

PARKINSON'S

Excellence
Network



Key information
for community
pharmacists

Introduction

The number of people diagnosed with Parkinson's in the UK is around 145,000. There's no cure yet for Parkinson's, but medication can greatly improve symptoms.

Medication routines can be complex. As Parkinson's is a progressive condition, these routines need to be reviewed and adjusted to maintain their benefits.

If an appropriate review of Parkinson's medication isn't completed, and a person's routine isn't properly maintained, symptoms can become poorly controlled. This can mean their Parkinson's symptoms get worse, even within a short period of time.

At the Parkinson's Excellence Network, we want to work with community pharmacists like you and your teams, and pharmacists within community services, to promote effective medicines management. You can play a vital role in ensuring people with Parkinson's achieve

good symptom control and the best possible quality of life.

Understanding Parkinson's

What is Parkinson's?

Parkinson's is a progressive neurological condition. It's more common in older people, but younger people can also develop symptoms.

Parkinson's develops when cells in the substantia nigra area of the brain stop working properly and are lost over time. It means these cells can no longer produce the chemical dopamine, and the symptoms of Parkinson's start to appear. Why this happens is unclear, but it's thought to be caused by a mix of genetic and environmental factors.

Parkinson's is a very individual condition in terms of how symptoms present, and the speed and nature of its progression.

Motor symptoms

The main symptoms of Parkinson's are slowness of movement (bradykinesia),

tremor and rigidity. Other motor symptoms can include postural instability and hypokinesia. Most drug treatments aim to ease these motor symptoms.

Non-motor symptoms

People with Parkinson's may also experience non-motor symptoms, which they say can often cause more distress in everyday life. These include mental health issues, sleep disorders, pain and bladder and bowel problems.

Non-motor symptoms are treated separately. As a result, it's essential that the most appropriate medications are used while ensuring that they're compatible with any existing ones.

Medicines management in Parkinson's

As Parkinson's is a progressive condition, patients will require ongoing changes to their medication over time.

There are different types of Parkinson's medication. These drugs compensate for the loss of the dopamine-producing neurons. These include:

- The levodopa group, which increase the levels of dopamine in the brain. Levodopa is the most effective medication for treating mobility issues in people with Parkinson's.
- The dopamine agonist group. These stimulate post-synaptic receptors that would normally be activated by dopamine. Includes ropinirole and pramipexole, the rotigotine patch and apomorphine.

Other drugs block the action of enzymes and neurotransmitters that break down dopamine. These include:

- monoamine-oxidase-B (MOA-B) inhibitors, such as rasagiline and safinamide
- catechol-o-methyl transferase inhibitors, including entacapone, and opicapone

The most commonly used medicines are listed at parkinsons.org.uk/information-and-support/parkinsons-drugs

Getting medication on time

The key issue with Parkinson's medication is timing. Medication needs to be taken at specific times for each patient so that their symptoms are controlled consistently, without getting worse.

Not getting medication on time can mean the difference between someone being able to function independently and them becoming reliant on others for simple everyday activities, such as walking and eating. For example, a prescription for levodopa 125mg capsules

might advise taking one tablet five times a day. So it's important that you ask your patient's GP to advise on specific medication timings. These timings will have been decided by the person's Parkinson's consultant or nurse. Include these timings on the medication label.

In extreme cases, missed doses of medication may lead to the potentially fatal neuroleptic-like malignant syndrome (NLMS).

The Parkinson's UK Get It On Time campaign raises awareness of the significance of drug timings in controlling the condition for people in hospitals and care homes. This is also just as important when people are in their home environments.

Help us to get the message out that people with Parkinson's need their medication on time – every time. Find out more about the campaign at parkinsons.org.uk/ontime



Your role as a community pharmacist

There are a number of things you can do as a community pharmacist to help your patients take control of their Parkinson's.

Supporting maintenance of prescribed medication routines

Because Parkinson's medication routines can be complex, making sure an individual is able to maintain their prescribed preparation, dosage and timing can be a challenge.

It might be necessary to dispense their medication into a monitored dosage system (MDS). This can be useful if they have more than four doses of medication per day, plus other medication.

Treatment for Parkinson's is usually lifelong and adjustments will be necessary, because the person's symptoms will change over time as the condition progresses.

