

GOING INTO HOSPITAL WHEN YOU HAVE PARKINSON'S



PARKINSON'S^{UK} CHANGE ATTITUDES. FIND A CURE. JOIN US.

GOING INTO HOSPITAL FORM

Speech (eg does Parkinson's affect your ability to communicate? Do you use any communication aids?)

Eating and drinking (eg do you have a special diet? Do you need any help with eating and drinking?)

Walking (eg can you move around easily on your own? Do you use any equipment to help with mobility?)

Personal care (eg do you need help washing or bathing? Do you use a handrail or raised toilet seat?)

Sleeping (eg do you need help turning over in bed? Do you use a back rest?)

Cognitive needs (eg do you experience cognitive difficulties? Do you use any aids to prompt your memory?)

Other information (eg do you have any religious or cultural needs?)

Going into hospital can be an anxious time for anyone. If you have Parkinson's, you may have other concerns, such as being cared for by people who may not know a lot about the condition.

This booklet looks at:

- how you can prepare for going into hospital, whether it is a planned or emergency admission
- what you can expect when you are admitted to hospital
- how having Parkinson's may affect your stay and treatment
- the importance of getting your medication on time
- anaesthesia and how Parkinson's may affect surgery
- outpatient appointments and how to get the most out of the time you spend with professionals
- how you can complain if you aren't happy with the treatment you have received

At the back of the booklet, there is a 'Going into hospital' form. It has a medication record and space to record what assistance you may need during a hospital stay. You may find it useful to complete this form as it can help you prepare for a planned or an emergency admission to hospital.

This booklet was the winner of the Long Term Conditions Award at the British Medical Association's Patient Information Awards 2015.

GOING INTO HOSPITAL FORM

If you have Parkinson's, you may find it useful to complete this form. It can help you prepare for a planned or an emergency admission to hospital. You can provide details of your medication regimen and emergency contact details. You can also note down what assistance you may need during a hospital stay.

Once you have filled out the form, it's a good idea to keep this record somewhere easy to hand at home - the fridge door, for example - and let other people know where you keep it. You could also leave photocopies with members of your family or your carer.

Name: Date:

I am taking the following medication (include all the medication you are taking, not just for Parkinson's):

Drug name Include brand and generic name, eg Co-beneldopa (Madopar)	Dose	Time I need to take my medication	Wearing off symptoms	Special requirements Eg do you need to take medication with food?

Problems I experience when I don't get my drugs on time:

Drugs I have had a reaction to:

Emergency contact details

My Parkinson's nurse My GP

My Parkinson's specialist My information and support worker

Contents

Key messages.....	2
Preparing for a hospital admission	5
Telling the hospital you have Parkinson's.....	10
During your hospital stay.....	13
Managing your medication.....	19
Surgery and anaesthesia	23
Leaving hospital.....	29
Outpatient appointments.....	31
Having your say	35
More support and information.....	38

KEY MESSAGES

Preparing for a planned admission

- Keep an up-to-date medication record, which includes all the medication you are currently taking (not just for Parkinson's) and what time you take each dose. You can use the 'Going into hospital' form at the back of this booklet to record your medication.
- Tell your GP, specialist or Parkinson's nurse you are going into hospital. They can provide details of your medication regimen to the healthcare team who will be looking after you in hospital. Your Parkinson's nurse can also talk to the ward staff about your medication needs and the importance of getting your medication on time.
- Make sure people know you have Parkinson's. You can do this at a pre-admission assessment, or when you are admitted.
- Prepare extra supplies of your medication. Your medication should be kept in its original packaging and make sure you have at least 24 hours' supply to make sure you don't miss any doses.
- Organise your work and home life – for example, cancel newspaper deliveries.
- Find out about the hospital's self-administration of medication policy and how this works practically on the ward.

Preparing for an emergency admission

- Keep an up-to-date medication record, which includes all the medication you are currently taking (not just for Parkinson's) and what time you take each dose. Keep this with you all the time and let others know where you keep it. You could also leave photocopies with members of your family and carers. You can use the 'Going into hospital' form at the back of this booklet to record your medication.
- Prepare extra supplies of your medication and let other people know where they are. Your medication should be kept in its original packaging and make sure you have at least 24 hours' supply so you don't miss any doses.
- Tell staff you have Parkinson's and how important it is to get your medication on time.
- Explain to staff what medication you take. Show them your medication record. Ask them to keep a copy of it in your notes and check they have recorded this accurately.
- You may be able to self-administer your medication. If you are able to do this, keep taking your medication as you normally would at home.
- Ask a member of staff to let your GP, specialist or Parkinson's nurse know you are in hospital.
- Tell staff if you have had deep brain stimulation and show them your patient ID card.



Waiting



PREPARING FOR A HOSPITAL ADMISSION

There are two ways of being admitted into hospital – through a planned (or ‘booked’) admission, or as an emergency.

Whether or not you go to hospital for something Parkinson’s related, your condition should be an important consideration for both your nursing care and medical treatments you receive.

If your admission is planned, you may have some time to prepare for your stay in hospital. But it’s worth thinking about what you may need if you are admitted in an emergency as well.

Keep a medication record

A medication record lists the medication you are taking and contact details for your healthcare team. This should include:

- all the medication you are currently taking (not just for Parkinson’s), including the dosage

“ I think getting prepared for being admitted to hospital is really helpful, both to me and my carer. ”

Jane, diagnosed in 2010

– you can use your repeat prescription from your GP as a reference

- the brand and generic names for each drug – levodopa such as co-beneldopa (Madopar), for example
- what time you take each medication and if you have any ‘wearing off’ symptoms
- any special requirements, such as needing to take a drug with food or water
- details of any drugs (including those for your Parkinson’s) you have taken before that gave you serious side effects

- the contact details of your GP, specialist or Parkinson's nurse (if you have one)
- other things your medical team should be aware of, for example if you ever accidentally take more medication than you are prescribed, or regularly miss doses
- any problems you experience if you don't get your medication on time, for example difficulty swallowing or increased risk of falling

It's a good idea to keep this record with you all the time and let other people know where you keep it.

