

## From Sandie's Desk

### The Flip Side: Understanding the Patient's Role in Hospital Care

Imagine that you are embarking on a journey to a foreign land. You know that the language and customs are different, but you really haven't prepared for the trip, instead trusting in the generosity of strangers that you will encounter. If you are thinking 'that's ridiculous - I would never do that', then you need to know how much planning you need to do before going to that foreign land: 'The Hospital'.

Whether going in for a planned surgery or an emergency room visit, hospital visits are stressful for anyone. For people living with Parkinson's disease (PD), hospital stays can be very challenging.

PD can be managed effectively for several years through regular visits with your movement disorder specialist. For these reasons, you are unlikely to be admitted to the hospital because of Parkinson's itself, but rather for (usually advanced) disease-related events, such as a fall with fractures, urinary tract infection, pneumonia, confusion or hallucinations.

Hospitals may be first-rate institutions, in which life-saving surgeries are performed, and critical emergencies fixed, but are often not well-suited to care for the day-to-day management of Parkinson's. Keep in mind PD affects only 1-2% of the population, and there are countless other conditions that staff deal with. Understand that while PD is top of mind for you, staff cannot be expected to know everything about it. This is why challenges may arise amongst hospital staff, as they are focussed on treating the condition that has brought you to hospital, not your overall health.

I believe your health care team wants to give you the best care, but need your help. Take charge of your care by educating hospital staff about PD, especially YOUR Parkinson's. This is key, as a lack of communication may seriously affect your quality of life, both in the hospital, and after you are discharged. Like any other potential emergency plan, prepare now!

We have a Get it on time! emergency hospital bag available to help you convey important information about your PD to the health care team. Add to it your meds in the original bottles; several copies of your current list of your meds, in an easy-to-follow schedule of dosages you take and when you take them, as these details may differ from what is written on the bottles.

#### Admission

Bring someone you trust who can take charge of communication with the hos-



#### Sandie Jones

Sandie Jones trained as a registered nurse, specializing in psychiatry. In 1998, she joined Parkinson Canada, and is now an integral part of the Information & Referral team. In this role she has provided information on support, education, medical aspects, coping strategies, community services, and other information about Parkinson's disease and its management, not only to people living with Parkinson's disease and their families, but to professionals working with these people as well. This role has given her a comprehensive insight into the problems of people living with Parkinson's disease, as well as their carepartners.



pital staff during your stay. This should be someone who is able to ask the staff for help on your behalf and can ensure they understand your situation.

Discuss your normal medication schedule at the time of admission. Many of you need to take your meds frequently with varying doses at specific times. In addition, some people find that their meds work better if taken 30-60 minutes before a meal or in 1-2 hours after. Hospital staff are accustomed to giving meds at their set times and some nurses may not realize that being half an hour too early or late can mean a marked difference to someone living with PD.

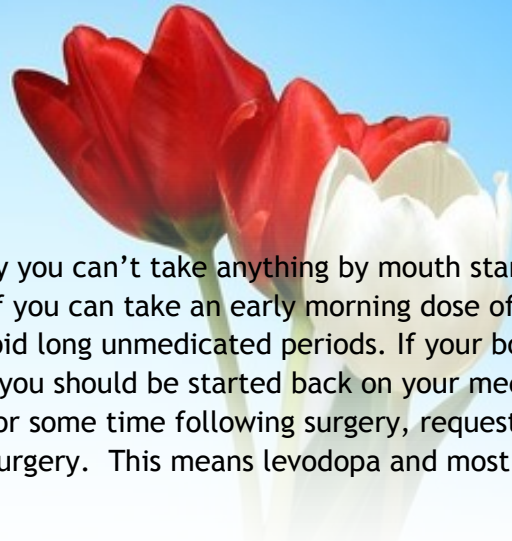
Given pressures on staff, a complicated schedule of oral medications may be difficult to follow with great accuracy. Rather than becoming upset with staff for not bringing your meds on schedule, take a proactive position. Ask about options for self-administering, or having a loved one administer just your antiparkinson meds, in order to control your PD symptoms, while staff focus on your acute care needs. Be sure to share your med list with everyone involved in your care. Many PD meds come in different-sized tablets and formulations, an inadvertent substitution can cause problems.

Hospital staff may not be familiar with the problems of motor issues, both “on-off” times and dyskinesia. Some may think the patient is trying to be difficult when they are ‘off’ and need help when they had been fine only a few minutes earlier, or that dyskinesias are attention-getting tricks. Letting staff know about your issues in advance will help avoid misunderstandings.

### Contraindications

Certain medications are contraindicated with PD and PD medications, and should be avoided. Ensure that hospital staff are aware of these:

Condition	Medication to Avoid	Better Choice Med
Nausea and Vomiting	Maxeran™, Reglan™ (metoclopramide); Stematil™, Compazine™ (prochlorperazine)	Gravol™ (dimenhydrinate); Zofran™ (ondansetron)
Post-operative confusion	Conventional antipsychotic drugs i.e. Haldol™ (haloperidol), Risperdal™ (risperidone) and Zyprexa™ (olanzapine)	Seroquel™ (quetiapine); Clozaril™ (clozapine)
Pain	Demerol™ (meperidine)	Morphine



## **Surgery**

When surgery requires general anesthetic, generally you can't take anything by mouth starting the night before surgery, including your PD meds. Ask if you can take an early morning dose of your levodopa with a sip of water just prior to surgery to avoid long unmedicated periods. If your bowel is working properly and your swallowing reflex is OK, you should be started back on your meds immediately after surgery. If nothing can be taken orally for some time following surgery, request that a nasogastric tube (NG tube) be inserted prior to your surgery. This means levodopa and most tablets can be crushed and dissolved to be administered.

## **Recovery**

Some of you may be at risk for developing pneumonia because it is difficult to produce the deep coughing necessary to prevent accumulation of fluid in the lungs. Ensure that you receive and understand instructions for postoperative management of the lungs. Others of you may be prone to aspiration pneumonia, which results from swallowing issues. If prior to going into hospital you know swallowing is a problem for you, make doctors and nurses aware of this so that special precautions can be taken to prevent aspiration pneumonia.

Recovery time is generally longer for people with PD as the body simply takes longer to readjust and recover from any surgical procedure. This is nothing to be overly concerned about - it simply has to be planned for. You may need to work harder to recover to your previous level of functioning than the average patient who is in hospital for a similar reason as you are.

## **Discharge**

After you are discharged, you may need to spend some time in a rehabilitation facility. With any new health care team, the education process starts all over again. Be persistent and educate new staff about PD and your needs.

Health teams want patients to well-cared for. Always assume staff want what is best for you, their patient. Explain things in a supportive manner e.g. "let me explain my husband's situation and give you some literature". Do not accuse the staff of being uncaring. If you don't feel you are getting your point across, suggest they call your own neurologist who may be able to advocate.

Parkinson Society is actively working to educate health care teams: the Parkinson Clinical Guidelines now have Continuing Medical Education credits, so that doctors will want to learn more about PD; Get it on time! continues to be presented to professionals; and advocacy efforts include getting an interdisciplinary system of care. These are long-term advocacy goals. It is still up to you to be prepared to self-advocate, and communicate your needs with your health care team.

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This article does not substitute for medical advice specific to an individual, but is for general information purposes. Please speak to your doctor(s) for all diagnostic and therapeutic information.