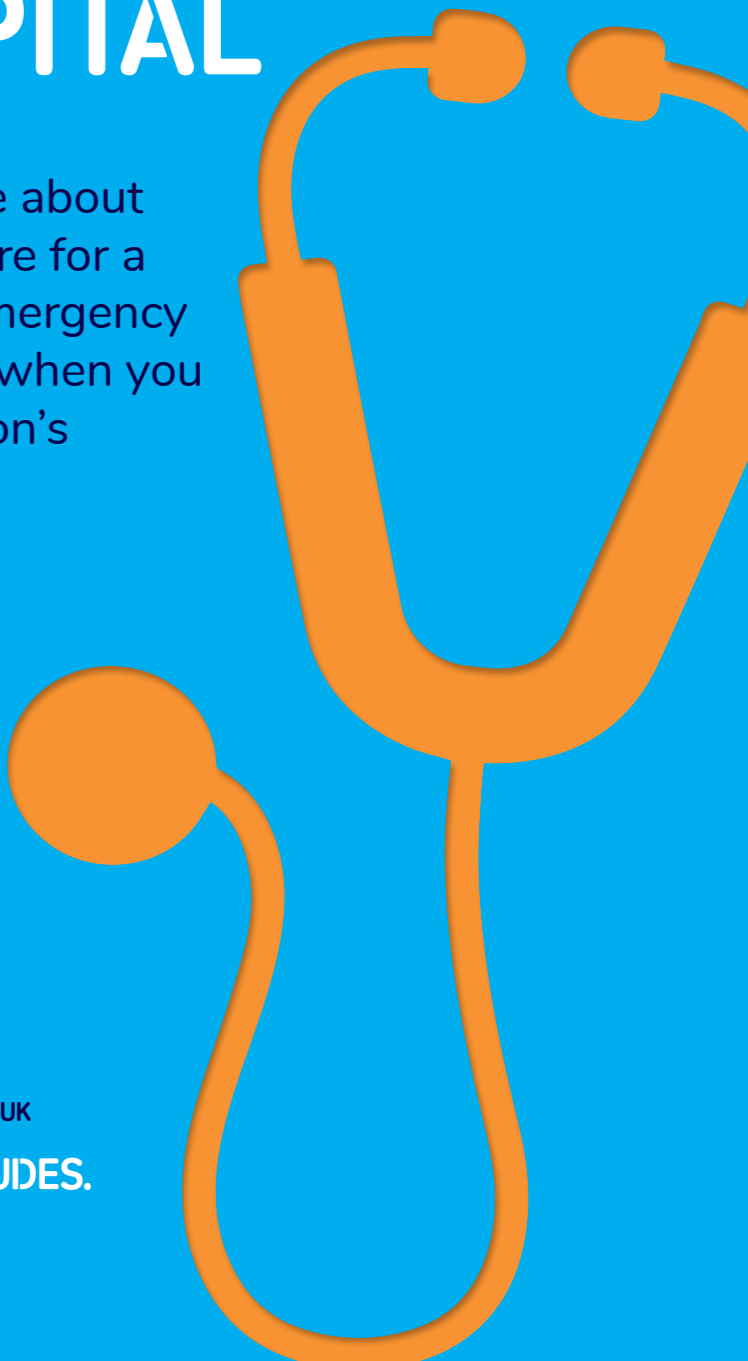


# GOING INTO HOSPITAL

## Everyday life

Find out more about how to prepare for a planned or emergency hospital stay when you have Parkinson's



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## GOING INTO HOSPITAL FORM

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Speech (eg does Parkinson's affect your ability to communicate?)

Eating and drinking (eg do you need any help with eating and drinking?)

Walking (eg do you use any equipment to help with mobility?)

Personal care (eg do you need help washing or bathing?)

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

Cognitive needs (eg do you experience cognitive difficulties?)

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

# GOING INTO HOSPITAL

Planning for a hospital stay when you have Parkinson's will help you manage your condition and make sure you can leave hospital as quickly as possible and recover well.

This information looks at:

- how you can prepare for going into hospital, as 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
- how you can complain if you aren't happy with the treatment you've 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.

