

Hospital Action Plan



 **Aware
in Care**

Parkinson's Foundation

PARKINSON.ORG

HELPLINE

800.4PD.INFO (473.4636)

HELPLINE@PARKINSON.ORG

As you already know, getting diagnosed with Parkinson's disease (PD) is a life-changing experience. What you may not know is that people with Parkinson's disease are admitted to the hospital 50 percent more than their peers. And, once admitted, they typically have longer hospital stays.

Fortunately, there is a lot you can do to change that. When your Parkinson's is well controlled — you get your medication on time, you receive consistently good medical care and you are an active participant in your treatment team — you are more likely to stay well. This lowers your chance of being hospitalized and improves your ability to recover more quickly from illness or surgery.

To help you get the high-quality hospital care you deserve, the Parkinson's Foundation created a program called the Aware in Care campaign. This initiative is one of many that we have undertaken to help you gain control of your health. We believe that one of the first steps is education — including educating your doctors and nurses on how to take good care of you during a hospital stay.

This is your guide to prepare for both planned hospital visits and emergency treatment. The information in this kit is relevant even if your visit to the hospital is unrelated to Parkinson's. In addition, these materials are useful beyond hospital walls. Bring your kit with you for any in-patient stay, whether it is a rehabilitation, assisted living, skilled nursing or other care facility.

Included in this guide are useful tips on how to use your Aware in Care kit to get the right care at the right time. We hope this blueprint to better care will help you and your family on your Parkinson's journey. Read on to get started today.

Acknowledgements

The Parkinson's Foundation's Aware in Care campaign is made possible through the efforts of many different individuals, institutions and organizations, all of whom are dedicated to the health and safety of people with Parkinson's.

Many of the world's leading medical institutions that treat Parkinson's disease are designated by the Parkinson's Foundation as a Center of Excellence.

These institutions are setting new standards for quality care for people with Parkinson's, while also conducting cutting edge research and providing outreach services to people with Parkinson's and their families. These esteemed institutions collaborated on two research papers that summarize best practices in caring for people with Parkinson's in the hospital:

Kelvin Chou, MD, and others: Hospitalization in Parkinson Disease: A Survey of National Parkinson Foundation Centers (*Parkinsonism and Related Disorders*, 2011).

Michael Aminoff, MD, and others: Management of the Hospitalized Patient with Parkinson's Disease: Current State of the Field and Need for Guidelines (*Parkinsonism and Related Disorders*, 2011).

The concept for the Aware in Care campaign was inspired by the *Get it On Time Campaign*, an awareness initiative by Parkinson's UK, the leading advocacy organization in the United Kingdom. We are grateful to the Parkinson's UK advocacy team for sharing insights and lessons learned to inform our efforts.

The Parkinson's Foundation would especially like to thank the Aware in Care Advisory Group, a dedicated team of individuals who provided valuable input to these materials.

Finally, we would like to thank all of the families who shared their hospital experiences. They are the inspiration for the Parkinson's Foundation Aware in Care campaign.

Contents

4 **Six Steps to Optimum Care**

TAKE ACTION AT HOME

1. Prepare Your Aware in Care Kit

2. Find a Good Hospital

WHEN YOU ARE IN THE HOSPITAL

3. Be Vocal

4. Get Moving

5. Stay on Top of Your Care

6. Follow Up and Provide Feedback

11 **Checklist For A Planned Hospital Stay**

14 **Checklist For An Emergency Situation**

15 **Special Considerations**

I have a deep brain stimulation device.

I have trouble swallowing.

I have special dietary needs.

I get dizzy or feel faint.

I have balance issues.

I have Parkinson's disease-related dementia.

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

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

20 **How Can We Make Hospitals Safer for People with Parkinson's Disease?**

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:

- 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.



- 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.
- 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.
- Update Medical ID on Apple cell phones/ICE on Android cell phones.** Learn more at Parkinson.org/Phone.

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.

