

KEEPING IT SAFE

*What families and care partners need to know
about hospitalization and Parkinson Disease*

Edie Simpson, RN, CNRN

Studies have shown. . .

- People with PD are hospitalized **50%** more than their peers without PD
- People with Parkinson Disease suffer **avoidable complications** at a higher rate than non-PD patients
- This yields **longer hospital stays** than non-PD patients (2-14 days)
- This results in a **44% higher risk-adjusted** mortality and markedly increased medical cost

Studies have shown . . .

- **3 out of 4** people with Parkinson's disease do not receive medications on time in the hospital
 - **61%** of patients who did not get their medications on time had **serious complications** from it.
- Approximately **50 – 70 %** of patients **missed** at least one dose of medication each day
- Approximately **80% of patients who received only 10% fewer doses** than their prescribed at home regimen, experienced complications during hospitalization

Studies have shown . . .

- Almost **80%** of **hospital personnel** (including pharmacists) are **unfamiliar with the importance of medications timing** in PD or of the **meds that can make PD symptoms worse**
 - **Drugs contraindicated** in Parkinson Disease were **prescribed in >40%** of cases and were administered in **22-25%**
- Pharmacies **may not carry** the full array of **PD meds**
- **PD patients** have an **increased risk of developing mental status changes**
 - Mental status changes affect up to **40%** of patients with PD who are in the hospital
 - PD patients with mental status changes stay in the hospital **twice as long** as those without

Why Does This Happen?

- **Lack of understanding of PD** – treatment, symptoms, etc, even in the very best hospitals in the US
- Lack of awareness about the **critical importance of PD medication timing**
- Lack of awareness that many common **medications** for pain, nausea, depression and psychosis are **unsafe for people with PD**
- Hospital pharmacies **do not stock the full array of PD medications**
- **Lack of awareness** that **poorly managed PD** might result in mental confusion and other serious symptoms and/or consequences

1. Aminoff MJ, et al. Parkinsonism and Related Disorders, 2010.
2. Derry CP, et al. Postgrad Med J, 2010. 86 (1016): 334-7
3. Guttman M, et al. Movement Disorders, 2004 19(1):49-53.

Lack of Understanding of PD

- Nurses not educated about PD in school
- MD training in PD may be “dated”
- PD treated as outpatient, not in hospital
- Treatment based on clinical response and NOT blood levels, etc

Lack of Awareness of Importance of Timing of Medications

- **On** and **Off** are not familiar concepts
- Don't understand what can happen when medications are not given on time, as they are taken at home
- In hospital, medications are given on fixed schedule
 - ▣ Everyone getting medications 4X per day gets them at the same time
 - ▣ +/- one (1) hour window is acceptable in the hospital setting
- Hospitals often won't allow self or caregiver to administer medications

Contraindicated Medications

□ Antiemetics

- Thorazine (chlorpromazine)
- Inapsine (droperidol)
- **Reglan (metoclopramide)**
- **Compazine (prochlorperazine)**
- **Phenergan (promethazine)**

□ *These medications block dopamine receptors in the brain, worsening PD symptoms*

□

□ SAFE ALTERNATIVES

- **Tigan (trimethobenzamide)**
- **Zofran (ondansetron)**

□ Antipsychotics

- **Haldol (haloperidol)**
- Thorazine (chlorpromazine)
- Prolixin (fluphenazine)
- Loxitane (loxapine)
- Mellaril (thioridazine)
- Navane (thiothixene)
- Stelazine (trifluoperazine)
- Orap (pimozide)

□ *These medications block dopamine receptors in the brain, worsening PD symptoms*

□

□ SAFE ALTERNATIVES

- **Seroquel (quetiapine)**
- **Clozaril (clozapine)**
- **Nuplazid (pimivanserin)**

Hospital Pharmacies Don't Carry Full Array of Medications

- Only carry most cost effective medications
- You may take your own supply of medication, **BUT**
 - ▣ Meds must be verified and then sent to the floor
 - ▣ Still must be administered by RN
 - ▣ Takes time and can delay delivery of meds

Poorly Managed PD....

