

Surviving Hospital

Going into hospital, whether planned or unplanned is never easy and living with Parkinson's has the potential to make it even more difficult. Parkinson's Specialist Nurse Consultant VICTOR MCCONVEY offers some advice to help reduce the chance of unnecessary problems or side effects occurring during your stay.

We now know that Parkinson's is "surprisingly prevalent". It is the second most common neurological condition affecting Australians (after dementia)*. In spite of this, there is a significant lack of familiarity with the condition and its nuances amongst hospital staff.

While Parkinson's is not an illness commonly associated with needing to be hospitalised, needless to say, many people with Parkinson's **are** admitted to hospital, whether in relation to their illness or for other reasons. Their anecdotal experiences attest to this lack of understanding of the condition, including medication and side effects.

The difficulties encountered by people with Parkinson's who are admitted to hospital are many and varied. This article explores just a few of the challenges and ways in which they can be minimized and/or managed.

Medication management

One of the most common problems experienced by people with Parkinson's in hospital is not getting their medication on time. (**Medication on time, every time** is essential to managing Parkinson's symptoms.)

In a hospital environment, all medications are typically administered at the one particular time.

Failure to administer Parkinson's medication at the appropriate time for each Parkinson's patient may simply be a result of that 'time' being outside the normal medication rounds. Alternatively, the need to administer Parkinson's medication at a particular time may have been forgotten by staff, ordered incorrectly by the doctor filling in the medication chart, or the medication may be unavailable from the hospital supply.

Beginning your stay in hospital with your medication administered on time will help reduce the chance of medication mismanagement occurring later in your stay, which may result in additional health problems and perhaps even extend your time in hospital.

One way of ensuring this happens is by advising the doctor of the times you take your medications.

Remember: Hospitals work on a 24-hour clock, and will prescribe medication accordingly. For example, if you take the drug Sinemet three times a day at 8, 12 and 4, the doctor could interpret a "three times daily medication" regimen as being due at 6, 2 and 10.

The best way to manage medication and ensure it is administered on time, every time, is to ask hospital staff if self administration is possible.

Self administration is where you take responsibility for your usual medication and the nurse simply asks whether or not you have taken it and then ticks it off your chart.

If you are able to self administer, keep using all the normal cues that you use at home to make sure that you take your medication at the correct time.

If self administration is not an option, it is a good idea to talk to the nursing staff about what **is** possible to help you access your medication on time. Nurses will often try to incorporate the importance of getting medication on time into your care plan, in a similar way that they would highlight if you had a wound that needed dressing.

Please remember: Hospitals are busy places and when emergencies occur all available staff are often called upon to assist. There may be occasions when "on time, every time" doesn't occur, so try and be patient. You may be able to assist staff by keeping track of when your medications are due and asking for them. At the time your doctor is admitting you into hospital, it is worth checking that the ward has a supply of your particular Parkinson's medications in stock. Most hospitals will not automatically have supplies of all medications and will have to order them from the on-site pharmacy. In small hospitals they may have to be ordered from an outside supplier. You may even have to use your own supply until the order has arrived. In private hospitals, patients generally use their own supply of medications, so keep check on how much you have left, particularly at the end of your stay as you may need to get a new prescription filled.

Editor's note: The issues around administering Parkinson's medications on time in a hospital or other care facility were recently explored by Moira Lewis as part of her **Leadership Plus** project (highlighted in **Signpost**, Autumn 2009).

With assistance from Parkinson's Specialist Nurse Consultant Victor McConvey, Ms Lewis conducted a trial on the impact medication timers had on nursing staff's ability to administer medication on time. (The Cadex™ watches, which were supplied by Medtex, signaled when medications were due).

The project results indicated consistent, significant improvement in the delivery of medication on time to Parkinson's patients, ultimately improving their hospital stay experience and significantly reducing the occurrence of unrelated health/mobility problems.

Parkinson's, what's that?

Another challenge experienced by people with Parkinson's in a hospital environment is the lack of awareness regarding the most common and/or variety of Parkinson's symptoms amongst general hospital staff, who have likely received little information about the condition during their training.