Checklist for a Planned Hospital Stay

BEFORE YOUR HOSPITAL STAY

Before you have surgery or undergo any procedure, here's what you should do:

- Notify your health care team.** Contact your Parkinson's doctor and let him or her know about your scheduled hospital visit. Ask your Parkinson's doctor to contact the specialist or surgeon who is performing the procedure prior to your scheduled hospital stay to share pertinent information about Parkinson's disease and any other medical conditions.
- Share important information.** Schedule a meeting with your surgeon or specialist prior to your hospital visit and take time to review your Parkinson's symptoms and medications as well as any other conditions you may have. Ask your doctor to make copies of your "Medication Form" and the "Parkinson's Disease Fact Sheet." Discuss the medications that are not safe for people with Parkinson's disease.
 - If you are ordered to stop taking certain drugs before surgery, find out exactly when you can resume taking them.
 - Provide the name and number of your Parkinson's doctor, and request that the surgeon or specialist contact them.
- Ask these key questions before surgery or any major treatment or procedure:**
 - Are my medications stocked in the hospital pharmacy? If not, will you allow me to bring my medications into the hospital?
 - Will I require anesthesia for my procedure? If so, ask your surgical team to consult with your Parkinson's doctor. Many people with Parkinson's have serious complications from anesthesia, and it is important that these conversations take place prior to the procedure taking place.

- What if I can't swallow my medications after surgery?
Make sure any changes are discussed with your Parkinson's doctor and your surgeon/specialist prior to surgery or other procedures.
 - Will physical therapy be a part of my recovery?
If so, ask if there is a physical therapist with experience working with people with Parkinson's disease or other movement disorders.
- Prepare your medications.** Before you leave for the hospital, gather enough of all of your medications to last for two days. They should be stored in their original bottles and clearly labeled with your name and the dosing schedule. Use your Aware in Care kit to carry your medicines to the hospital.

DURING YOUR HOSPITAL STAY

Once you are admitted, here is what you should do:

- Request a consultation with the hospital's neurologist.** Provide the neurologist with a copy of your "Medication Form" and discuss your medical condition with him or her. Make sure the neurologist is consulted on all medication and treatment decisions during your entire hospital visit even if you are hospitalized for a non-neurological reason.
- Discuss your medication schedule.** As soon as you're admitted, set up a visit with the nurse overseeing your care. Explain why it is critical for you to get your medications on time, every time. Be prepared to remind staff when your drugs are due.
- Ask about medication management.** Each hospital has a different policy on drug administration. If the hospital pharmacy doesn't stock your prescription medications, ask if you can supply your own.

- Introduce yourself.** When you meet a new member of your care team, introduce yourself and say, "My name is ____ and I have Parkinson's." Give that person one of your "Parkinson's Disease Fact Sheet for Nurses" and share your chief symptoms. Remember to say this even if the reason you are hospitalized is unrelated to your Parkinson's diagnosis. Ask questions before taking any new medications. Before accepting any new medications, review the safe/unsafe medications list. Never be afraid to ask questions or to share the list of unsafe medications with the nurses and doctors in the hospital.
- Get an explanation.** If a staff member will not allow you the chance to provide important information about your medication timing or symptoms, request that the medical staff contact your neurologist or personal physician.
- Request physical therapy evaluation & treatment.** Soon after your medical procedure, it is vital that you get out of bed and start moving, if possible. Ask the doctor who is treating you to recommend physical, occupational or speech therapy, depending on your symptoms and needs.
- Call for help.** If you feel confused or your loved ones notice changes in your behavior, share this information with your doctor and nurse. Make sure your health care team knows that confusion and disorientation are commonly caused by multiple drugs, and that these side effects are more common in people with Parkinson's.

Checklist for an Emergency Situation

ADVANCED PREPARATION

Before an emergency can happen, here is what you should do to prepare:

- Devise an emergency plan.** Gather your care partner and close family and friends and draft an emergency plan. Go over key procedures such as how to use the Aware in Care kit and where you will store your second set of Parkinson's medications. Make sure everyone knows who will accompany you to the hospital, where you keep the kit and who will bring it to the hospital.

AT THE HOSPITAL

Once you are admitted, here is what you should do:

- Notify your Parkinson's doctor.** Ask him or her to contact the medical staff in the ER as soon as possible to help coordinate your care.
- Bring your Aware in Care kit.** Ask your care partner or a family member or friend to bring the kit to the hospital as soon as possible. Keep an extra supply of all your medications in your Aware in Care kit or leave them in a convenient place at home. That way, you or your care partner will be able to get them in case of an emergency. Remember, you should always have a 48-hour supply (or more when appropriate) of your medicines, and they should be stored in their original bottles clearly labeled with your name and the dosage.
- Have someone stay with you in the emergency room.** Your care partner, a family member or friend can make a critical difference during a medical emergency by relaying important information about your Parkinson's symptoms and medication schedule. If you are able, tell the emergency room staff that you have Parkinson's, and provide them with a copy of your "Medication Form" and "Parkinson's Disease Fact Sheet for Nurses." This is important to do even if you are in the ER for a condition unrelated to Parkinson's.