Remember that timings of medication may change as the condition progresses. This is because the longer a person

has been taking medication, the more likely they are to experience 'wearing off'. The patient can experience 'off' times when their symptoms return.

They will also have to be under continual review because of potential adverse effects and intolerance to the drugs.

Medication routines prescribed for Parkinson's can vary between individuals in the types of preparation, the dosages given, and the time drugs are taken.

Medication for Parkinson's will initially have been prescribed by a specialist. Any changes to a patient's drugs will be made by the specialist (not the GP), so it's useful to have their contact details in case of any issues.

People with Parkinson's are usually aware of the importance of getting their medication on time. Therefore, they may be anxious if their supplies are running out or there's a problem in getting the drugs they need.

It may have taken some time to establish a routine that best

suits a person. It's vital that this is maintained as prescribed to achieve the most effective control of symptoms.

You can support medication routines by ensuring:

- there's no delay in dispensing the range of prescribed medications, and that you're aware of how and where to get them quickly. This will mean medication is easily available and individual routines can be maintained without disruption.
- prescribed medication is dispensed in containers that the person can open. Parkinson's can affect fine finger dexterity, so opening containers can be difficult.
- wherever possible, branded drugs should be prescribed, but if these are unavailable, then a generic substitution would be an acceptable alternative to leaving the patient with no medication at all. Where substitution does occur, explain to the patient and carer why a different preparation has been dispensed to help

reduce any anxiety or confusion.

Helping care home staff understand the importance of medication

It's particularly important that staff in care homes are aware of the importance of medication timing for people with Parkinson's. To help care home staff, you can:

- print out timings on the pharmacy label, adding them to any blister packs issued and printing out timings on the MAR (medication administration record)
- make sure care home staff you work with understand the importance of keeping to the prescribed medication routine, and adjusting activities accordingly. For example, carers who support people taking their medication from blister packs should time their visits around when the medication is due.

Caring for your residents with Parkinson's and Parkinson's: a guide for home care workers can help you explain the

importance of getting medication on time. They are available to order from [parkinsons.org.uk/professionals/resources-professionals](https://www.parkinsons.org.uk/professionals/resources-professionals)

Helping people to understand their medication routines and possible side effects

As a community-based pharmacist, you have a great opportunity to establish an ongoing relationship with people who have Parkinson's.

You can also get to know how the condition affects them and their health. It's important to listen to patients and help them understand their treatment.

There are a number of things you can do to help your patient, including:

- educating them on the medication they're taking
- explaining how their medication works
- explaining the side effects they can expect. For example, movement problems caused by the 'on/off' effect of levodopa.

- explaining any changes that may have been made to your patient's medication. This can include increased dose frequency or the addition of a new medication.

It's also important to inform your patients about what side effects to look out for. Side effects of Parkinson's medication may include:

- vomiting
- drowsiness
- nausea
- low blood pressure leading to dizziness and fainting

[Visit parkinsons.org.uk/information-and-support/parkinsons-drugs](https://www.parkinsons.org.uk/information-and-support/parkinsons-drugs)

Impulsive and compulsive behaviour

With some Parkinson's drugs, particularly dopamine agonists – and, in a small number of cases, levodopa – some people experience issues with impulsive and compulsive behaviour.

Examples of impulsive and compulsive behaviour include:



- gambling
- compulsive spending
- binge-eating
- hypersexuality

This behaviour can have a huge impact on people's lives, so it's important that people with Parkinson's are aware of this.

If people are concerned about this behaviour, they should speak to their specialist about getting their medication reviewed.

However, people with Parkinson's shouldn't suddenly stop taking their medication as this may make other symptoms worse.

It's also helpful to inform carers and family members of impulsive

and compulsive behaviour, as they might recognise changes first.

To help your patients understand this side effect, you can access our impulsive and compulsive behaviour information at parkinsons.org.uk/icb

For more information about 'red flags' in Parkinson's, see Appendix 1.

Make sure other medications do not make Parkinson's worse

People may speak to you about problems that may or may not be associated with their Parkinson's.

While managing these effectively is clearly a priority, it's also important to make sure that medication given to treat these problems doesn't make their Parkinson's worse.