## 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 specialist  My local adviser

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# KEY POINTS

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## Preparing for a planned admission

- Prepare an accurate and up-to-date list of all the medication you're currently taking (not just for Parkinson's). This should include your drug timings and doses, and whether it's branded or generic. You can get a printed list from your GP, or record these details on the Medication Record at the end of this information.
- Tell your GP, specialist or Parkinson's nurse you're going into hospital. They can also provide details of your medication routine to the healthcare team who'll be looking after you. It's vital that ward staff know the importance of you getting your medication on time. Your Parkinson's nurse should tell them this.
- Make sure people involved in your care know you have Parkinson's. You can do this at a pre-admission assessment or when you're admitted.
- Prepare extra supplies of your medication, which should be kept in its original packaging.
- Find out whether your hospital has a self-administration policy for medication on your ward.
- Tell staff if you've had deep brain stimulation (DBS) and show them your patient ID card.



## Emergency admissions

If you're admitted to hospital in an emergency, you should also:

- Tell staff you have Parkinson's and how it's vital that you get your medication on time.
- Explain to staff what medication you take. Show them your medication record if you have one and ask them to keep a copy of it in your notes. Check they've recorded this accurately.
- Ask a member of staff to let your GP, specialist or Parkinson's nurse know you're in hospital.
- Tell staff if you've had deep brain stimulation (DBS) and show them your patient ID card.

# PREPARING FOR A HOSPITAL ADMISSION

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A planned or emergency hospital admission may or may not be related to your Parkinson's. But it's important that your condition is carefully managed during your hospital stay. You'll need to make sure you can continue with your drug routine, and that hospital staff understand how the condition affects you day-to-day.

Because of this, it's important to plan for a booked hospital admission. But having some things prepared in case of an emergency stay can also help you ease any anxiety.

## In this section:

- Make sure people know you have Parkinson's
- Tell your GP, specialist or Parkinson's nurse
- Pre-admission assessment
- Preparing your medication
- Tell staff about your Parkinson's treatment
- Deep brain stimulation (DBS)
- What if I'm admitted to hospital in an emergency?

## Make sure people know you have Parkinson's

### **The Message in a Bottle scheme**

This is a free scheme designed to alert emergency services to your condition quickly. The kit includes a form to record your medical details on. The form is stored in a bottle in your fridge. The kit also contains two green stickers. One should be put on your fridge door, and the other on the inside of your front door. This will let emergency services know you're part of the scheme.

See the 'More information and support' section for contact details, or speak to your pharmacist or Parkinson's nurse.

### **MedicAlert**

A MedicAlert bracelet or pendant is a piece of jewellery that provides contact details and medical information, including what medications you're taking. It can be helpful if you're not able to communicate in an emergency. See the 'More information and support' section for details about how to order one.

### **Carry a Parkinson's UK alert card**

This is a plastic alert card you can keep in your purse or wallet in case of emergencies. You can order an alert card using the contact details at the end of this information.

### **Smartphone medical ID**

Many smartphones have a Medical ID app. You can record that you have Parkinson's and any medication you take (not just for Parkinson's).

You can also include the contact number of a family member, friend or the person who supports or cares for you. This will let emergency services know who to call.



## 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. They can pass on your medical details to the team who'll look after you in hospital. They should also stress that you need your Parkinson's medication on time. This is very important for helping to control your symptoms effectively.

## Pre-admission assessment

The hospital may invite you to a pre-admission assessment. This is an appointment with a doctor or nurse.

It's an opportunity for you to discuss your Parkinson's and any specific needs you have. For example, any special equipment you use or daily routines you have. You'll also be asked to bring in an up-to-date list of the medications you're taking. It's a good idea to carry this list with you at all times, not just when you're in hospital.

If the hospital doesn't have a pre-admission assessment process, you can discuss your needs when you're admitted. The admissions nurse will be responsible for asking about these needs when you go into hospital.

The pre-admission assessment can make sure you have a good stay in hospital and recover well. This is important because Parkinson's can increase the time it takes some people to recover. But with the right care, you'll be able to recover as quickly as possible.