Special Considerations

This section is designed to share with your doctors. If you checked off any of the "special consideration" boxes on your medication form, share additional information from this section with all who provide care.

I have a deep brain stimulation device.

Some people with Parkinson's disease have a deep brain stimulation (DBS) device that helps to control symptoms. A deep brain stimulator is a surgically implanted battery-operated neurostimulator, and includes a pacemaker located in the chest region with a wire leading to the brain.

SHARE THIS WITH YOUR DOCTOR

MRI Warning

- MRI should not be performed unless the hospital has MRI experience imaging a DBS device safely.
- MRI should never be performed 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.

If you have any questions, check with the prescribing or implanting clinicians, call the manufacturer (Medtronic: 1-800-510-6735; Abbott: 1-800-727-7846; Boston Scientific: 1-833-327-8324) or call the Parkinson's Foundation Helpline (1-800-473-4636).

I have a Duopa Pump.

8i cdU'h\YfUdm]g'Ub`YbhfU`[Y`gi gdYbg]cb`cZ'h\Y`D8`a`YX]W]h]cb`
W]fV]XcdU#`Y] cXcdU`"H\Y [Y`gi gdYbg]cb`]g`UXa`]b]ghYfYX`VmiU`di`a`d`
V`bbYVW`YX`hc`h\Y`VcXmi`g]b[`U`dYfW`hUbYci`gYbXcgv`d]W`
[Ughfcg]ca`mk`]h`'Y`f`bU`'hi`VY`'fD9;` !>`hi`VY`E`"

8i cdU'h\YfUdm]g': 8 5`5ddfcj`YX`Zcf`XU]`mi`gY`cZi`d`hc`%`'`ci`fg`
DUh]Yb]hg`i`g]b[`8i`cdU`h\YfUdm]UfY`Ugg][`bYX`U`W]UgY`a`UbU[`Yf`h`Uh`
W]b`VY`fYUW`YX`h`fci`[`\'5VVJ`]Y`g`8i`c7`cbbYV`U`h`%,`((`!

8I`C`!(`MCI`fI`,`*!`(-`*,`E`" **Onsite pump training can also be requested through DuoConnect.**

5`W]ggYhhY`W]b`VY`UhhUW`YX`hc`h\Y`di`a`d`k` \Yb`]h` \Ug`VYYb`ci`h`cZ`
h\Y`fYZf][`YfUhc]f`U`a`]b]a`i`a`'cZ`&\$`'a`]bi`hYg`"

K` \Yb`U`W]ggYhhY`]g`XYhUW`YX`Zcf`'a`cfY`h`Ub`hk`c`'ci`fg`zh`h\Y`'D9;` !>`
hi`VY`g`'ci`X`VY`Zi`g` \YX`k`]h` \U`a`]b]a`i`a`'cZ`&\$`'a` @`cZ`k`UhYf`"

H\Y`8i`cdU`di`a`d`]g`bch`k`UhYf`dfcc`Z`"

6YZcfY`i`bXYf[`c]b[`Ub`L`!`fUmžl` `hfUgci`bX`ŽA`F`ž9?;`'cf`99;`žh`Y`
di`a`d`a`i`gh`VY`ghcdd`YX`žhi`fbYX`c`ZZž`UbX`fYa`cj`YX`Zfca`h\Y`d`Uh]Ybh`
UbX`h\Y`fcca`]b`k` \]W`h\Y`dfc`W`Xi`fY`]g`c`W`W`ff]b[`""F`Y`gi`a`Y`di`a`d`
Zi`b`W]cb`Ug`gccb`Ug`h\Y`dfc`W`Xi`fY`]g`V`a`d`Y`hY`"

- **The pump should not be removed even if the hospital does not have the proper medication for the pump.**

I have special dietary needs.

Gastrointestinal, digestion and constipation issues are common in people with Parkinson's disease.

- Eating protein may impact medication absorption.
- Ask for a nutrition consultation if you have special dietary needs that impact the absorption of your medications.
- Watch out for dehydration. Ask for a large, sturdy cup or glass to make drinking fluids easier.
- Some foods, such as sweets, cause drooling for people with Parkinson's. This can make speech and swallowing more difficult. Ask the nutritionist to guide your food selection or call 1-800-4PD-INFO (473-4636) for more information.

I have trouble swallowing.

Problems with swallowing (dysphagia) are common in people with Parkinson's. If you have trouble swallowing, it is important to share this information with hospital staff as early as possible.

