



Key information for community pharmacists



Introduction

The number of people diagnosed with Parkinson's in the UK is around 145,000¹.

There's no cure yet for Parkinson's, but medication can greatly improve symptoms.

Medication routines can be complex and 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 is not completed, and a person's routine is not properly maintained, symptoms can become poorly controlled. This can mean their Parkinson's symptoms get worse, even within a short period of time.

At Parkinson's UK, 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 with 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 is thought to be 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), rigidity and resting tremor. 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. Symptoms include mental health issues, sleep disorders, pain and bladder and bowel problems. Non-motor symptoms are treated separately. As a result it is essential that the most appropriate medications are used while ensuring that they are compatible with any existing ones.

Medicines management in Parkinson's

Different types of medication

The most commonly used medicines are listed at parkinsons.org.uk/drug-treatments

They compensate for the loss of the dopamine-producing neurons.

- The levodopa group increases the levels of dopamine in the brain.
- The dopamine agonist group stimulates post-synaptic receptors that would normally be activated by dopamine.
- Other drugs block the action of enzymes and neurotransmitters that break down dopamine.

Get it 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 someone becoming



reliant on others for simple everyday activities such as walking and eating.

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

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/getitontime

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.

Support 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 is a challenge. It's also essential to consider issues around adherence to drug regimes, as well as possible adverse effects and drug interactions.

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

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

It may have taken some time to establish a routine that best suits a person. So it is vital that this is maintained as prescribed to achieve the most effective control of symptoms.

You can support medication routines by ensuring:

- there is no delay in dispensing the range of prescribed Parkinson's medications and that you are 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 and so opening containers can be difficult.
- branded preparations are issued where prescribed and are not substituted with generic versions unless absolutely necessary. This is because the level of active ingredients may vary² and because of the effect of non-active components on the absorption of active ingredients³.

Where substitution does occur, explain to the patient and carer why a different preparation has been dispensed to help reduce anxiety or confusion.

Help care homes

It is particularly important that people 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 and domiciliary 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.

Our *Medicines management for residents with Parkinson's* DVD may help you explain the importance of getting medication on time.

There are also two booklets, *Caring for your residents with Parkinson's* and *Parkinson's: a guide for home care workers*. They are available to order from parkinsons.org.uk/orderingresources

Help people to understand their medication routines and possible side effects

As a pharmacist based in the community, you have a great opportunity to establish an ongoing relationship with people who have Parkinson's and to get to know how the condition affects them and their health.

There are a number of things you can do to help.

- Educate your patients on what medication they are taking.
- Explain how their medication works.
- Explain what side effects they can expect. An example might be movement problems because of the 'on/off' effect of levodopa.

Helpful resources include our *Drug treatments for Parkinson's* booklet which is available from parkinsons.org.uk/drugs-treatments

Inform your patients about what side effects to look out for. Side effects with Parkinson's medication may include:

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



Impulsive and compulsive behaviour

With some Parkinson's drugs, particularly dopamine agonists and in a small number of cases levodopa, some people experience problems 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 and so it is 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 should not suddenly stop taking their medication as this may make other symptoms worse.

It is also helpful to inform carers and family members of impulsive and compulsive behaviour as they might recognise changes first.

You can access our impulsive and compulsive behaviour information at parkinsons.org.uk/icbsupport to help your patients understand this side effect.

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

MURs

Parkinson's UK and the Excellence Network have developed a specialised Parkinson's Medication Use Review (MUR). There are specific questions you can use with your Parkinson's patient.

Because Parkinson's is a long-term condition managed with potentially complicated medication routines, medication reviews are ideal to help ensure your patients are using their medication as effectively as possible.



A Medication Use Review will also help identify adherence issues or adverse drug reactions.

The training needed to deliver a MUR will be added to the Parkinson's: Foundation module for pharmacists in 2019. After completing the training you will have access to the MUR tools.

Make sure other medications do not make Parkinson's worse^{4,5}

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 is also important to make sure that medication given to treat these problems does not make their Parkinson's worse.

Treating nausea and vomiting

Domperidone (Motilium) is the anti-emetic used to prevent and treat nausea and vomiting caused by Parkinson's medication. This is available orally or as suppositories. If an injectable or alternate anti-emetic 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 Parkinson's symptoms without the condition being present. Because of this it is vital that you think through the mechanisms of action when a person with Parkinson's is prescribed, or is 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

Avoid:

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

Refer to a specialist for review and management.