Treating nausea and vomiting

Domperidone (Motilium) is the antiemetic used to prevent and treat nausea and vomiting caused by Parkinson's medication. As well as being available in suppository form, it can be taken

as tablets or oral suspension. For maximum effect, it should be taken about 30 minutes before Parkinson's medication.

If an injectable or alternate antiemetic is required, cyclizine (Valoid) may be considered.

Drugs to avoid

Any drug that blocks dopamine receptors could make the symptoms of Parkinson's worse, or even mimic them without the condition being present.

Because of this, it's vital that you think through the mechanisms of action when a person with Parkinson's is prescribed medication.

The same applies if they're considering purchasing a new over-the-counter medicine. You should use some drugs with caution and Parkinson's symptoms should be monitored. In other cases, some drugs should be avoided.

For hallucinations and confusion, patients should avoid:

- chlorpromazine (Largactil)

- fluphenazine (Modecate)
- trifluoperazine (Stelazine)
- flupenthixol (Fluanxol/Depixol)
- haloperidol (Serenace/Haldol)

You should refer to a specialist for review and management.

For nausea and vomiting, patients should avoid:

- metoclopramide (Maxalon)
- prochlorperazine (Sternetil)

For coughs and colds, they should avoid:

- preparations containing sympathomimetics (such as pseudoephedrine and ephedrine) with MAO-B inhibitors

This is because there is a risk of hypertensive crisis – high blood pressure, which, in extreme cases, can cause a stroke.

Vigilance is particularly required with use of:

- antihistamines, especially cinnarizine (Stugeron/Arlevert) which, if used

long-term, can mimic Parkinson's symptoms

- antipsychotics

Note that the following two examples can worsen motor symptoms:

- antidepressants
- antihypertensives, such as diltiazem (Adizem/Angitil/Dilcardia/Dilzem/Slozem/Tildiem/Viazem/Zemtard) and other calcium channel blockers.

Note that pharmacy patient medication record systems may support the monitoring of this type of drug-disease interaction.

You can find more information about potential interactions with Parkinson's medications in Appendix 1 of the British National Formulary.

The 'NICE guideline [NG71] – Parkinson's disease in adults' also has more information about which drugs to avoid with Parkinson's.

Supporting people with hospital admissions

In England, people over 65 with Parkinson's are three times more likely to have an unplanned admission to hospital than those over 65 without Parkinson's. An admission may be planned, but it may also be as an emergency.

People with Parkinson's are also more likely than the general population to experience falls, fatigue, mental health problems and infections.

Because of these factors, it's likely that people with Parkinson's who you see in the community will have an admission to hospital at some point in their lives.

You can support any admission and their transition back into the community following discharge.

If a person with Parkinson's goes into hospital, it's vital that they continue to take their medication to prevent missed doses.

You can also:

- provide information that will support people with Parkinson's to administer their medication themselves in hospital if they're able to

- support people to be more knowledgeable about their drugs, which can help them to maintain more control over their medication. Hospitals are encouraged to have a self-administration policy and to assess if a patient can follow it.
- signpost your patient to local schemes, such as the Lion's Club Message in a Bottle. The scheme aims to ensure emergency services are aware of specific needs of the person they're attending to and the whereabouts of vital medication.
Visit www.lionsclubs.co/MemberArea/knowledge/lions-message-in-a-bottle
- review medication of a person with Parkinson's in your community after they are discharged, as their needs may have changed. Patients discharged from hospital with a new medication for Parkinson's are eligible to use the Discharge Medicine Service (DMS), an essential service provided by all community pharmacies.
Visit <https://psnc.org.uk/national-pharmacy->

Help people with Parkinson's take control

Parkinson's is a lifelong condition and there's currently no cure. However, by looking after themselves, there's no reason why people with Parkinson's cannot enjoy a fulfilling life. You can play an important role in supporting them to be proactive in the management of their health and wellbeing.

Advise people with Parkinson's in your community about activities that can help them to maintain a healthy lifestyle, such as:

- stopping smoking
- eating a balanced diet
- maintaining a healthy weight
- moderating alcohol intake

Physical activity

Physical activity is good for everyone and it's especially good for people with Parkinson's.