Here are some important tips:

- Sit up while eating.
- Tuck in your chin each time you swallow.
- Ask for a speech-swallowing therapist if you are having problems swallowing. Make sure you are evaluated when you are in your medication "on" state.
- Ask the therapist to make necessary dietary changes so the food you are eating is easier to swallow.
- Alert staff that your medications may need to be crushed and administered through a tube. Make sure medications are administered one hour prior to meals or feeding, especially if medications are crushed.
- Another option is to use the dissolvable form of carbidopalevodopa called Parcopa®, which can be given by placing on the tongue.
- Make sure any changes of this nature are discussed with your Parkinson's doctor prior to surgery.

I have balance issues.

Balance issues also are commonly seen in people with Parkinson's.

- Tell medical staff that you have balance issues or that you fall often.
- Ask medical staff to help you to get out of bed, move around the room, go the bathroom or exercise.
- Ask for physical therapy in your hospital room if you have any of the above problems.

I get dizzy or feel faint.

Low blood pressure (hypotension) is common in people with Parkinson's and may cause dizzy or fainting spells.

- If you feel dizzy or have issues with fainting, tell the doctor or nurse immediately.

I have Parkinson's disease-related dementia.

People with PD-related dementia may become disoriented and unable to be left alone. They may show signs of agitation, delusions, mood fluctuations and increased impulsivity.

Make sure your care team understands your needs.

- Watch out for sensitivity to medications. Many antipsychotic medications that are commonly prescribed for people with Alzheimer's who have disruptive behavior are contraindicated in PD and can cause severe, sometimes dangerous, side effects.

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

Hallucinations are most often a side effect of medication and are not necessarily a sign of a decline in cognitive abilities. Most hallucinations experienced by people with PD are fleeting and non-threatening. However, in some cases hallucinations may become threatening or bothersome. Be sure to communicate with your care team whether you have consulted with your neurologist about how and when treatment for your hallucinations or delusions is necessary.

- Medication, dementia and delirium are the three main contributors to the development of psychosis in Parkinson's disease. Determining the cause can be difficult because these conditions can overlap and produce similar symptoms.
- The best person to determine how to manage Parkinson's hallucinations or delusions is your regular Parkinson's doctor. Request that your hospital care team speaks with your neurologist about this before making any changes in treatment.

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

Many people with Parkinson's feel disoriented or confused in the hospital. If you feel this way, share the following list of likely causes with your doctor:

- Urinary tract infection or pneumonia.
- Infections can worsen confusion.
- Pain medications can worsen confusion and cause constipation.
- Confusion accompanied by psychosis sometimes requires a simpler medication regimen and sometimes the addition of "safe" antipsychotic medications such as pimavanserin (Nuplazid™), quetiapine (Seroquel®) or clozapine (Clozaril®).



How Can We Make Hospitals Safer for People with Parkinson's disease?

At the Parkinson's Foundation, we are always looking for volunteers from the Parkinson's community to help. Here are some ways you can help make hospitals safer.

- If you did not receive attentive care while in the hospital, call or send an email to the hospital's patient advocate or community relations department. Explain what went wrong. Your effort will help point hospital staff in the right direction. If you had a good experience, write a letter praising the staff members who cared for you in the hospital. Include how important it is to you, and the Parkinson's community, to receive proper care.
- Learn how to talk to your local Parkinson's support and exercise groups about Aware in Care so they can advocate for themselves like you did. Visit Parkinson.org/AwareInCare for a webinar, discussion guide, and PowerPoint presentation to help us spread the word. Make sure you let us know that you are going out and sharing this kit by contacting the Parkinson's Foundation Helpline at 1-800-4PD-INFO (473-4636).
- Would you like to do more? Become an Aware in Care Ambassador, a trained volunteer of the Parkinson's Foundation who works with other volunteers to help local hospitals change policies so that all people with Parkinson's receiving care in their facility get their medications on time and are not given contraindicated medications. Learn more at Parkinson.org/AwareInCare.
- In addition to providing kits to people with Parkinson's and speaking about Aware in Care in communities around the country, we are working to change how Parkinson's disease is taught in nursing schools through The Edmond J. Safra Visiting Nurse Faculty Program at the Parkinson's Foundation. Learn more at Parkinson.org/EJS.

MEDICATIONS THAT MAY BE CONTRAINDICATED IN PARKINSON'S DISEASE

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

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)**.



200 SE 1ST STREET, SUITE 800
MIAMI, FLORIDA 33131

1359 BROADWAY, SUITE 1509
NEW YORK, NEW YORK 10018

PARKINSON.ORG

HELPLINE:
1.800.4PD.INFO (473.4636)
HELPLINE@PARKINSON.ORG