- Most often, “managing PD” just means to maintain the “**home medication schedule**”
 - Illness/injury by itself makes PD worse
 - May need increase in dose
 - Timing often stays the same

- Worsening PD symptoms
 - More **Off** time = greater disability
 - Increased risk of hospital acquired complications
 - Falls, infections, etc
 - Greater risk of mental status changes

The Good News is....

- Most doctors and nurses want to give good care and will listen and honor your wishes

- National PD programs educating patients and medical personnel
 - ▣ Edmond J Safra Visiting Nurse Faculty Program
 - ▣ “Aware in Care” program

- Movement disorder programs are working to educate hospital personnel
 - ▣ In-services for staff
 - ▣ Implementing strategies to ensure appropriate medication deliver

How to help keep the PLWP Safe



BE

PREPARED

“Aware in Care” Kit



www.parkinson.org

www.awareincare.org

1-800-473-4636

“Aware in Care” Kit Contents



Things to Add to Your Kit

- Current, complete medication list
 - ▣ Specific times for PD meds

- 1 to 2 days of PD medication
 - ▣ In bottles with pharmacy labels
 - ▣ Medicine bottles labelled with specific dosing information

- Letter from PD doctor
 - ▣ Should include any relevant information about **YOU**
 - Bowel regimen, anxiety, difficulty swallowing, chronic UTIs, etc

- Contact information
 - ▣ PD doctor, psychiatrist, GI or GU doctor, family and friends

Letter from PD Physician

- Re: Pt. Name DOB:
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- Mr./Mrs. Name is anticipating hospitalization for _____. As you are aware, Mr./Mrs. _____ suffers from Parkinson Disease. Below are some recommendations that will help to keep Mr./Mrs. _____ Parkinson symptoms stable, and reduce potential complications during his/her hospitalization.
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- Mr. Mrs. _____ requires his/her Parkinson medications on time, based on the specific time he/she takes them at home. This schedule allows his/her Parkinson symptoms to remain under control. Her current medication schedule is as follows: _____.
- Compazine, Phenergan and Reglan are contraindicated for use in Parkinson Disease. Should an anti-emetic be required, safe alternatives are Tigan (trimethobenzamide) and Zofran (ondansetron)
- Should delirium occur, avoid Haldol and most neuroleptics, other than Seroquel (quetiapine) and Clozaril (clozapine)
- If safe, please allow Mr./Mrs. _____ to take his/her Parkinson medications as close to the time of surgery as possible, with a sip of water, and to resume his/her 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 Mr./Mrs. _____ require a nasogastric tube, CD/LD 25/100 immediate release tablets can be crushed and administered via the tube.
- A swallow evaluation may be indicated should dysphagia develop post operatively.
- Infections can cause sudden changes in behavior and motor function. Monitor closely for urinary tract and upper respiratory infections.
- Selective MAO B inhibitors, such as Azilect or selegiline, are contraindicated with Demerol and tramadol, among other commonly prescribed medications. We will ordinarily hold the Azilect 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.
- If a Deep Brain Stimulator is in place, please see the recommendations to follow, from Medtronic Corp. If you have additional questions, please contact Medtronic Corp. at 1-800-510-6735
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- Thank you for your attention to these issues to help provide a complication free hospitalization and a rapid recovery for Mr./Mrs. _____.
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- Should you have additional questions or concerns, please don't hesitate to contact us.
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- Sincerely,
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-
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- Doctor's Signature
- Contact information

Stay Current

- Keep your “Aware in Care” kit **updated**
 - Update med bottles when you refill meds
 - Update med lists at each MD appt and/or when there are changes
- Make sure family and friends **know where you keep your kit**
 - Return kit to same place after updates

