

Parkinson's disease and going to hospital

Parkinson's disease is a progressive neurological condition that affects the control of body movements. A person with Parkinson's who is going into hospital may worry about managing their condition throughout their stay.

Common concerns include the fear that hospital routines may overlook the condition or that hospital staff may fail to accommodate the person's individual needs. There are practical things you can do to prepare for a planned or elective hospital admission.

Prior to admission

Most hospital staff will not know as much about Parkinson's disease as you do. Talk to the hospital admissions coordinator (also called an access coordinator) about particular concerns regarding your stay. If you are unsure who this is, ask for the Charge Nurse when you arrive at the ward.

Suggestions include:

- Give the admissions coordinator a list of your medications, including the dosage and times for each dose. Include information on how these medications are taken – for example, with a glass of water or without food.
- Find out if you can administer your own medications while in hospital. If not, discuss the alternatives.
- Give the admissions coordinator written information about Parkinson's. Include information on symptoms specific to you – for example, speech difficulties or constipation. If you have a particular nurse assigned to oversee your care, give them a copy of this information.
- Some people with Parkinson's experience motor fluctuations or 'on-off syndrome'. This is the sudden appearance of symptoms resulting from medication wearing off. If this happens to you, inform the admissions coordinator so that hospital staff can care for you during these times.
- Some people with Parkinson's use mobility equipment. Discuss your needs with the admissions coordinator. Some hospitals can provide the equipment. In other cases, you need to bring your own. Make sure you clearly label your own equipment.

Hospital kit

You may like to prepare a hospital kit to give to staff. The kit, small enough to fit into an envelope, could include:

- Telephone numbers for your family or friends, doctor, neurologist and other specialists
- Information on Parkinson's disease that includes a list of your particular symptoms
- A list of current medication that includes dosage and times for each dose
- A list of medications that **should not be taken** by a person with Parkinson's
- A list of activities you need help with – for example, walking, dressing or turning in bed.

Contact Parkinson's Victoria, who can send you a ready-made kit, which includes a range of important information relevant to a hospital stay.

Medication tips

Suggestions include:

- Take all medications with you in its regular containers.

- Make sure your medication schedule (the times you take various medications) is clearly explained and documented (written down) on your hospital drug chart.
- If you keep your medications in a pillbox, bring the original containers with you. This will, for example, help the pharmacist to refill your prescriptions.
- If you are participating in a drug trial, take the letter of explanation.
- Pack your medication timer or alarm, if you use one, and continue to use it during your hospital stay so you can ask for your medication when you need it.
- Request that information about your condition, including your medication schedule, is included on your chart (usually located at the end of the hospital bed) so that all nurses are made aware of your needs. The nurse assigned to your care may not be available at all times throughout your hospital stay.
- If you are having a surgical procedure give the anaesthetist a list of your medications. Your medications may influence the choice of anaesthesia.
- Discuss any medication concerns. Certain medical procedures require 'nil by mouth' for some time beforehand.

During your stay

Hospital staff members are busy looking after many patients, so it helps to be tolerant. However, don't be embarrassed to calmly remind staff about your needs. Suggestions include:

- Appreciate that stress may worsen symptoms of Parkinson's and that a hospital stay is a stressful event.
- Ask a close family member or friend to be a support person or advocate on your behalf.
- Talk to the hospital physiotherapist or occupational therapist (or both). A hospital stay increases the risk of falls for people with Parkinson's. Some of your mobility needs may be met in simple ways – for example, ask staff to place your hospital bed close to the bathroom and keep a chair in the bathroom for your use.
- Tell staff if you have a special diet – for example, if you require pureed foods.
- Talk to the radiographer if you experience dyskinesia (involuntary movements). Certain diagnostic tests, such as x-ray examinations, require you to keep still.
- Speak with the nurse in charge or medical consultant if you feel that staff are not managing your Parkinson's. Arrange an interview at a specific time – this is better than trying to talk to them 'on the fly'.

Going home

Discuss your concerns about discharge with hospital staff and family. Issues to consider include:

- You may have specific at-home instructions. Ask staff, your doctor or your specialist about how these instructions will impact on your condition and vice versa.
- Victorian public hospitals can offer some patients up to four weeks of at-home nursing care. Find out from hospital staff if you are eligible for the Post Acute Care Program.
- Ongoing support is offered to eligible patients through the local government's Home and Community Care (HACC) program. The social work or welfare department can give you more information.
- Your local council can advise you on eligibility for support programs such as meals on wheels or home help. Waiting lists may be long, so try to arrange these services well ahead of your admission date.
- The hospital social worker can advise you about hospital discharge concerns and support services for coping at home.

Emergency admissions – issues to consider

A medical emergency may require immediate treatment in a hospital emergency department. Suggestions include:

- Wear a medical alert bracelet or pendant to inform emergency department staff of your condition.
- Carry a copy of your 'hospital kit' in your handbag or wallet.
- Make sure that your family or friends know about your condition, so they can advocate on your behalf if you cannot communicate with hospital staff.

Where to get help

- Your doctor
- Family and friends
- Hospital admissions coordinator
- Hospital physiotherapist
- Hospital occupational therapist
- Hospital social worker
- Your local council
- Parkinson's Victoria Tel. (03) 9581 8700 or 1800 644 189

Things to remember

- Talk to the hospital admissions coordinator about particular concerns regarding your hospital stay.
- Don't be embarrassed to remind hospital staff about your needs.
- The hospital social worker can advise you about hospital discharge concerns and support services for coping at home.

This page has been produced in consultation with, and approved by:

Parkinson's Victoria

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