



# GOING INTO HOSPITAL WHEN YOU HAVE PARKINSON'S

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

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 specialist

My GP

My local adviser

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# KEY MESSAGES

## Preparing for a planned admission

- Keep an up-to-date medication record with our 'Going into hospital' form at the end of this information. This should include all the medication you're currently taking (not just for Parkinson's) and what time you take each dose.
- Tell your GP, specialist or Parkinson's nurse you are going into hospital. They can provide details of your medication regime to the healthcare team who will be looking after you. Your Parkinson's nurse can also talk to ward staff about 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, 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 have had deep brain stimulation and show them your patient ID card.

## Emergency admissions

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

- 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 and ask them to keep a copy of it in your notes. Check they have recorded this accurately.
- 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.

# PREPARING FOR A HOSPITAL ADMISSION

A planned (booked) or emergency hospital stay may or may not be related to your Parkinson's. But managing your condition in terms of your care and medication should always be a priority. You will need to make sure you can continue with your drug regime 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 for an emergency stay will also help you ease any anxiety.

## **Make sure people know you have Parkinson's**

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

This is a free scheme from Lions Clubs International. It is designed to help alert emergency services to your condition if they need to enter your property in an emergency by keeping your medical details in your fridge. See the end of this booklet to find out more 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 are taking. It can be helpful if you are not able to communicate in an emergency. See our section on more information and support for how to order one.

## **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 at the end of this information.

## **Smartphone medical ID**

Many smartphones, including Apple and Samsung devices, have a Medical ID app. You can record that you have Parkinson's along with the names of any medication you take. You can also include the contact number of a family member, friend or carer so that 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. This will mean they can pass on your medical details to the team who will look after you in hospital. They can also tell them you need your medication on time.

## **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 Parkinson's, and specific needs you have. You will be asked to bring in an up-to-date list of the medications you are taking.

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

Pre-admission assessment can make sure you have a good stay in hospital and recover well. This is important because Parkinson's can increase recovery time in some people, but with the right care you will be able to recover as quickly as possible.

## **Preparing your medication** **Keep a record of your medication**

You can use the 'Going into hospital' 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 will not be able to use it in hospital without this, even in an emergency.

Check that your medication 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 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 regime.

It can also be a good idea to store extra supplies of your medication. Let other people know where they are in case you need to use them.

## **Tell staff about your Parkinson's treatment**

It is important that hospital staff know what medication you take and when you need to take it as



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 or the APO-go helpline for more advice (**0844 880 1327**). Depending on hospital policy, your carer may be able to continue managing this treatment.

## Deep brain stimulation

It's also important to tell staff if you've had deep brain stimulation.

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

You should take your patient ID card when you go into hospital as this carries vital contact details if 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.
- 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 our section on deep brain stimulation for more information).
- 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.





# DURING YOUR HOSPITAL STAY

During your hospital stay it's important that you feel comfortable and have everything you need to be able to manage your symptoms.

## 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.

You should tell your nurse about your usual routine with Parkinson's and any specific needs you have. The 'Going into hospital' form at the end of this information is a useful place to note down everything you'd like to talk to your named nurse about.

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.

## 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. Hospitals will normally have a policy on this. You can discuss your equipment at your pre-admission assessment or with your named nurse during admission.

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

**Find out more:** see [our information on daily living equipment](#).

## Sleeping

Wards can be busy, even at night. There can also be more lights on than you would be used to at home. 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. This could include help turning over in bed, getting up several times during the night to go to the toilet or making your bed more comfortable.

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

## Eating and drinking

You might have special requirements linked to your diet and any swallowing issues. These may include thickened fluids, pureed meals or a PEG feed (feeding tube).

If you have any dietary needs linked to your medication you should talk to a hospital dietitian so that you can plan ahead. This will help you continue with your medication regime. You can also discuss anything specific at your 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' periods and need help at meal times, make sure the staff are aware of this, so they don't just assume you aren't hungry. It's important to eat well while in hospital because this will help to fight off infection and maintain regular bowel and bladder function.

## Using the bathroom

Bladder and bowel problems such as constipation or bladder incontinence can be more common for people with Parkinson's. It is important that you are able to manage these symptoms if you experience them. 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 communicate, make sure the hospital staff know about this so that you have 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.

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.

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 end of this information.

**Find out more:** see our [information on 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. 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 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 policy.

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?
- 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 are 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 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.

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 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 can also order a free Get It On Time washbag to use if you go into hospital. It includes a medication card. See the end of our information for details on how to order any of our resources, including a washbag.

### **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.

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.

### **On/off 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 return before the next dose is due.

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'.