Being active for 2.5 hours a week can help manage

Parkinson's symptoms, and has a positive impact both physically and mentally.

You can encourage people with Parkinson's to get active. **Visit parkinsons.org.uk/information-and-support/exercise**

Know and utilise your local Parkinson's experts

The medical specialists who manage people with Parkinson's may be a neurologist or a geriatrician. They may have contact with a Parkinson's nurse.

The local hospital may also have specialist pharmacists. Knowing who these local experts are, and their contact details will be useful, should you need to seek specialist advice.

Find out more about the Parkinson's Excellence Network

The Parkinson's Excellence Network brings together and supports health and social care professionals to better care for people with Parkinson's, and is supported and facilitated by Parkinson's UK.

At the Excellence Network, we share best practice, resources and support through our regional and working groups, and online and face to face networking opportunities. You can see the full range of activity and resources at **parkinsons.org.uk/professionals**

Education

We also offer free online courses of various durations to help pharmacists increase their knowledge and understanding of Parkinson's.

Visit the Parkinson's learning pathway for pharmacy professionals to find out more. Alongside this, you can view resources, and a range of

Parkinson's courses from other pharmacy education providers. Visit parkinsons.org.uk/professionals/parkinsons-learning-pathway-pharmacy-professionals

There are also pharmacy networks with a special interest in Parkinson's and neurology. For example, the Parkinson's Disease Specialist Pharmacy Network (PDSPN), one of our working groups, and the United Kingdom Clinical Pharmacy Association, which has a Neurosciences group.

More details can be found at parkinsons.org.uk/professionals/parkinsons-disease-specialist-pharmacy-network and ukclinicalpharmacy.org

Key contacts

Parkinson's nurse:

Parkinson's UK contact:

Local pharmacy tutor:

Nearest pharmacist with specialist interest in Parkinson's:

Appendix 1

'Red flags' that need referral to Parkinson's specialist:

- fibrotic reactions with ergot-derived dopamine agonists (including bromocriptine, pergolide and cabergoline) including dyspnoea, persistent cough, chest pain, cardiac failure, abdominal pain or tenderness
- signs of liver disorder with tolcapone, including nausea, vomiting, fatigue, abdominal pain, dark urine, pruritus
- increased falling especially early in condition history
- hallucinations/dementia/depression/cognitive decline, especially early in condition history

There are other considerations when performing a consultation or medication review with your patients with Parkinson's.

Parkinson's can lead to difficulties in communication, such as quietening of the voice, slurring of speech, and reduced facial expressions and body language. So it's important to allow sufficient time to conduct a consultation, to ensure the environment supports people with Parkinson's to communicate as well as they can.

Parkinson's can also lead to swallowing difficulties. It's advisable to ask your patient if they're having any difficulty with taking their medication or with eating, which could lead to weight loss. If this happens, it's recommended that you refer them to a speech and language therapist.

Adherence to medication routines can be affected if someone with Parkinson's feels that the side effects of taking their medication outweigh the benefits. Asking your patient how the medication is affecting their ability to function is key to understanding what impact the treatment is having on their daily life.

More information and support for your patients

The Parkinson's UK free confidential helpline can provide general support and information. Call **0808 800 0303** (calls are free from UK landlines and most mobile networks) or email **hello@parkinsons.org.uk**

The helpline can put your patients in touch with a Parkinson's UK adviser, who can give information and support to anyone living with or caring for someone with Parkinson's. They can also provide links to local groups and services.

The **parkinsons.org.uk** website has a lot of information about Parkinson's and everyday life with the condition. There are details of local support teams and local group meetings at **localsupport.parkinsons.org.uk**

Your patients can visit **parkinsons.org.uk/forum** to chat to other people with similar experiences on the charity's online discussion forum.

Driving

Advise people with Parkinson's of the need to inform relevant authorities of their condition at the time of diagnosis, such as the DVLA (DVA in Northern Ireland) and their car insurer. For information on driving and Parkinson's, visit **parkinsons.org.uk/driving**

Thank you

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

The Parkinson's Excellence Network is the driving force for improving Parkinson's care, connecting and equipping professionals to provide the services people affected by the condition want to see.

This is your Network. Get involved at parkinsons.org.uk/professionals

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