You could also leave photocopies with members of your family or carers. This could help if you are unable to communicate in an emergency, as they can give the healthcare professionals the record on your behalf.

Make sure you keep your medication record as up-to-date as possible.

You can order a medication card from us using the contact details on the inside back page of this booklet. This is small enough to keep in your wallet or purse and allows you to record drug names, times and doses.

The 'Going into hospital' form at the back of this booklet can also help record your medication.

Tell your GP, specialist or Parkinson's nurse

If your admission is planned, it's a good idea to tell your GP, specialist or Parkinson's nurse in advance. You could:

- ask them to provide details of your medication regimen to the healthcare team who will be looking after you in hospital
- ask your Parkinson's nurse to talk to the ward staff about your medication needs and the importance of getting your medication on time

Make sure people know you have Parkinson's

The Bottle in the fridge scheme

This is a free scheme designed to help alert emergency services to your condition if they need to enter your property in an emergency situation.

As part of the scheme you record basic medical details and emergency contact numbers on a standard form and keep it in the fridge. You then put

a green sticker on your fridge door, and another on the inside of your front door, so emergency services know you are part of the scheme.

Speak to your pharmacist or GP about getting a kit.

MedicAlert

A MedicAlert bracelet or pendant is a piece of jewellery that provides contact details and medical information, including what medications you are taking.

It can be helpful if you are not able to communicate in an emergency. See page 38 for contact details.

Prepare extra supplies of your medication

It can be a good idea to store extra supplies of your medication. If you do keep spare sets, let other people know where they are in case you need to use them.

Your medication should be kept in its original packaging – you will not be able to use your medication in hospital without this, even in an emergency.

Check that the dosage written on the labels matches what you are actually taking – this will be helpful if your hospital records are out



of date. You should have at least 24 hours' supply to make sure you don't miss any doses.

Make sure you keep a copy of our medication card with the supply too and rotate the medication to ensure they are kept in date. See page 43 for more details about ordering a medication card.

Carry a Parkinson's UK alert card

This is a plastic alert card that you can keep in your purse or wallet in case of emergencies. You can order an alert card using the contact details on page 43.

Organise your home and work life

If you're going into hospital and live alone, it's a good idea to think about any arrangements you need to make – do you need to cancel milk or newspaper deliveries, for example?

You may also need to arrange for a pet to be looked after. Your local vet may be able to recommend local pet sitters, catteries or kennels. If you are over 60, the Cinnamon Trust may be able to help arrange dog walking or pet fostering. See page 38 for contact details.

If you will be staying in hospital for any length of time, you may wish to tell your friends and trusted neighbours where you will be.

Find out more: see our [information sheet *Living alone with Parkinson's*](#).

You may find it useful to put items like the TV remote control, your phone, and books and magazines on a table next to a chair or bed, where you may be spending a lot of time when you return home. Stock up on easy-to-prepare food and essential household items.

If you work, you may need to take time off for a procedure or recovery afterwards. Talk to your employer about your needs before you go into hospital.

When you do return to work, you may feel more tired than usual. Your employer may be able to make some reasonable adjustments until you are fully recovered, such as flexible working hours or letting you take more frequent breaks during the day. You should also discuss a phased return to work if that's likely to be necessary.

Find out more: see our [booklet *Work and Parkinson's*](#).



TELLING THE HOSPITAL YOU HAVE PARKINSON'S

Pre-admission assessment

If your admission is planned, the hospital may invite you to a pre-admission assessment. This is an appointment with a doctor or nurse.

It is an opportunity for you to discuss your health, medical history and circumstances at home. You will be asked to bring in an up-to-date list of the medications you are taking.

You should use the appointment to tell the healthcare professional you have Parkinson's and what your specific needs are because of the condition.

Talk to the healthcare professional about what medication you take and the importance of getting it on time.

During the appointment, you will be told about what will happen when you are admitted to hospital, and where to report to on the day.

If you are having surgery or tests, you may be advised not to eat or drink anything before your admission.

You will also be routinely screened for your risk of the MRSA infection and hospital-acquired blood clots.

If the hospital doesn't have a pre-admission assessment process, you can discuss your needs when you are admitted.

Parkinson's UK has a booklet for ward staff called *Caring for your patient with Parkinson's*. You may find it helpful to take this with you to your pre-admission appointment or when you are first admitted to hospital. Details on how you can order a copy of the booklet can be found on page 43.

Apomorphine

If you have an apomorphine pump, you should ask if a staff member on the ward knows how to administer it before you are admitted.

A Parkinson's nurse can discuss with the ward staff how to control the pump if they have no previous experience of this. They can also speak to the APO-go helpline for more advice (**0844 880 1327**).

Depending on hospital policy, your carer may be able to continue managing this treatment.

Duodopa

You should make it clear if you are taking Duodopa – a type of levodopa that is pumped continuously through a tube which is surgically inserted in the intestine.

As with apomorphine, a Parkinson's nurse can discuss with the ward staff how to manage your pump if they have no previous experience of this.

Depending on hospital policy, your carer may be able to continue managing this treatment.

Deep brain stimulation

It is important to make staff aware if you have had deep brain stimulation surgery.

MRI scans can only be used under very strict conditions, and antibiotics have to be prescribed when there is a risk of germs getting in to the blood stream, for example during dental procedures.

