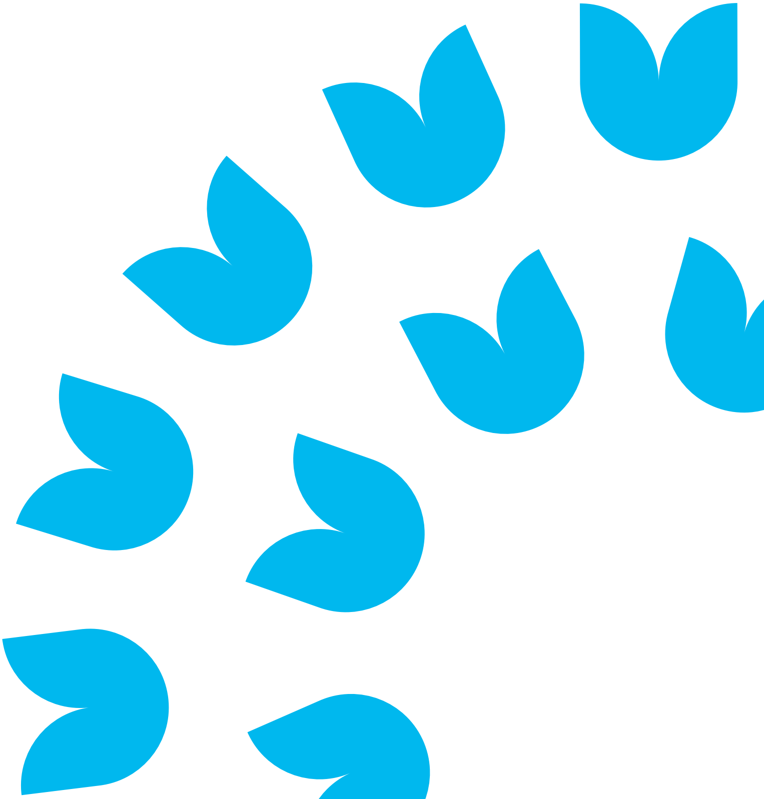
Parkinson's UK
Excellence Network

Key information for hospital pharmacists



Introduction

There are 153,000 people are already living with Parkinson's. Every hour, two more people are diagnosed. That's the same as 18,000 people every year. There's no cure yet for the condition, but medication can greatly improve symptoms.

Medication routines can be complex. Because Parkinson's is a progressive condition, people need regular, specialist reviews of their medication. If necessary, medication can be adjusted to maintain its benefits.

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

In England, people over 65 with Parkinson's are three times more likely to have an unplanned admission to hospital than over-65s without the condition.

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 you'll see a person with Parkinson's in your hospital. It could be a planned admission, but it could also be an emergency.

When a person with Parkinson's is admitted to hospital, their day-to-day life changes. They're more likely than the general population to experience disruption to their medication, including wrong doses or timing. They may also miss doses completely. These factors mean that a stay in hospital can have negative effects on someone's condition and could make it worse.

At the Parkinson's UK Excellence Network, we want to work with pharmacists like you to highlight the importance of effective medicines management in easing these problems in hospitals.

You can play a vital role in making sure that people with Parkinson's take the correct medication, on time. This will help people with the condition to achieve good symptom control, and have the best possible outcome from a hospital stay.

Understanding Parkinson's for a better hospital stay

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.

Motor symptoms

The main symptoms of Parkinson's are slowness of movement (bradykinesia), rigidity and tremor. Most drug treatments aim to ease these motor symptoms.

Non-motor symptoms

People with Parkinson's can experience a wide range of non-motor symptoms. This is because dopamine plays a role in neural pathways involved in cognition, arousal, motivation and reward. People with the condition often say non-motor symptoms can cause more distress in everyday life.

Non-motor symptoms include pain, fatigue, mental health issues (such as depression and anxiety), sleep problems, and bladder and bowel issues.

Constipation is particularly problematic in Parkinson's, as it can affect the absorption of medications. This can worsen symptoms.

It's important to treat these symptoms appropriately. You should take care to use medications that are compatible with those for Parkinson's, but which will not worsen motor symptoms. (See the section 'Make sure other medications do not make Parkinson's symptoms worse' further on in this booklet).