## Preparing your medication

It's a good idea to prepare your medication before your hospital stay, if you're able to. This can help hospital staff quickly understand your medication routine. You should be able to take your own medication into hospital with you, including any that aren't for Parkinson's.

You might find the following tips helpful.

### Keep a record of your medication

You can use the Medication Record form at the end of this information to list your medication and how your symptoms affect you.

### Storing your medication

- Your medication should be kept in its original packaging. You won't be able to use it in hospital without this, even in an emergency.
- Check that your medication dose stated on the labels matches what you're actually taking. This will be helpful if your hospital records are out of date. You should also have at least 24 hours' supply so you don't miss any doses.
- Keeping a copy of our medication card with your supply will help medical professionals to quickly understand your treatment routine. You can order one of these for free on our online shop at [shop.parkinsons.org.uk](https://shop.parkinsons.org.uk)
- It can also be a good idea to store extra supplies of your medication. Let your healthcare team, and anyone who cares for you, know where they are in case you need to use them.

Any medication you bring to hospital will be stored in a safe place by your nurse. This is usually a locker by your bed, which only you and ward staff can access.

## Tell staff about your Parkinson's treatment

It's important that hospital staff know what medication you take and when you need to take it. This will mean you don't miss doses and can recover as quickly as possible.

Apomorphine and duodopa require specialist care, so it's particularly important to tell staff about them.

Staff can speak to your Parkinson's nurse, the APO-go helpline **(0844 880 1327)**, or the Dacepton helpline **(0800 254 0175)** for more advice.

The person who supports or cares for you may be able to continue managing this treatment. This will depend on your hospital's policy.

## Deep brain stimulation (DBS)

It's also important to tell staff if you've had DBS. MRI scans can only be used under very strict conditions if you've had DBS.

If you're having surgery, the surgeon and anaesthetist should be told you have a DBS device implanted. There are certain safety measures they'll need to take during the operation, such as prescribing antibiotics when there's a risk of germs getting into the bloodstream. This can include during dental procedures, for example.

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

## What if I'm admitted to hospital in an emergency?

**If you have to wait to see a doctor in the Emergency Department, try to remember the following:**

- Tell staff you have Parkinson's and how vital it is to get your medication on time.
- Explain to staff what medication you take. Show them your medication card or the Medication Record at the back of this booklet. Ask them to keep a record of it in your notes and check they've recorded everything accurately.
- Ask a member of staff to let your GP, specialist or Parkinson's nurse know you're in hospital.
- If your medication is in its original packaging, you may be allowed to self-administer your medication. If you're able to do this, keep taking your drugs as you normally would at home.
- Tell staff if you've had DBS (see the 'Deep brain stimulation (DBS)' section for more information).
- Emergency Department 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.

# DURING YOUR HOSPITAL STAY

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When you're in hospital, it's important that you feel comfortable and have everything you need to be able to manage your symptoms.

## In this section:

- Your nurse or named nurse
- Equipment and mobility
- Sleeping
- Eating and drinking
- Using the bathroom
- Communication
- Hallucinations and delusions
- Benefits payments

## Your nurse or named nurse

When you're admitted to hospital, you may be given a named nurse. They are responsible for your care during your stay. This is more likely if you're a day patient.

If you're staying in hospital overnight or for a longer period of time, it's likely that several nurses will care for you. For example, the day nurse will hand over your care to another nurse at night. You may also move wards during a stay.

It's important to tell each nurse who cares for you about your usual routine with Parkinson's and any specific needs you have. Tell them how vital it is that you get your medication on time. The 'Going into hospital' form at the end of this information is a useful place to note this.

Your admissions nurse or named nurse should arrange for information about your Parkinson's and your drugs to be included in your bedside notes.

This will make the nursing and other ward staff aware of your needs across the day and overnight.

It might also help to ask for a sign to be put above your bed, stressing the importance of getting your medication on time.

## Equipment and mobility

At home, you may use equipment to help with daily tasks. You should check with the hospital if you can bring these with you. You can discuss your equipment at your pre-admission assessment, or with your nurse during admission.