You should make sure you take your patient ID card when you go into hospital as this carries vital contact details if the ward staff have any further questions.



What if I am admitted to hospital in an emergency?

If you have to wait to see a doctor in the accident and emergency department, try to remember the following:

- Tell staff you have Parkinson's and how important it is to get your medication on time.
- Accident and emergency staff may not know a lot about Parkinson's. Be patient and try to provide as much information as possible about how the condition affects you – the more they know, the more they can help you with your specific needs.
- Explain to staff what medication you take. Show them your medication card or the form at the back of this booklet. Ask them to keep a record of it in your notes and check they have recorded everything accurately.
- Ask a member of staff to let your GP, specialist or Parkinson's nurse know that you are in hospital.
- If your medication is in its original packaging, you may be allowed to self-administer your medication. If you are able to do this, keep taking your medication as you normally would at home.

- Tell staff if you've had deep brain stimulation surgery (see page 28 for more information).

After assessment in the accident and emergency department, you may be discharged. Depending on the reason for your admission, follow-up appointments may be made with a hospital clinic or your GP.

Healthcare staff may want to monitor your condition and carry out more tests to help decide if you need to be admitted to hospital. If this is the case, you may be moved to a Clinical Decisions Unit (CDU). Alternatively, you may be admitted directly to a medical or surgical ward.



DURING YOUR HOSPITAL STAY

Your named nurse

When you are admitted to hospital, you will be given a named nurse. They may also be known as a key, or primary, nurse. They are responsible for your care during your stay.

Your nurse will explain processes to you and what you can expect. You will also be fitted with an ID bracelet that must be kept on until you leave hospital.

You should tell your nurse about your usual routine and any specific needs you have, such as help with communication or mobility.

Ask to speak to your named nurse's deputy as well so they are aware of your needs when your named nurse isn't on duty.

The 'Going into hospital' form at the back of this booklet is a useful place to note down everything you'd like to talk to your named nurse about.

“ If you have Parkinson's and need to go into hospital, be firm about what you want and don't be intimidated. Be strong and make your point. I had a friend with me when I went into hospital and they supported me in doing this. ”

Debbie, diagnosed in 2003

Your named nurse may be able to arrange for information about your Parkinson's and your drugs to be included on the notes at the end of your bed. This will make night nurses and other ward staff aware of your needs when your named nurse is not on duty.

You may also wish to provide additional information about your needs, likes, dislikes, and preferences,

so staff can build up a picture of who you are.

You should include anything that is important to you – what makes you anxious? Do you have any religious or cultural needs that should be observed? The information you provide can be included in your ‘care plan’.

The Alzheimer’s Society have produced a simple and practical leaflet called *This is me* which is designed to provide information about the person going into hospital. You may find this is a useful starting point for thinking about the type

of information you’d like to share. You can find out more on their website, www.alzheimers.org.uk/thisisme or call their helpline on **0300 222 1122**.

If you are not able to, you should also ask your friends and family to tell your Parkinson’s nurse that you have gone into hospital. Your nurse can then contact the hospital to ensure they have all the information they need about your treatment.

If you don’t have a Parkinson’s nurse, you may like to ask if there is one based at the hospital and if they can be told about your stay.



Equipment

At home, you may use equipment to help with daily tasks. You should check with the hospital if you can bring these with you. Hospitals will normally have a policy on this. You can discuss this at your pre-admission assessment or during admission with your named nurse.

If you can take your own equipment with you, label it clearly. You may want to add valuable pieces of equipment to your household insurance. If you can't take your own equipment, check suitable alternatives will be available.

You may find that using new pieces of equipment in hospital makes your stay easier, even if you do not use them at home. New equipment should only be used under the guidance of a healthcare professional, such as an occupational therapist.

Find out more: see our [information sheet *Occupational therapy and Parkinson's*](#) and our [booklet *Daily living equipment for people with Parkinson's*](#).

Sleeping

Wards can be busy places, even at night. There can also be more lights on than you would be used to at home.

“If you are sensitive to light, consider getting a sleep mask. Hospital wards often have lights which are difficult to ignore. At home we have thick dark blue curtains which make the bedroom dark, but the ward has no such benefits!”

Jim, whose wife has Parkinson's

Try and stick to your regular sleep routine. If ward staff know your usual routine, they can try and accommodate it as far as possible.

Let the ward staff know about any specific needs you have for sleeping. Do you need help turning over in bed? Do you need to get up several times during the night to go to the toilet and do you need help to do this? Do you need a backrest or plenty of pillows?

Find out more: see our [booklet *Sleep and night-time problems in Parkinson's*](#).

Eating and drinking

If you usually have a special diet – thickened fluids, pureed meals or PEG feed for example – this will need to be ordered through the hospital dietitian. You should discuss any specific needs at the pre-admission assessment.

You should also let ward staff know if you use any special equipment to eat and drink with.

If you experience 'on/off's' and need help at meal times, make sure the staff are aware of this, so they don't just assume you aren't hungry (see page 21 for more information).

It's important to eat well while in hospital because this will help to fight off infection and maintain regular bowel and bladder function.

The type of food you get in hospital may be different to what you usually eat. You may find it useful to order small meals from the ward menu and ask your friends and family who visit to bring in extra snacks.

Using the bathroom

It's important to discuss any concerns you have about using the bathroom at the pre-admission assessment.

These may include whether you usually use a handrail or a raised toilet seat, and whether you can

get to the toilet without help.

If you experience bladder and bowel problems such as constipation or bladder incontinence, tell the hospital staff so they are aware.