As the symptoms of Parkinson's – and therefore medication regimens - tend to be highly individual, it is easy to appreciate that some hospital staff struggle to understand the illness, let alone the importance of medication on a case by case basis.

Typically, every Parkinson's patient they have cared for was, and will be, different. To assist staff to better understand Parkinson's – and your particular Parkinson's – it's a good idea to provide them with information about the condition.

A range of information materials are available from Parkinson's Victoria, including a Hospital Kit, multilingual information, and information online which can be downloaded.

To support this *general* information, we encourage you to share what living with Parkinson's is like **for you**, and some of the daily challenges you face.

You may draw their attention to your experience of freezing, dyskinesia (abnormal movement of voluntary muscles) or hallucinations.

This can be of particular importance if you have symptoms that are significantly worse during "OFF" periods. (ON/OFF periods are defined as fluctuations that occur in response to levodopa therapy, in which the person's mobility changes suddenly and unpredictably from a good response (on) to a poor response (off)). For example, some people find that swallowing is more difficult during "off" times, so eating and drinking should be avoided at this time.

Sometimes a letter from your neurologist, GP or Parkinson's nurse outlining your symptoms can also help when briefing staff about your condition and "handing over" (relinquishing) some of the care related to your Parkinson's.

There is no doubt that when staff learn how Parkinson's affects you, (whether through general information or hearing your personal experience), it makes it easier for them to plan your care, and of course you, the patient, benefit from this.

Keep in mind that you may need to tell your story a number of times to a number of staff during your stay, as even with short hospital admissions, you are likely to have a number of nurses and other staff looking after you.

When you have to halt your medication

Many people living with Parkinson's, at some stage, will need to be admitted to hospital for a review of their Parkinson's symptoms or when a new medication is being added to their existing regimen (to monitor its effects).

When this occurs, it is common to have your medications withheld for a period of time so that the physician can obtain a clear picture of how Parkinson's is currently affecting you and the impact of any new treatment that is being commenced. Unfortunately, this will result in you experiencing more Parkinson's symptoms than you normally would, and you may experience some associated discomfort. However, this assessment is typically carried out in Neuroscience or movement disorder units, where nursing staff will do their best to keep you as comfortable as possible.

This is one of the few occasions that it is okay to halt your Parkinson's medications.

If you need to fast for a medical procedure, discuss whether or not you are still able to take your Parkinson's medication. While medical and anesthetic staff often allow tablets with a sip of water for most procedures, you **must** discuss this with them. This will help ensure they are aware of what Parkinson's-related symptoms you experience and your need for medication. If you are having major surgery or an operation where you are unable to take your medication, make sure your neurologist or treating Parkinson's doctor is aware of this. They will be able to put a plan in place to manage your Parkinson's symptoms post procedure, and to gently reintroduce medication with the least amount of side effects possible. They will also communicate with the nurses looking after you that you may have some additional needs post procedure, such as medication or personal care needs.

While they are rarely pleasant, with good management and some pre-planning, hospital stays can be made less difficult, ensuring the reason you were admitted in the first place is addressed effectively and efficiently without being compromised or complicated by unrelated issues.

For more information or assistance with planning your hospital visit or if you require assistance during your stay, contact the Parkinson's Victoria Health Team.

Quick tips for "surviving hospital"

- Check with hospital staff to find out if self-administration of medication is possible during your stay.
- Use prompts to ask for medication when it's due (for example your pill timer)
- Provide the hospital staff with relevant, reliable information to help them understand Parkinson's.
- Communicate with your doctor/s about your Parkinson's, your symptoms and medication regimen (and any other treatment management strategies you currently employ).
- Encourage your doctor/s to talk with each other, and other treating staff to ensure that they have a plan to manage your Parkinson's and your hospital stay.

* Access Economics, 2007

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To see the complete newsletter, click here:

www.parkinsonsvic.org.au/about-ps/publications.htm#signposts

For more information about Parkinson's and hospital stays, or if you have any question in relation to Parkinson's, please contact Parkinson's Victoria.