



Coming into hospital: A guide for patients with Parkinson's

This leaflet is for patients with Parkinson's who are coming into hospital for surgery or overnight treatment.

One month before your admission

- Let the Parkinson's nurse know as soon as you know that you will be going into hospital on 0118 322 6855 (Neuro Navigator).
- If you are having gastro-intestinal surgery or major surgery that will affect your ability to swallow or absorb your Parkinson's medication you will need to inform the Parkinson's nurse so that she can work with you and the surgical team to find an alternative route for the administration of your medication, using guidelines created for this purpose.

Pre-operative assessment/two weeks before surgery

- You should inform pre-operative staff that you are taking the drug Azilect (Rasagiline) as if Pethidine and other painkillers are going to be used you will need to stop it 14 days before surgery. Talk to your Parkinson's nurse about this as you may need to increase other Parkinson's medication temporarily to compensate for this.
- You should also let the staff know that you must not be given: Metoclopramide (Maxalon®); Prochlorperazine Stemetil ®); Valoid (Cyclizine®) or Haloperidol (Haldol®) for sickness as these drugs can make your Parkinson's symptoms worse.
- This is a good opportunity to let the staff know that you have Parkinson's and exactly how your condition affects you, and for them to document this and pass on any relevant information to those caring for you during your stay.
- If you experience the on-off phenomenon, bring with you a list of explicit problems that you personally experience when you are off such as:
 - Appearing withdrawn
 - Appearing confused
 - Having difficulty with speech
 - Experiencing considerable amount of pain
 - Unable to get out of bed
 - Unable to raise yourself from a chair
 - Have difficulty with balance
 - Unable to walk
 - Unable control of your bladder
 - Unable to smile or laugh

Going into hospital/admission

Check list for admission

- Drugs in original packaging.
- List of your normal drugs (such as a repeat prescription).
- Bring your medication with you into hospital in its original packaging to ensure there is no delay with you being able to take your medication and have sufficient medication for your predicted length of stay just in case your drug is not available from the hospital pharmacy.
- On the day of your operation you will be seen by a nurse, an anaesthetist and the surgeon undertaking your operation. This will give you a good chance explain the problems you have and for you to ask any questions about the operation.
- Ask where you are on the theatre list (the time you are likely to go to theatre) in case you to have to wait several hours. It is safe to take your Parkinson's medication up to one hour before your operation.
- It is helpful for the nurse to know exactly when and how you take your Parkinson's drugs because every person with Parkinson's is different.
- You may need to say when during the day you are generally at your best to undergo physiotherapy or occupational therapy as it will be counter-productive to undergo therapy when you are off.
- If you need a snack box or a low protein diet, let the staff know at this stage and they can inform the kitchen.
- Tell the staff what time your medication is due and ensure they are documented correctly.

Immediately after your operation / treatment

- You should (where possible) take your medication at the normal time. However, you may find that after operation your medication has begun to wear off which makes you feel particularly helpless because you are still recovering from anaesthetic.
- If you have any problems with your medication whilst in hospital ask to speak to the ward pharmacist, Parkinson's nurse, your neurologist or Dr Chatterjee.
- If you are very dysphonic or lose your voice when you are off, it would be a good idea to have a paper and pencil to hand so that you can communicate with the hospital staff?
- If you have had any surgery that affects walking, this may make getting out of bed very difficult, because your balance will be affected badly and you'll feel very wobbly after the anaesthetic.
- Let the nursing staff know what your problems are. Ask them to look at your notes which should have been passed on from the pre-operative team.
- It is likely that you may have a nerve block if you have limb surgery and if this affects your feet or legs you may be unable to balance properly. You can ask for a nurse to help you to the bathroom, make you comfortable in bed or manage food and drinks.

Managing the rest of your stay in hospital

- Let the ward staff know how you are feeling from day to day as Parkinson's is a fluctuating condition and the ward staff may not appreciate your particular problems from day to day as you looking fine one moment and off and feeling helpless half an hour later.
- As you recover you will find it less difficult to get out of bed and it is important to start moving around when as soon as you possibly can. The therapists will assess you for the safest equipment to use to aid your balance.
- If you have had orthopaedic surgery the physiotherapist may ask you to attempt to walk with crutches, this can be very difficult. For any attempt to manage stairs on crutches you will be assessed and supervised until you are safe to do this on your own. Explain your home environment to your physiotherapist who will advise you and can arrange a home assessment in if the situation warrants this.
- If you have other surgery and it has affected your balance and mobility you can ask the ward staff to let the physiotherapist know that you would like to see him/her.

Discharge from hospital

- On return home you find it a relief to be back in your own surroundings, but you will need help to carry out many tasks and you'll need equipment to make for your life easier.
- You may be lent equipment from the hospital on a temporary basis such as crutches, walking frame, a shower stool to help you balance and more permanent adaptations such as grab rails for toilet shower or bath can be organised through social services.
- You may also to temporarily loan a wheelchair by contacting the local branch of the Red Cross.

Getting help at home

If you have any worries about managing at home you should let the staff know at pre-operative clerking and certainly before you leave the hospital. If you only realise after your operation the problems you may encounter on discharge the ward nurse can contact the district nurse and/or social services for you.

Contacting us

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To find out more about our Trust visit www.royalberkshire.nhs.uk

Please ask if you need this information in another language or format.

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