Using equipment or asking the ward staff to help may also make it easier for you to move around.

**Find out more:** see our information on daily living equipment.

## Sleeping

Wards can be busy, even at night. There may be noises around you that you find distracting. There can also be more lights on than you would be used to at home.

Try to 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. This could include help turning over in bed, or getting up often during the night to go to the toilet. If you need extra pillows or blankets, staff can arrange this for you.

**Find out more:** see our information on sleep and night-time problems in Parkinson's.

## Eating and drinking

When you're admitted to hospital, staff will ask if you have any special dietary requirements. This includes any eating or swallowing issues that you experience as part of your Parkinson's symptoms. For example, you may need thickened fluids, pureed (softened) meals or a PEG feed (feeding tube).

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

If you have any dietary needs related to your medication, you should talk to a hospital dietitian so you can plan ahead. For example, if high-protein meals affect how well your body absorbs levodopa. This will help you continue with your medication routine. You can also discuss anything specific about your dietary needs at your pre-admission assessment.

If you experience 'on/off' periods and need help at meal times, make sure staff are aware of this. During 'off' periods, certain symptoms, such as stiffness or slowness of movement, might make it harder for you to eat. Staff might not realise this and assume you're not hungry.

It's important to eat a healthy and balanced diet during your hospital stay. This can help prevent infection and maintain good bowel and bladder health.

## Using the bathroom

Bladder and bowel problems, such as constipation or poor bladder control, can be more common in people with Parkinson's. Make hospital staff aware of any issues so they can help you.

**Find out more:** see our information on bladder and bowel problems.

## Communication

If Parkinson's affects your ability to speak or communicate, make sure the hospital staff know about this. This can help them give you more time to speak and answer their questions. 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.

If you use communication aids, bring them to the hospital to help you.

If your symptoms cause your facial muscles to become stiff, a lack of facial expression may make staff think you're not responding when they ask you something. You may find it helpful to explain this to staff if you experience this.

If there are times of the day that are particularly good or bad for you, make sure you discuss this with your nurse. For example, if your speech is quieter or less clear when you're feeling tired, or when your medication wears off. You can also record this on the 'Going into hospital' form at the end of this information.

**Find out more:** see our information on speech and communication problems.



## Hallucinations and delusions

Some people with Parkinson's may experience hallucinations or delusions. They usually happen as a side effect of your Parkinson's medication. But in some cases they may be a symptom of your Parkinson's, or another condition, such as dementia.

If you experience these symptoms, you should let the ward staff know, so they can support you.

**Find out more:** see our information about hallucinations and delusions.

## 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're receiving benefits and are admitted to hospital, you need to inform the Department for Work and Pensions or ask someone to do it for you.

Check the website of your local office at **[www.gov.uk/dwp](http://www.gov.uk/dwp)**

For more information on rights and benefits, you can contact our benefits advisers on the Parkinson's UK helpline on **0808 800 0303** or **[hello@parkinsons.org.uk](mailto:hello@parkinsons.org.uk)**

**Find out more:** see our information on money, grants and benefits.

# MANAGING YOUR MEDICATION

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There are some important things to consider with your medication before you go into hospital. Planning these things ahead can help make sure you get your medication on time.

**In this section:**

- Can I be responsible for my own medications in hospital?
- Getting your medication on time
- What if I miss a dose of medication during my stay in hospital?
- ‘On/off’ side effects of your medication

## Can I be responsible for my own medications in hospital?

This will depend on the hospital you’re going to. Some hospitals allow patients to bring in their own medication, if the medication is in its original packaging. If you have time, contact the hospital to find out about their self-administration policy.

If you’re able to bring your own medications with you, find out how they’ll be managed and looked after on the ward.

**You might want to ask the following questions:**

- Where will my medication be stored on the ward?
- Can I keep my medication with me?
- 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?

Make sure your healthcare team is aware you're self-administering your medication.

## Getting your medication on time

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's one based at the hospital.

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

During your hospital stay, you may change wards or be cared for by different members of staff. You should tell each staff member who cares for you about your medication routine.