Walking around

Floor surfaces, furniture and the distances you need to walk will all be different in hospital. There may also be extra people and obstacles to get around. You may find these things make it harder to move around the ward on your own.

Other people find their mobility improves in hospital because there is more space to move around.

It may be possible to be given a bed that is closer to the bathroom. Using equipment or asking the ward staff to help may also make it easier for you to stay mobile.

If you experience 'on/off's', let the staff know you may need more help when you are 'off' (see page 21 for more information).

If you are having specific problems with your mobility, a physiotherapist may be able to help.

Find out more: see our [information sheet *Physiotherapy and Parkinson's*](#).

Communication

If Parkinson's affects your ability to communicate, make sure the hospital staff know about this.

A soft, quiet voice may be difficult to hear on a noisy ward. You may also have to talk more than usual, which may make your voice tired. Some people may take a while to get used to your speech patterns.

Lack of facial expression may make staff think you are not responding when they ask you something, so you may find it helpful to explain

to staff that you experience this symptom.

Tell staff you need time to speak and answer their questions. Make sure you know how to operate the nurse-call buzzer to get the ward staff's attention and position it near enough to you so you can use it even if you are 'off' (see page 21 for more information).

If you use communication aids, bring them to the hospital. If there are times of the day that are particularly good or bad for you, make sure you talk about this with



your named nurse, or record it on the 'Going into hospital' form at the back of this booklet.

If you are having particular problems with communication in hospital, you may benefit from seeing a speech and language therapist.

Find out more: see our [information sheets](#) *Communication and Parkinson's* and *Speech and language therapy and Parkinson's*.

Benefits payments

Going into hospital may affect your benefits payments. This will depend on how long you spend in hospital and what benefits you receive.

If you are receiving benefits and are admitted to hospital, you need to notify the Department for Work and Pensions, or ask someone to do it for you. Your local office should be in the phone book or check their website, www.gov.uk/dwp

For more information on rights and benefits, you can contact our dedicated employment and benefits adviser on the Parkinson's UK helpline on **0808 800 0303** or email hello@parkinsons.org.uk

Find out more: see our [information sheet](#) *General information about benefits*.



MANAGING YOUR MEDICATION

Can I be responsible for my own medications in hospital?

This will depend on the hospital you are going to.

Some hospitals allow patients to bring in their own medication when they are admitted, but only if the medication is in its original packaging – blister packs or pill boxes are not used in hospitals.

If you have time, contact the hospital to find out about their self-administration of medication policy.

If your admission to hospital is planned, you should discuss whether you can bring your own medication at the pre-assessment appointment.

If you are able to bring your own medications with you, find out about how this works practically on the ward by asking the following questions:

- Where will my medication be stored on the ward?

- If medicines need to be locked away on the ward, who will have the key?
- Who will update the drugs chart when I take my medication?

On the ward, keep taking your medication on time. Your Parkinson's nurse may be able to help you arrange this. If you don't have your own Parkinson's nurse, ask if there is one based at the hospital.

They may also be able to find out for you if the drugs you take are stocked in the hospital pharmacy. This will alert pharmacy staff if they are not already in stock.

Make sure your healthcare team is aware you are self-administering your medication and work with them to avoid over-medicating.

If at any point you feel too unwell to keep taking your medication, make sure you tell a member of staff on the ward as soon as possible.

If you can't bring your own medication into hospital, you need to make sure you get your medication on time.

Don't be afraid to remind staff each time your tablets are due and stress to them that the timing of your medication is important for the drugs to control your condition effectively.

The timings of your medication may be different from the usual

ward drug rounds. One solution may be for the nurse to have a pill timer in their pocket that rings when it is time for your medication.

You could also order a free Get It On Time washbag to use if you go into hospital. It includes tips for preparing for hospital stays and a medication record book. See page 43 for details on how to order a washbag.



Telling staff about the side effects of your medication

If you experience side effects from your medication, it is important ward staff know about them.

‘On/off’

This is a side effect of Parkinson’s medication that can cause confusion and misunderstandings in hospital.

‘On/off’ usually happens to people who have had Parkinson’s for several years and their medication does not last as long as it used to. This causes their symptoms to recur before the next dose is due.

Being ‘on’ describes when a person’s symptoms are controlled and they are feeling at their most capable. Being ‘off’ is when Parkinson’s symptoms recur and are at their most debilitating.

Some people have described this as like a light switch being turned on and off, or like a yo-yo going up and down.

If you have ‘on/off’s’, make sure the staff understand that your ability to do things will change during the day. You may need more help when you are ‘off’ than you do when you are ‘on’.

What if I miss a dose of medication during my stay in hospital?

Share your concerns with the senior nurse on duty and explain how important it is to get your medication on time. Be clear about the impact the missed dose had on your condition. Ask them to report the incident as a drug error and discuss how they will make sure it doesn’t happen again.

If you don’t feel comfortable having this conversation yourself, you could ask a family member or friend to talk to staff on your behalf. Your Parkinson’s nurse may also be able to help you.

You may find it useful to keep notes on who you spoke to, when you spoke to them, what you discussed and what was agreed. After the meeting, follow-up with the staff to make sure what was agreed has been done.

Never feel you are being difficult. Remember, failing to give you your drugs on time makes extra work for the ward staff.



SURGERY AND ANAESTHESIA

Anaesthesia

Anaesthesia means 'loss of sensation'. Drugs that cause anaesthesia are called anaesthetics.

Anaesthetics are used to put someone to sleep for surgery, and stop you feeling pain and discomfort during the procedure. They work by blocking the signals that are sent along your nerves to your brain, which keep you awake and aware.

Anaesthetists are responsible for giving you the anaesthetic before your surgery, ensuring you are safe and well during the surgery and for managing your pain after your surgery has finished.

