermy should be avoided.