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

Don't be afraid to remind staff each time your tablets are due. Tell them that the timing of your medication is important for helping 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 carry a pill timer that rings when it's time for your medication. Setting alarms on your mobile phone or watch can also help you keep track of time.

You can also order a free Parkinson's UK Get It On Time washbag to use if you go into hospital. To order one, visit our online shop at [shop.parkinsons.org.uk](http://shop.parkinsons.org.uk)



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

Share your concerns with the on-duty senior nurse and your Parkinson's nurse. 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'll make sure it doesn't happen again. Your Parkinson's nurse can also explain this to staff, if you would prefer.

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.

If you're not given your medication on time and this continues, tell the hospital's Adult Safeguarding Team. Their role is to make sure patients are looked after properly during their hospital stay. This includes any special needs you have relating to your medication.

You should be able to contact the Adult Safeguarding Team via your hospital's main telephone number.

## On/off side effects of your medication

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

### 'On/off'

This is a side effect of Parkinson's medication that ward staff may not understand.

On/off usually happens to people who've had Parkinson's for many years, and their medication doesn't last as long as it used to.

The 'on' period is when a person's symptoms are well controlled. This means that medication is working well. When symptoms return before the next dose is due, this is known as the 'off' period.

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



# SURGERY

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If you're having surgery for something not related to your Parkinson's, make sure the healthcare professionals who'll be looking after you know about your condition.

This will allow them to consider anything about your Parkinson's that could create problems, so that you can still be treated properly. For example, dystonia or a tremor.

If you need to have an emergency operation, it's important that the healthcare team looking after you know you have Parkinson's as soon as possible.

**In this section:**

- Meeting your anaesthetist
- Surgery and medication
- Parkinson's drugs and surgery
- Surgery and Parkinson's symptoms

## Meeting your anaesthetist

Before your operation, you'll be given an anaesthetic. This is a medication that stops your body from feeling pain. It will be given by an anaesthetist – a doctor who specialises in anaesthetics and pain management.

Your surgery may be done under general anaesthetic (when you're asleep), or under local anaesthetic (when you're awake). Local anaesthetics are given to numb a small part of the body, so you don't feel pain in that area. Regional anaesthetics are a type of local anaesthetic given to numb a larger part of the body during surgery.

You'll usually meet your anaesthetist on the ward before your surgery. It's very important that your anaesthetist knows you have Parkinson's and what medication you take for it.

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 your anaesthetist, they will:**

- go through your answers to the pre-admission questions
- discuss your Parkinson's symptoms and how they may affect you during surgery
- explain any risks or side effects of the drugs they give you might have

## **Surgery and medication**

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

It's important that you can keep taking your Parkinson's medication as close to your surgery as possible. You should also take it 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're usually allowed to keep taking your medication with a few sips of water during this time. 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. This can mean that the risk of the surgery being cancelled is lower. For example, if other procedures in the hospital take longer than expected.

Organising your medication routine is also easier if you know what time your surgery will be in advance.

## Parkinson's drugs and surgery

Medication may be given during surgery if your operation is taking longer than planned and there's a risk of missing a dose.

### Levodopa

If you usually take levodopa, it may be possible to give you your dose using a tube that goes into your stomach. You should discuss this with your anaesthetist.

### Dopamine agonists

If you normally take oral dopamine agonists and are nil by mouth due to surgery, you may be changed to a rotigotine patch. The patch is applied to your skin and, once in place, lasts for 24 hours.

You may also be changed to a patch if medication needs to be given during surgery. This will be applied before your operation.

The patch will deliver the same dose of medication as you'd normally take orally. Your specialist can advise your surgical team about this.



## Apomorphine

For some procedures, you may not be able to take your usual oral medication after surgery.

But it may be possible to use different drugs, such as apomorphine. It's a strong dopamine agonist and can be taken by injection, or using a pump which can deliver a continuous dose from a syringe.

Before you go into hospital, your healthcare team should discuss the option of apomorphine after surgery with you. Your Parkinson's specialist will also be involved in the decision.