There are different types of anaesthetic, including the following:

Local anaesthetic

This numbs a small area of your body, so you can't feel anything, but you are awake throughout the procedure.

Regional anaesthetic

This can numb a larger or deeper area of the body. You will be awake during the procedure and not be able to feel pain, although you may still feel sensation such as pushing or movement.

General anaesthetic

This will make you totally unconsciousness and you will be unaware of the surgery. It is usually used for long operations or ones that may be very painful.

Sedation

This is medication that makes you feel sleepy and relaxes you physically and mentally. It can be used to keep you calm during minor, painful or unpleasant procedures.

Different types of anaesthesia can be used in combination. For example, a regional anaesthetic can be used with a general anaesthetic to relieve pain after an operation.



answered at the pre-admission assessment. They will discuss your Parkinson's symptoms with you and how they may affect you during surgery. There is more information about this on page 26.

You will be able to discuss with them which kind of anaesthetic is most suitable for you and what pain relief you may need afterwards. The anaesthetist will also discuss any risks or side effects of the drugs you will be having.

During the meeting, you should try to ask any questions you have about the anaesthetic and clarify anything you are unsure about.

Meeting your anaesthetist

You will usually meet your anaesthetist on the ward before your surgery.

It is very important that your anaesthetist knows you have Parkinson's and what medication you take for the condition.

Some anaesthetics may make Parkinson's symptoms worse or interfere with Parkinson's medication. The anaesthetist can plan your care appropriately around this.

When you meet, the anaesthetist will go through the questions you

Can I keep taking my Parkinson's medication right up until the time of surgery?

It's important you can keep taking your Parkinson's medication as close to the time of your surgery as possible, and as soon as possible after the operation.

You may be asked not to eat or drink for a period of time before the operation ('nil by mouth'). But you are usually allowed to keep taking your medication with a few sips of water during this period. Your anaesthetist will discuss plans for this with you before your operation.

If you have Parkinson's, your surgery may be put at the start of the day's operating schedule. This can mean that the risk of the surgery being cancelled is lower, for example if other procedures take longer than expected.

Organising your medication regimen is also easier if you know what time your surgery will be in advance. It is not always possible to arrange this though, so you should discuss this with the anaesthetist.

You should also talk about what you should do if your operation is delayed.

Medication may also be given during surgery if the operation is taking longer than planned and there is a risk of missing a dose. For example, if you usually take levodopa, it may be possible to give the drug using a tube that goes into your stomach. You should discuss this with your anaesthetist before your surgery.

Parkinson's drugs and surgery

Apomorphine

Depending on the procedure, you may not be able to take oral medication after surgery. It may be possible to use different drugs, such as apomorphine, which is

a strong dopamine agonist. It can be taken by intermittent injection or via infusion, using a pump.

Your healthcare team should discuss the possibility of being prescribed apomorphine after surgery with you before you go into hospital. Your Parkinson's specialist will also be involved in the decision.

If this is not discussed with you, ask your healthcare professional to talk to you about apomorphine.

Find out more: see our [information sheet *Apomorphine*](#).

Dopamine agonists

If you normally take oral dopamine agonists and are nil by mouth due to surgery, you may be switched to a dopamine agonist patch.

The patch is applied to your skin and, once in place, lasts for 24 hours. It will deliver the same dose of medication as you would normally take orally.

Your specialist can advise your surgical team about this.

Find out more: see our [booklet *Drug treatments for Parkinson's*](#).

Parkinson's symptoms and surgery

Low blood pressure

Some people with Parkinson's may experience problems with low blood pressure.

Postural hypotension (also known as orthostatic hypotension) is a large drop in blood pressure when standing or changing position, such as standing from a seated position.

If you experience this symptom, you should tell the anaesthetist. Having Parkinson's can cause people to have higher blood pressure readings when lying flat.

Find out more: see our [information sheet *Low blood pressure and Parkinson's*](#).

Involuntary movements (dyskinesia)

Dyskinesia are involuntary movements of the arms, legs, body or hands that can't be controlled. It is a side effect of some Parkinson's drugs when they have been used for a long time.

Involuntary movements may affect procedures such as x-rays, scans or radiotherapy, when you need to keep still.

Radiographers usually have techniques such as putting foam wedges in place to help overcome this, but it is important to talk to your healthcare professional about your movement problems before any procedure.

Sometimes for CT or MRI scans, you may need to have a general anaesthetic or be sedated so you are able to keep still. (See page 23 for more information).

If you are having a dental operation you may wish to contact the British Society for Disability and Oral Health. This organisation has a special interest in treating people with disabilities and may be able to advise the dentist on ways to overcome the problem. Their contact details are listed on page 38.

Saliva control and swallowing problems

Some people with Parkinson's develop problems controlling their saliva, which can lead to drooling or dribbling. The medical term for this is sialorrhea.

When you have Parkinson's, the natural tendency to swallow happens less often. We all swallow many times a day, but the rigidity and slowing down of movement that people with Parkinson's experience may reduce

this. If you swallow less, saliva can pool in your mouth.

If you experience these symptoms and are having a general anaesthetic, you may need to have a tube put down your throat to help you breathe. This is called intubation. This allows the anaesthetist to make sure your airway stays clear during the surgery.

Speak to your healthcare professional if you have any concerns about saliva control or swallowing problems during surgery.

After surgery

After your surgery has finished, you will be moved to a recovery room and told how the procedure went.

As the anaesthetic begins to wear off, you may feel pain or discomfort. Your anaesthetist is responsible for the management of pain after surgery and will have discussed this with you beforehand.

It's important to tell staff if you are in pain, so they can provide pain relief quickly before it gets worse.