# SURGERY

If you are having surgery for something not connected to your Parkinson's, make sure the healthcare professionals involved know about your condition.

This will mean that anything about your Parkinson's that could create problems, such as dystonia or a tremor, can be taken into account so you can still be treated properly.

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.

## 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 they will go through your answers to the pre-admission questions. They will also discuss your Parkinson's symptoms and how they may affect you during surgery, as well as explaining any risks or side effects of the drugs 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, 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 regime 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 is 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.

### Apomorphine

Depending on the procedure, 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 is a strong dopamine agonist and can

be taken by intermittent injection, or via infusion using a pump.

Your healthcare team should discuss the option of 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 on 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 [information on drug treatments for Parkinson's](#).

## Surgery and Parkinson's symptoms

### Low blood pressure

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

**Find out more:** see our [information on 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. You may need to have a general anaesthetic or be sedated so you are able to keep still.

### 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 sialorrhoea.

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.

**Find out more:** see our [information on eating, swallowing and saliva problems in Parkinson's](#).

# LEAVING HOSPITAL

## Being discharged

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.

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. 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, living aids and technology](#).

## Transport to and from hospital

You may be able to use the Patient Transport Services if your condition makes it difficult for you to travel to the hospital.

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**. In Wales, you can arrange your own transport by calling **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 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 on 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.

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 have received was excellent, compliment staff or let them know when you get home.

You should also let Parkinson's UK know so we can make sure we highlight organisations that offer great care to help spread best practice. 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 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. 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 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 **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 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](http://www.wales.nhs.uk/sitesplus/899/home)**

## In Northern Ireland

The Patient and Client Council (PCC) can help you make a complaint about health and social care you've received. Visit **[www.patientclientcouncil.hscni.net](http://www.patientclientcouncil.hscni.net)** or call **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 **0800 100 3352** (10am-2pm, Monday-Friday) or at their website **[www.yellowcard.mhra.gov.uk](http://www.yellowcard.mhra.gov.uk)**



# MORE INFORMATION AND SUPPORT

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

[Lions Clubs International](#) –  
[Message in a Bottle scheme](#)

**0121 441 4544**

**[mdhq@lions.org.uk](mailto:mdhq@lions.org.uk)**

**[lionsclub.co](http://lionsclub.co)**

[MedicAlert](#)

**01908 951 045**

**[info@medicalert.org.uk](mailto:info@medicalert.org.uk)**

**[www.medicalert.org.uk](http://www.medicalert.org.uk)**

## [Parkinson's nurses](#)

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

The role of the Parkinson's nurse varies. Each will offer different services, aiming to meet local needs. Some nurses are based

in the community, whereas others are based in hospital settings. Many Parkinson's nurses are independent prescribers. This means they can prescribe and make adjustments to medication, so someone with Parkinson's doesn't always need to see a specialist for changes to or queries about their Parkinson's drugs.

Parkinson's nurses may not be available in every area, but your GP or specialist can give you more details on local services. You can find out more at **[parkinsons.org.uk/nurses](http://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](mailto:hello@parkinsons.org.uk)**

We now run a peer support service if you'd like to talk on the

phone with someone affected by Parkinson's who has faced similar issues to you. The service is free and confidential – ring the helpline and they will match you with a peer support volunteer.

Our helpline can also put you in touch with one of our Parkinson's 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](https://parkinsons.org.uk/localtoyou)**. You can find details of our local groups and your nearest meeting at **[parkinsons.org.uk/localgroups](https://parkinsons.org.uk/localgroups)**. You can also visit **[parkinsons.org.uk/forum](https://parkinsons.org.uk/forum)** to speak with other people in a similar situation on our online discussion forum.

## Going into hospital (B182/2020)

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](mailto: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





## 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](https://parkinsons.org.uk/termsandconditions)



Thank you to everyone who contributed to or reviewed this information, including experts and people affected by Parkinson's.

All of the photographs in this booklet feature people affected by Parkinson's, health and social care professionals involved in caring for people with Parkinson's and Parkinson's UK staff. Thank you to everyone involved for letting us use their photograph.

### Our information

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

**[parkinsons.org.uk/information-support](https://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](https://parkinsons.org.uk/ordering-resources)** or by calling **0300 123 3689**.

We make every effort to ensure that our services provide current, unbiased and accurate information. We hope that this will add to any professional advice you receive and 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](mailto: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](https://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](http://www.ngts.org.uk)**

**[hello@parkinsons.org.uk](mailto:hello@parkinsons.org.uk)**  
**[parkinsons.org.uk](http://parkinsons.org.uk)**

Order code: PKB182

**Last updated February 2020. 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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