To manage non-motor symptoms effectively, it may be helpful to consider non-pharmacological interventions. These include advice about sleep, hygiene and referral to other professionals, such as dietitians.

Communication difficulties

It's important to remember that Parkinson's can also lead to difficulties in communication. This includes:

- quietening of the voice
- slurring of speech
- reduced facial expressions and body language.

This means it's important to make sure that your hospital environment supports your patient to communicate as well as they can.

It's recommended that people with Parkinson's are referred to a speech and language therapist as soon as possible after diagnosis. This can be arranged through their GP or Parkinson's nurse, or they can refer themselves.

Find out more: about speech and communication problems in Parkinson's at **parkinsons.org.uk/speech-problems**

Medication considerations when managing a person with Parkinson's

There are a range of drugs available for the treatment of Parkinson's. These drugs compensate for the loss of the dopamine-producing neurons:

- The levodopa group increases the levels of dopamine in the brain. Levodopa is considered the most effective drug for treating mobility issues in people with Parkinson's.
- 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.

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

Levodopa

People using levodopa to manage their Parkinson's may notice that, over time, it becomes less effective. When symptoms are well controlled with levodopa, people with Parkinson's are experiencing an 'on' period.

As the body metabolises the drug, symptoms become poorly controlled and the person may have an 'off' period. When this happens, movements become stiffer and the person may become completely unable to move. These motor fluctuations can be managed by taking medication on time.

As the condition progresses, 'on' and 'off' periods may increase, so medication is needed more frequently.

But increasing the amount of levodopa may also increase the chance of developing dyskinesia. These are involuntary, jerky movements that can affect any part of the body. Because of these complexities, a specialist should oversee any significant changes in Parkinson's medication routines.

When a person with Parkinson's experiences issues linked to levodopa in your hospital, there are a number of strategies you can try. These include:

- Using smaller doses more frequently, to reduce the 'peaks and troughs' of levodopa and the incidence of dyskinesia. But any reduced dose should still achieve symptom control.
- Advising a person with Parkinson's to wait for 30 to 60 minutes before having a meal after taking their medication, as protein may inhibit levodopa absorption. Medication can also be taken 30 to 60 minutes after a meal to prevent protein interaction with levodopa. To avoid any nausea, a low protein snack, such as crackers, can be eaten with medication.
- Recommending that patients eat most of their daily protein intake in their final meal of the day, as part of a protein redistribution diet. This can help to increase the effectiveness of levodopa absorption
- Managing any underlying issues that might affect levodopa absorption, such as constipation or timings of any prescribed iron supplements. This is because, in some cases, chelates can form in the gastrointestinal tract. It's advised that 2 to 3 hours is left between levodopa preparations.

Side effects

Parkinson's medications have potential side effects you should be aware of. These may include nausea, vomiting, drowsiness and low blood pressure, which can lead 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 this behaviour may include gambling, compulsive spending, binge-eating or hypersexuality.

These behaviours can have a huge impact on people's lives.

If, during an admission, impulsive and compulsive behaviour is observed or reported, it's important that medications are not suddenly stopped. Doing so may make other symptoms worse.

Instead, people with Parkinson's and their family or carers should speak to their specialists about getting their medication reviewed as soon as possible. Helpful information for patients about impulsive and compulsive behaviour can be found at **parkinsons.org.uk/icb**

When a person with Parkinson's is admitted to hospital, there are other possible complications or 'red flag' signs that a specialist should review. These are discussed in Appendix 2.

Remember that people with Parkinson's may not adhere to medication routines if the side effects of taking their medication outweigh the benefits. This means that asking your patient how their medication routine is helping them to function is key to understanding if it's improving their quality of life.

Helping a person with Parkinson’s to take their medication

It’s important to identify if a person with Parkinson’s might be having difficulty taking their usual oral medication, and if so, to manage it accordingly. Some of the common issues include:

Difficulties with swallowing

A person with Parkinson’s may experience swallowing problems. There are different ways to manage this.