You may experience side effects of the anaesthetic after surgery. It is common to feel sick or vomit as you begin to wake up. You may also feel cold or shiver, have a headache or feel faint or dizzy. These symptoms don't usually last very long and you may be given medication for them.



Your anaesthetist will discuss possible side effects of the anaesthetic and how they can be reduced with you before the surgery.

Surgery to treat Parkinson's

Deep brain stimulation is the main type of surgery used to treat the physical symptoms of Parkinson's.

It doesn't cure or slow down the progress of Parkinson's, but it can help some people control their symptoms.

It involves inserting very fine wires, with electrodes at their tips, into targeted parts of the brain. The wires are then connected to a battery-powered pacemaker-like device called a neurostimulator, which is implanted under the skin of the chest.

The device contains batteries and electronics that create an electric current. The current stimulates the targeted areas of the brain and has an effect on a person's symptoms.

Deep brain stimulation is only carried out at certain centres in the UK. Surgery can take place under general or a regional anaesthetic, depending on which surgical centre you are at.

Like any surgical procedure, you will meet your anaesthetist before your

operation and they will talk to you about the anaesthetic and what you may expect after the surgery has finished.

Find out more: see our booklet *Surgery for Parkinson's*.

Emergency surgery

If you need to have an emergency operation, it is important that the healthcare team looking after you know you have Parkinson's as soon as possible. You can read more about things you can do to prepare for an emergency admission on page 3.



LEAVING HOSPITAL

Being discharged

Making preparations for going home (discharge planning) often starts at admission.

To make sure everything is in place to get home safely, you will be asked for information, such as phone numbers of people who will help you at home.

Before you are discharged, healthcare staff should assess what support you may need when you leave hospital. If any support needs are identified, these should be recorded in a written care plan. You should not be discharged until the support you will need has been put in place.

If you rely on home care services, avoid going home over a weekend if you can. These services normally need 48 hours notice to start care again.

If you weren't receiving care at home before you were admitted to hospital and now need it, you

will be assigned a social worker who will arrange the care you need.

Hospitals try and give you a specific discharge time. It is important you keep taking your Parkinson's medication, even while you are waiting to leave.

Check with the pharmacy that you will be given enough medication for when you get home – you will usually get a two-week supply. This is especially important if your medications have been changed during your stay in hospital, as you may not have stocks of this medication in the right doses at home.

Follow up care may include visits from community nurses and therapists as well as hospital outpatient visits (see page 31 for more information).

If you are concerned about arrangements for going home after a hospital stay, you may be able to speak to a hospital social worker.



It is also worth thinking about how you will get to outpatient appointments if your mobility needs have changed – if you are unable to drive for a period of time, for example (see page 33 for more information).

If you have been in hospital for a long time or your mobility has changed, it may be possible for an occupational therapist to arrange a home visit with you before you are discharged.

This can help identify activities you may find difficult when you get home. The occupational therapist can suggest special aids, equipment, or other plans to make tasks easier.

Find out more: see our booklet *Daily living equipment for people with Parkinson's*.

Will having Parkinson's affect my recovery time?

Being in hospital can be stressful and having Parkinson's may mean you need longer to recover than someone who doesn't have the condition.

If you have any concerns about this, talk to the healthcare team in charge of your treatment, your specialist or Parkinson's nurse.

How important is aftercare once I have left hospital?

This is very important. If you have a hip operation for example, physiotherapy will be crucial in helping you get better.

Your healthcare team will talk to you about how your Parkinson's symptoms may have an impact on your aftercare and create a recovery programme that meets your needs.

OUTPATIENT APPOINTMENTS

If you are receiving hospital care, but do not need to stay in hospital, you are treated as an outpatient.

Preparing for your appointment

Making a list of the questions you want to ask before your appointment will help you feel more prepared. For example:

- What are my treatment options for this condition?
- What are the advantages or disadvantages of the different treatment options?
- How may my Parkinson's be affected by treatment?

At your appointment

Take someone with you

You may find it helpful to take someone with you to your appointment for support – perhaps your partner, a family member or friend.

Tell whoever comes with you what you want to talk about before your appointment, so that they can remind you if anything slips your mind.

If you have problems speaking or writing, the person with you may also help by speaking on your behalf or taking notes.

Take everything you need

You will usually be asked to bring details of the medication you are taking. You may find it helpful to bring your medication with you, including the bottles or packaging.

If you use glasses or hearing aids, make sure you take these with you to the appointment.

If you have communication problems, make sure your GP, specialist or Parkinson's nurse is aware of these and any methods or equipment you use to make it easier for you to communicate.

Don't be afraid to ask questions

If a healthcare professional says things you don't understand, ask them to explain.

It is much better to admit you don't understand than to pretend you do, and then find you don't know what you need to do when you get home.

Take notes

You may find it helpful to write down the answers to the questions and any instructions you are given, to help you remember after your appointment. If you have trouble writing, ask the healthcare professional to write it out for you.



Find out more: see our information sheet *Talking to your GP, specialist or Parkinson's nurse about Parkinson's*.

Transport to and from hospital

If you have an outpatient appointment, it's worth considering how you will get to and from the hospital.

You will normally be expected to make your own way to your appointment. If this is not possible, you may be able to use the Patient Transport Services.

This NHS service offers free transport for people who have a medical need. You should discuss whether you are entitled to this service with your GP or the healthcare professional who referred you to the outpatient clinic.

If you live in England or Northern Ireland, your GP will need to book transport for you.