**Find out more:** see our information on apomorphine, and drug treatments for Parkinson's.

## Surgery and Parkinson's symptoms

### Low blood pressure

You may experience low blood pressure because of your Parkinson's. You should tell your anaesthetist if this affects you. During some types of surgery, anaesthetic can cause blood pressure to drop. This can include surgeries that aren't heart related that are done under general anaesthetic.

**Find out more:** see our information on low blood pressure and Parkinson's.

### Involuntary movements (dyskinesia)

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

Involuntary movements may affect procedures where you need to keep still. This includes x-rays, scans or radiotherapy. Radiographers usually have ways to help stop this, such as using foam wedges. These can help to support your body, or body part, and hold it in place while you're being examined. But it's still important to talk to your health professional before any procedure as stress may increase motor fluctuations and involuntary movements.

You may need to have a general anaesthetic, or be sedated (given drugs to help you relax) so you're able to keep still.

**Find out more:** see our information on dyskinesia and wearing off.

### Saliva control and swallowing problems

Some people with Parkinson's have problems controlling their saliva. This can lead to drooling or dribbling.

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 allows the anaesthetist to make sure your airway stays clear during surgery.

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

**Find out more:** see our information on eating, swallowing and saliva control in Parkinson's.

# LEAVING HOSPITAL

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Before you leave hospital, it's important to plan your care needs for when you get home. These may have changed during your stay in hospital.

In this section:

- Being discharged
- Transport to and from hospital

## Being discharged

Before leaving hospital, check if your medications have been changed during your stay in hospital. Make sure you understand how you should take this new medication.

If your medication has been changed, check with the pharmacy that you'll be given enough medication for when you get home. You'll usually get a two-week supply.

If you've been in hospital for a long time or your mobility has changed, you may be able to see an occupational therapist. They can arrange a home visit with you before you're discharged.

The occupational therapist can suggest special aids, equipment, or other plans to make tasks easier.

**Find out more:** see our information on daily living equipment, and occupational therapy for Parkinson's.

## Transport to and from hospital

You may be able to use patient transport services (PTS) if your condition makes it difficult for you to travel to the hospital. This is a non-emergency service that's available in certain parts of the UK.

If you live in England, you'll need to talk to your GP or the person who referred you to hospital, to see if you're able to use this service. They'll also tell you how you can access it.

If you're in Northern Ireland, your GP will need to book transport for you.

In Scotland, you can see if you're eligible for patient transport by calling **0300 123 1236**. In Wales, you should contact the Welsh Ambulances Services on **0300 123 2303**.

If you can't get free transport, you may be able to claim a refund for the cost of transport from the Healthcare Travel Cost Scheme.

To get a refund, you'll need to show you're not able to afford the cost of travelling to hospital, and don't have a friend or relative that can take you.

**Find out more:** see our information on money, grants and benefits.



# HAVING YOUR SAY

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If you're 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're in hospital.

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

## In this section:

- In England
- In Northern Ireland
- In Scotland
- In Wales
- Medicines and Healthcare products Regulatory Agency (MHRA)

Complaining will not affect your 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've received was excellent, share this with them. You can do this while you're in hospital or when you get home.

You might also want to let Parkinson's UK know, so we can make sure we highlight organisations that offer great care and set a good example. Our contact details are at the end of this information.

## 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 the NHS complaints procedure. Ward staff will have contact details for them.

Healthwatch is an independent organisation that invites people to share their views and experiences of health and social care services. Healthwatch shares this feedback with these services, and actively works to make sure they improve on complaints.

Your local Healthwatch can help with complaints you have about services, including those related to your Parkinson's. For more information, visit [www.healthwatch.co.uk](http://www.healthwatch.co.uk) or call **03000 683 000**.

## In Northern Ireland

The Patient and Client Council (PCC) can help you make a complaint about health and social care you've received. Visit [pcc-ni.net](http://pcc-ni.net) or call **0800 917 0222**.

## In Scotland

You can contact the Patient Advice and Support Service (PASS) run by Citizens Advice. They're not based in hospitals, but you can find out more by calling **0800 917 2127** or by visiting their website [www.cas.org.uk](http://www.cas.org.uk)

## In Wales

You can contact the Community Health Council for the local health board where you're being treated.