- Consider the best posture for an effective swallow. Sitting upright with the chin neutral can help.
- Review by a speech and language therapist for specialist advice.
- Ask patients if they’re having any trouble with taking their medication, as swallowing can make this more difficult Thickened fluids or soft food can help.
- Use liquid or dispersible versions of drug preparations. This may help with swallowing. NEVER crush or split modified release preparations, labelled CR, MR, XL or PR.

Nausea and vomiting

A patient may also experience nausea or vomiting, altered levels of consciousness, confusion, agitation or hallucinations. In these cases, it’s important to:

- check for any previous history or underlying cause, including infection or dehydration, and treat it accordingly
- only use preparations of medication that don’t worsen Parkinson’s symptoms.

(See the next section for more information on other medications that can make Parkinson’s symptoms worse).

If a person still isn’t able to take their next prescribed oral dose, it may be necessary to consider administration via a naso-gastric, naso-jejunal or PEG tube, or via rotigotine patches.

Some people with Parkinson’s may also be using non-oral medications or have had surgery to help them control their symptoms. See Appendix 1.

Make sure other medications do not make Parkinson’s symptoms worse

People may speak to you about problems that may or may not be associated with their Parkinson’s. While managing these problems effectively is clearly a priority, it’s also important to make sure that medication given to treat these issues doesn’t make their Parkinson’s worse.

Treating nausea and vomiting

Usually, oral or PR domperidone (Motilium) is the antiemetic used to prevent and treat nausea and vomiting for people with Parkinson’s.

A study in 2014 identified an increased risk of serious cardiac side effects with domperidone. The review advised that it’s contraindicated in people with known cardiac conditions. But the advice also highlighted the need to consider the safety of domperidone with the clinical need to use it with other Parkinson’s medication.

*Since this guidance was issued, further research supports that caution is needed when prescribing domperidone. This includes evidence from a UK-based cohort study published in 2018.

Drugs to avoid

Any drug that blocks dopamine receptors could make the symptoms of Parkinson’s worse. These drugs can also mimic Parkinson’s symptoms without the condition being present.

When introducing any new medications for patients with Parkinson’s, it’s important that you think through the mechanisms of action.

Some drugs should be used with caution, and the person with Parkinson's should be closely monitored in case their symptoms get worse. In other cases, some drugs should be avoided.

For nausea and vomiting, avoid:

- metoclopramide (Maxalon)
- prochlorperazine (Stemetil)

If an injectable or alternate antiemetic is required, cyclizine (Valoid) may be considered post-operatively. Ondansetron can also be used, although a common side effect is constipation. In addition, it's contraindicated if the person is using apomorphine because of the risk of hypotension.

For hallucinations/confusion, patients should avoid:

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

Refer to a specialist for review and management.

For coughs and colds, avoid:

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

Vigilance is particularly required with the use of:

- antihistamines, especially cinnarizine (Stugeron/Arlevert), which, if used long-term, can mimic Parkinson's symptoms
- antidepressants
- antipsychotics
- antihypertensives, such as diltiazem (Adizem/Angitil/Calcicard/Dilcardia/Dilzem/Slozem/Tildiem/Viazem/Zemtard) and other calcium channel blockers. Note that these should also be monitored by the GP clinical system.

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.

Supporting the maintenance of prescribed medication routines

Parkinson's affects everyone differently in terms of how symptoms present, and the speed and nature of its progression. Because of this, medication routines may vary significantly between different people with Parkinson's in terms of preparation, dosage and timing.

Routines will also need adjusting as the person's Parkinson's symptoms change over time and the condition progresses.

Therefore, it's important that people with Parkinson's are regularly reviewed by a specialist doctor to ensure they're getting the right treatment for them. This specialist may be a consultant neurologist, geriatrician, Parkinson's nurse or pharmacist.

It often takes time for someone with Parkinson's to establish a medication routine that works for them. It's vital that this is maintained so symptoms are controlled effectively. But this can be difficult in hospitals because:

- information about medication routines might not be easily accessible (particularly with an emergency admission, or if the person is transferred between departments)
- the medications that a person with Parkinson's is taking might not be easily available
- the medication routines may not fit easily with hospital procedures, such as timings of traditional drug rounds, or theatre schedules for surgery.