What to Always Have On You

- List of contraindicated medications
 - ▣ Can use wallet card from “Aware in Care” kit

- Contact information
 - Next of kin, care partner, local friend/family familiar with your PD, doctor’s name and contact info

- Up to date medication list (with specific times)
 - ▣ Care partner should have a list, too

Updated and Accurate Medication Lists

- **Example:**
- **CD/LD 25/100**
 - 1 ½ tabs at 6:30 am
 - 1 tab at 10:30 am
 - 1 tab at 2:30 pm
 - 1 tab at 6:30 pm
- **CD/LD 50/200**
 - 1 tab at 10 pm
- **Azilect 1 mg**
 - 1 tab at 6:30 am
- **Mirapex 0.5 mg**
 - 1 tab at 6:30 am
 - 1 tab at 12:30 pm
 - 1 tab at 6:30 pm
- **Miralax 17 gm (1 capful)**
 - 1 capful daily at 6:30am – may increase to 1 capful at 6:30 am and 1 capful at 10:30 pm if constipation develops
- **Dulcolax 30 mg tab**
 - 1 tab at 10 pm
- **Sertaline 50 mg tab**
 - 1 tab at 6:30 am

*This regimen is current as of 5/15/17

Know How to Pass on Medication Information

□ ***Never assume the staff knows about PD***

□ **BE SPECIFIC**

- Daughter: “My mom takes her CD/LD 1 tab at 7am/11am/3pm/7pm. She needs to get it exactly at these times or her Parkinson symptoms will come back and she won’t be able to move.”
- Nurse: “ OK. Your mom takes her CD/LD 4 times daily
- Daughter: “ No. She takes 1 tablet at 7 am/11am/3pm and 7 pm. These specific times are very important for her to be able to move well. Please record these specific times in her record. Also, could you please post this information so that the other shifts are aware.”

Note: Teach direct caregivers how to speak for your family member

Talk to the Staff Early

You are the Educator

- Ask to schedule tests, therapy, etc. when you are “on”
 - *Tell staff when best time would be so that you get the greatest benefit*
 - *Ask doctor for prn med order if schedule can't accommodate*

- Tell staff what happens if you don't get your medications on time
 - *“I need to get my medication on time or my tremor comes back and I can't dress myself and I will be too stiff to be able to get out of bed on my own”*

- Tell them what **meds on time** means
 - *“If I don't get my medication with 15 minutes of when it is prescribed, my symptoms begin to come back”*

- Ask that they pass this information to the next staff on duty
 - *Post information in your room*
 - *Pass on in staff change of shift report*

BE PREPARED TO REPEAT AS NECESSARY

Be a Partner in Your Care

- ***Working together always gets the best result***

- Discuss with your nurse how you and/or your care partner can help make sure you get your medications on time, without interrupting staff work flow or care of others
 - “I know you are busy with all of the patients you need to care for. But it really makes a difference if my medications are late. What can I do to help remind you that it is time for my medications, without getting in your way? Can my spouse come out to the desk ahead of time to remind you? Can we come to the med cart to get the medication?”

But if necessary, don't be afraid to “go to the top”

Avoid Unnecessary Hospitalization

- Take the time to find a PCP who “gets” PD
- Don’t wait until Friday afternoon to seek medical attention
- Know ***your*** PD
 - *what is important to you should be important to hospital staff*
 - Be proactive with chronic problems
 - Constipation, anxiety, urinary issues, etc.
- Stay as healthy as you can
 - Pay attention to comorbidities
 - Good nutrition
 - Good hydration
 - Exercise !!!

Final Thoughts

- Hospitalization can be challenging for those with Parkinson Disease
- But you can help to make it a positive experience by:
 - ***Being prepared***
 - ***Educate*** staff ***early*** about your PD
 - Know ***what to say*** and ***how to say it (be specific)***
 - ***Partner with staff*** regarding your care