You can find out which Community Health Council to contact on the Board of Community Health Councils website at [www.llaiswales.org](http://www.llaiswales.org)

## Medicines and Healthcare products Regulatory Agency (MHRA)

If you want to complain about not getting your medication on time while you were in hospital, we also encourage you to tell the MHRA.

They have a Yellow Card Scheme, which helps them monitor how safely medicines are being used. Call **0808 100 3352** (10am-2pm, Monday-Friday) or visit <https://yellowcard.mhra.gov.uk>



# MORE INFORMATION AND SUPPORT

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## Lions Clubs International - Message in a Bottle scheme

**0121 441 4544**

**enquiries@lionsclubs.co**

**www.lionsclubs.co**

## MedicAlert

**01908 951 045**

**info@medicalert.org.uk**

**www.medicalert.org.uk**

## Parkinson's nurses

Parkinson's nurses have specialist experience and knowledge of Parkinson's. They can:

- support people coming to terms with their Parkinson's diagnosis
- help people to manage their medication, so they get the best results and fewer side effects

- make referrals to other professionals such as speech and language therapists and physiotherapists

Some nurses are based in the community, such as your GP surgery. Others are based in hospital settings and clinics.

Talk to your GP or specialist for more details on speaking to a Parkinson's nurse.



## Parkinson's UK information and support

You can read our most up-to-date information at [parkinsons.org.uk](https://parkinsons.org.uk)

You can order printed information by calling **0330 124 3250** or visiting [parkinsons.org.uk/orderingresources](https://parkinsons.org.uk/orderingresources)

If you'd like to speak to someone, our specialist adviser team can provide information about any aspect of living with Parkinson's.

They can talk to you about managing symptoms and medication, social care, employment rights, benefits, how you're feeling, and much more.

Call our team on: **0808 800 0303** or email [hello@parkinsons.org.uk](mailto:hello@parkinsons.org.uk)

We'll provide expert information over phone or email or put you in touch with an adviser locally.

If you'd like to meet other people living with Parkinson's in your local area, you can

find friendship and support through our network of volunteers and local groups. Go to [parkinsons.org.uk/localgroups](https://parkinsons.org.uk/localgroups) or call our helpline to find out more.

Our forum is also a very active space to share and chat with others who really understand, at a time that suits you. Visit [parkinsons.org.uk/forum](https://parkinsons.org.uk/forum)

## Thank you

Thank you very much to everyone who contributed to or reviewed this information.

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

## Feedback

If you have any comments or feedback about our information, please call **0800 138 6593**, email [feedback@parkinsons.org.uk](mailto:feedback@parkinsons.org.uk), or write to us at Parkinson's UK, 215 Vauxhall Bridge Road, London SW1V 1EJ.

If you'd like to find out more about how we put our information together, please contact us at **healthcontent@parkinsons.org.uk** or visit our website.

### 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 Care team on **0800 138 6593** or visit our website at **parkinsons.org.uk/donate**

Thank you.



## Medication Record

Date	Medication name	Dose	Times of doses	Notes

Date	Medication name	Dose	Times of doses	Notes





## Medication Record

My Details	Useful Contacts
Name	GP name and phone number
Date of birth	Parkinson's nurse name and phone number
Address	Consultant specialist name and phone number
Phone number and email	In case of emergency contact
Email	In case of emergency contact

Apomorphine	DBS
Name and phone number of the person who administers my pump is	I have a DBS unit. The serial number is
Flow rate and start stop time of my pump is	My DBS nurse and phone number is
Apomorphine devices that I use are (Name of syringe, needle pen, vile, cartridge?)	My DBS specialist and phone number is



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We are Parkinson's UK.  
Powered by people.  
Funded by you.  
Improving life for everyone  
affected by Parkinson's.  
Together we'll find a cure.

**PARKINSON'S<sup>UK</sup>**

Free confidential helpline **0808 800 0303**

Monday to Friday 9am–6pm, Saturday 10am–2pm  
(interpreting available)

NGT relay **18001 0808 800 0303**

(for textphone users only)

**hello@parkinsons.org.uk**

**parkinsons.org.uk**

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



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