For nausea and vomiting

Avoid:

- metoclopramide (Maxalon)
- prochlorperazine (Stemetil)

For coughs and colds

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/Solzem/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.

More information about potential interactions with Parkinson's medications can be found in Appendix 1 of the British National Formulary. The NICE Clinical Knowledge Summaries service also has information about which drugs to avoid with Parkinson's.

Support 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's⁶. 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, symptoms such as fatigue and mental health problems, as well as infections.

Because of these factors it is 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.

There are a number of things you can do to help ensure people's symptoms are properly controlled with the right medication at the right time during a hospital stay.

- Make sure your patients have an up-to-date list of their medication on them at all times with clear information about the preparation, dosage and timing.

Parkinson's UK produce a medication card small enough to be kept in a wallet or purse. It allows people to record drug names, doses and times. This is available from parkinsons.org.uk/orderingresources

- Advise your patients to order a Parkinson's UK Get It On Time washbag that contains resources to help prepare for an admission. This is available from parkinsons.org.uk/orderingresources
- Ensure your patients have some medication that is suitable for use in a hospital environment.

Medication that has already been taken out of their original packaging will generally not be accepted by hospitals. Keeping some medication intact in its packaging will help ensure that doses required early in an admission can still be taken.

- Signpost your patient to local schemes such as the Lion's Club Message in a Bottle (lions105sw.org.uk/message-in-a-bottle) that aim to ensure emergency services are aware of specific needs of the person they are attending to and the whereabouts of vital medication.
- Provide information that will support people with Parkinson's to administer their medication themselves in hospital if they are able to.

Hospitals are encouraged to have a self-administration policy and to assess if a patient can follow it. Supporting people to be more knowledgeable about their drugs will help them to maintain more control over their medication.

- Review medication of a person with Parkinson's in your community after they are discharged as their needs may have changed.

One of the national target areas for MURs in England is patients who have recently been discharged from hospital and have had a change in their drugs.

The training needed to deliver a MUR will be added to the Parkinson's: Foundation module for pharmacists in 2019. After completing the training you will have access to the MUR tools.





Help people with Parkinson's take control

Parkinson's is a lifelong condition and there is 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 such as:

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

Exercise

Exercise is good for everyone and it is especially good for people with Parkinson's. Evidence shows that doing 2.5 hours of exercise a week can slow the progression of Parkinson's symptoms.

You can encourage people with Parkinson's to find exercise that is right for them and get moving.

Find out more at parkinsons.org.uk/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 specialist 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 Parkinson's

Parkinson's UK not only provides information and support to people affected by Parkinson's.

See the end of this information for more details.

We also provide specific support to professionals.

The UK Parkinson's Excellence Network is an online Professionals' Network that allows you to keep up-to-date with activities relevant to your work and to engage in learning opportunities such as Q&A sessions with renowned experts.

We also develop resources specifically for professionals. You can view and order our full range of resources at parkinsons.org.uk/professionals

Education and training

We provide education and training to professionals in your local area. For example, we have developed a session with the Centre for Pharmacy Postgraduate Education about Parkinson's and its medication as part of their 'learning at lunch' series. For more details, go to cppe.ac.uk

There are also pharmacy networks with a special interest in Parkinson's and neurology. For instance, the United Kingdom Clinical Pharmacy Association has a Neurosciences group. More details can be found at ukcpa.net

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 specialist⁷:

- 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 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 is important to allow sufficient time to conduct a medication review and to ensure the environment supports people with Parkinson's to communicate as well as they can.

Parkinson's can also lead to swallowing difficulties, so it is advisable to ask them if they are having any difficulty taking their medication.

Adherence to medication routines can be affected if someone with Parkinson's feels 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 medication is having on their daily life.

References

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More information and support for your patients

Our 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**.

We run a peer support service if your patient would like to talk on the phone with someone affected by Parkinson's who has faced similar issues to them. The service is free and confidential –our helpline can talk to your patient about being matched with a volunteer.

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

Our website **parkinsons.org.uk** 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 **parkinsons.org.uk/localtoyou**

Your patients can visit **parkinsons.org.uk/forum** to chat to other people with similar experiences on our 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 information sheet:

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The UK 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/excellencenetwork

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