In Scotland, you can arrange your own patient transport by calling **0300 123 1236**. More information can be found at www.scottishambulance.com/whatwedo/pts.aspx

In Wales, you can arrange your own transport depending on where you live. In North Wales, you can arrange transport by calling **0845 60 76 181**, or **0844 87 00 888** if you live in the Central and West regions. In South Wales, you should call **0800 32 82 332** for the first journey you make. For any future journeys, you should call **0300 100 0012**. If you live in any other region in Wales, you should talk to your GP about arranging transport.

For more information on transport services, you should speak to your GP, or local PatientAdvice and Liaison Service (PALS). See page 35 for more information on PALS.

If you aren't eligible for the Patient Transport Services, you may be able to claim a refund for the cost of transport to your outpatient appointment from the Healthcare Travel Cost Scheme.

To get a refund you will need to show you are not able to afford the cost of travelling to hospital and do not have a friend or relative that can take you.

Find out more: see our information sheet *Help with health costs*.



HAVING YOUR SAY

If you are unhappy with the treatment you receive in hospital, you may want to complain. You should raise your concerns with the ward staff first if you are in hospital.

By complaining, you can improve care for both yourself if you go into hospital again, and for other people affected by Parkinson's.

Don't worry about how a complaint will affect your future care – hospital staff are committed to providing the best possible care for all patients, and complaining can highlight issues.

You may also like to let staff know when things have gone right. If you feel the care you have received was excellent, compliment staff and write to hospital managers when you get home.

You should also let Parkinson's UK know so we can make sure good practice is spread by highlighting organisations that offer great care.

Our contact details can be found on the back cover of this booklet.

In England

The Patient Advice and Liaison Service (PALS) is based in your hospital and can help you resolve concerns or problems you're facing with the NHS.

They can also give you advice on health-related questions and give you information about the NHS complaints procedure. This includes how to get independent help if you want to go ahead and lodge a complaint. Ward staff will have contact details for them.

In England, you can also get involved in Healthwatch. This is an independent consumer organisation that aims to make sure the views and experiences of people who use health and social care services are heard and taken seriously – both locally and nationally.

Your local Healthwatch can help with complaints you have about services, including those related to your Parkinson's.

To find your local Healthwatch visit www.healthwatch.co.uk, or call **03000 683 000**.

In Scotland

You can contact the Patient Advice and Support Service (PASS) run by the Citizens Advice Bureau. They are not based in hospitals, but you can find out more by calling **0808 800 9060**, by visiting their website www.patientadvicescotland.org.uk, or contacting your local Citizens Advice Bureau.

In Wales

You can contact the Community Health Council for the Local Health Board where you are being treated. You can find out which Community Health Council to contact by looking at the Board of Community Health Councils website, www.wales.nhs.uk/sitesplus/899/home

In Northern Ireland

The equivalent body in Northern Ireland is the Patient and Client Council (PCC).

The council is an independent body whose aim is to provide a powerful

voice for patients, carers, and communities on health and social care issues.

They listen, act on people's views, help people make a complaint, and provide advice and information.

More information about the council can be found on their website, www.patientclientcouncil.hscni.net or by calling **0800 917 0222**.

Medicines and Healthcare products Regulatory Agency (MHRA)

If you want to complain because you did not get your medication on time while you were in hospital, we also encourage you to tell the Medicines and Healthcare products Regulatory Agency (MHRA), using their Yellow Card Scheme.

The scheme helps the MHRA monitor how safely medicines are being used. They can be reached at **0808 100 3352** (10am–2pm, Monday–Friday) or at their website, www.yellowcard.mhra.gov.uk

Regulatory professional bodies

If you have a complaint against a nurse or doctor, it is always best to raise the issue with the hospital where you received the care first,

or take advice from the organisations mentioned on pages 35–36.

If you are not satisfied with the outcome of your complaint, you are able to contact the General Medical Council or Nursing and Midwifery Council directly.

The General Medical Council registers doctors to work in the UK. The Nursing and Midwifery Council does the same for nurses and midwives. The contact details for both organisations can be found on page 38.

The General Medical Council has produced some helpful information, *What to expect from your doctor:*

a guide for patients. The guide explains what you can expect from your doctor and how you can help create a partnership with them. The guide is available to download at www.gmc-uk.org/guidance/patients.asp or by calling **0161 923 6602**.

The Nursing and Midwifery Council have also produced a booklet, *Raising concerns about nurses or midwives*, that gives you guidance on what you can do if you are worried about the care you have received. It is available at www.nmc-uk.org/documents/NMC-publications/raising-concerns-about-nurses-or-midwives.pdf or by calling **020 7637 7181**.



MORE INFORMATION AND SUPPORT

The following organisations may be useful if you are preparing to go into, or have recently had a stay in hospital.

British Society for Disability
and Oral Health
www.bsdh.org.uk

Cinnamon Trust
01736 757 900
www.cinnamon.org.uk

Community Health Councils
(Wales)
[www.wales.nhs.uk/
sitesplus/899/home](http://www.wales.nhs.uk/sitesplus/899/home)

General Medical Council
0161 923 6602
www.gmc-uk.org

Healthwatch England
03000 683 000
www.healthwatch.co.uk

MedicAlert
01908 951 045
info@medicalert.org.uk
www.medicalert.org.uk

Nursing and Midwifery Council
020 7637 7181
www.nmc-uk.org

Patient Advice and Support Service
(Scotland)
0808 800 9060
www.patientadviceScotland.org.uk

Patient and Client Council
(Northern Ireland)
0800 917 0222
www.patientclientcouncil.hscni.net
info.pcc@hscni.net

Yellow Card Scheme
0808 100 3352
www.yellowcard.mhra.gov.uk
[pharmacovigilanceservice@mhra.
gsi.gov.uk](mailto:pharmacovigilanceservice@mhra.gsi.gov.uk)

Parkinson's nurses

Parkinson's nurses provide expert advice and support to people with Parkinson's and those who care for them. They can also act as a liaison between other health and social care professionals to make sure your needs are met.

Parkinson's nurses may not be available in every area, but your GP or specialist can tell you about local services.

You can find out more at **parkinsons.org.uk/nurses**

Information and support from Parkinson's UK

You can call our free confidential helpline for general support and information. Call **0808 800 0303** (calls are free from UK landlines and most mobile networks) or email **hello@parkinsons.org.uk**

Our helpline can also put you in touch with one of our local advisers, who provide one-to-one information and support to anyone affected by Parkinson's. They can also provide links to local groups and services.

Our website has information about your local support team and how to contact them at **parkinsons.org.uk/localtoyou**

You can find details of our local groups and your nearest meeting at **parkinsons.org.uk/localgroups**

You can also visit **parkinsons.org.uk/forum** to chat to other people with similar experiences on our online discussion forum.

NOTES

A series of horizontal dotted lines for writing notes.

Going into hospital (B182/2014)

Do you have any feedback about this information? Your comments will help us ensure our resources are as useful and easy to understand as possible. Please return to [Information Content team, Parkinson's UK, 215 Vauxhall Bridge Road, London SW1V 1EJ](#), or email publications@parkinsons.org.uk. Thank you!

1. Please choose the option that best fits you.

- I have Parkinson's and was diagnosed in
- I care for someone with Parkinson's
- I have a friend or family member with Parkinson's
- I'm a professional working with people with Parkinson's
- Other (please specify)
-
-

2. Where did you get this information from?

- GP Specialist
- Parkinson's nurse Parkinson's UK local group
- Parkinson's UK local adviser Ordered directly from us
- Call to the helpline
- Other (please specify)
-
-

3. Has it answered all your questions?

- Yes, completely Not sure
- Yes, mostly Not at all
- Partly

4. How easy was it to understand?

- Very easy Quite difficult
- Easy Very difficult
- Not sure

Continued over the page



5. Has it helped you manage your condition better, or make choices that have improved your life in some way?

- | | |
|---|---|
| <input type="checkbox"/> It helped a lot | <input type="checkbox"/> It didn't help |
| <input type="checkbox"/> It helped a little | <input type="checkbox"/> It made things worse |
| <input type="checkbox"/> No change | |

6. What is your ethnic background?*

- | | |
|---|--|
| <input type="checkbox"/> Asian or Asian British | <input type="checkbox"/> Mixed |
| <input type="checkbox"/> Black or Black British | <input type="checkbox"/> White British |
| <input type="checkbox"/> Chinese | <input type="checkbox"/> White other |
| <input type="checkbox"/> Other (please specify) | |
-

*We ask about your ethnicity to ensure our information is reaching a broad range of people. However, this question is optional.

Want to hear more from us?

- I would like a response to my feedback
- I would like to be a member of Parkinson's UK
- I'm interested in joining the Information review group, to offer feedback on Parkinson's UK information

If you've answered yes to any of these options, please complete your details below.

Name

Address

Email

Telephone

How would you prefer us to contact you?

- Email Post Phone

We will not pass on your details to any other organisation or third party. To find out more, read our privacy policy at parkinsons.org.uk/termsandconditions



Thank you to everyone who contributed to or reviewed this booklet:

Louise Ebenezer, Parkinson's Disease Nurse Specialist, Princess of Wales Hospital, Bridgend

Grainne Nicholson, Senior Lecturer and Honorary Consultant Neurologist in Anaesthesia, St George's Hospital, London

Suma Surendranath, Professional Engagement and Education Manager, Parkinson's UK

Thanks also to our information review group and other people affected by Parkinson's who provided feedback.

Our information

All of our most up-to-date information is available at

parkinsons.org.uk/information-support

If you'd prefer to read one of our printed leaflets or booklets, find out how to place an order at **parkinsons.org.uk/ordering-resources** or by calling **0300 123 3689**.

We make every effort to make sure that our services provide current, unbiased and accurate information. We hope that this will add to any professional advice you receive and will help you to make any decisions you may face. Please do continue to talk to your health and social care team if you are worried about any aspect of living with Parkinson's.

If you'd like to find out more about how we put our information together, including references and the sources of evidence we use, please contact us at **publications@parkinsons.org.uk**.

Can you help?

At Parkinson's UK, we are totally dependent on donations from individuals and organisations to fund the work that we do. There are many ways that you can help us to support people with Parkinson's.

If you would like to get involved, please contact our Supporter Services team on **0800 138 6593** or visit our website at **parkinsons.org.uk/donate**. Thank you.

Every hour, two people in the UK are told they have Parkinson's – a brain condition that turns lives upside down, leaving a future full of uncertainty.

Parkinson's UK is here to make sure people have whatever they need to take back control – from information to inspiration.

We want everyone to get the best health and social care. So we bring professionals together to drive improvements that enable people to live life to the full.

Ultimately, we want to end Parkinson's. That's why we inspire and support the international research community to develop life-changing treatments, faster. And we won't stop until we find a cure.

Together we can bring forward the day when no one fears Parkinson's.

Parkinson's UK
215 Vauxhall Bridge Road
London SW1V 1EJ

Free confidential helpline **0808 800 0303**
(Monday to Friday 9am–7pm, Saturday 10am–2pm).

Interpreting available.

NGT Relay **18001 0808 800 0303** (for use with smart phones, tablets, PCs and other devices). For more information see **www.ngts.org.uk**

hello@parkinsons.org.uk
parkinsons.org.uk

Order code: PKB182

Last updated October 2014. We review our information within three years. Please check our website for the most up-to-date versions of all our information.

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