Disruption to someone's medication routine can have significant implications for the person with Parkinson's, and the level of support they require from hospital ward staff.

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

Because specific Parkinson's medication routines can be complex, it can be challenging to maintain the right preparation, dosage and timing. Staff are also often required to give more assistance to a person with Parkinson's.

However, there's a lot that you can do as a hospital pharmacist to make sure that routines are maintained. This can help people with Parkinson's stay in control of their condition while they're in hospital (which you can read about in the following section).

What can I do to make sure people with Parkinson's get the most out of a hospital stay?

Make sure people get their medication on time

The key issue with Parkinson's medication is timing. Medication needs to be taken at specific times so that symptoms are controlled consistently without deterioration. 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.

People with Parkinson's tell us that when they're able to get their medication on time in hospital, it helps them stay in control of their own condition, and speeds up the time it takes them to recover.

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. For example, walking and eating.

Get It On Time

Our *Get It On Time* campaign raises awareness of the significance of drug timings in controlling the condition for people in hospitals and care homes. You can help us to get the message out to staff in hospitals that people with Parkinson's need their medication on time - every time.

Find out more: about the campaign and order our booklet and other materials at **parkinsons.org.uk/ontime**

Caring for your patient with Parkinson's: information for ward staff can help you explain the importance of getting medication on time.

This, and our other resources, are available to view and order from **parkinsons.org.uk/professionals/resources-professionals**

A Parkinson's dose calculator can help you care for someone with Parkinson's in a hospital setting, where they might have been admitted as an emergency, or where they might be nil by mouth. **You can access them online at parkinsons.org.uk/professionals/resources/nil-mouth-medication-dose-calculators-and-guidelines**

Help people with Parkinson's to take control of their condition

- People with Parkinson's are encouraged to bring a small supply of their medication in its original packaging to hospital with them, so that it can be used during an admission. However, this may not be available if they're admitted in an emergency.
- Assess the patient to see if they're able to self-administer their medication, and support them to do so if they can. A person's capability may change during an admission, such as immediately after an operation. It's therefore important that information about their self-administration status is accurately updated on all documentation and communicated to all relevant staff. However, the aim should always be to encourage people with Parkinson's to be as independent as possible with their medication.

Preparing Parkinson's medications

- Liaise with medical and nursing colleagues to make sure they have a comprehensive list of a person's medications. This includes information about preparations, dosages and timings. This can help with accurate prescribing and administration. People with Parkinson's and their carers are usually aware of how important their medication is in managing their condition, and may have this information with them. Make sure you ask them about this and check any formal documentation that they have.
- Medicine reconciliation should be a priority. This involves making a list of all medications a person with Parkinson's is taking, to make sure they can continue to take them in hospital. It's important that procedures can support this at any time, including out-of-hours.
- Make sure a wide range of Parkinson's medication is stocked, or that you're aware of how and where to get supplies, so that individual routines can be maintained.
- Parkinson's medications must be on the trust's critical medicines list, so that supplies can be accessed at any time.
- Wherever possible, branded drugs should be prescribed, but if these are unavailable, a generic substitution would be an acceptable alternative to leaving the patient with no medication at all.

- The differences between formulations are small and can be regulated, but they might be clinically significant in terms of symptom control.
- Always explain to the person or their carer why a different preparation has been dispensed to help reduce any anxiety or confusion. For example, if medicines aren't available locally.
- Print out timings on the pharmacy label or add them to any blister packs issued. This will help to make sure that ward staff can support people with Parkinson's to get their medication on time.

Adjust and plan hospital activities

- Make sure that other hospital staff understand the importance of keeping to the prescribed medication routine, and adjust the patient's activities accordingly. Ward staff will need to ensure that a person with Parkinson's gets their medication on time. This is important even if it doesn't fit in with the usual timings of drug rounds, or coincides with other ward activities, such as mealtimes.
- Surgery or clinical tests will need to be planned around the timings of someone's medication routine. Ideally, someone should be put at the start of operating lists to optimise their medication. Unless they're nil by mouth, people with Parkinson's can still take prescribed oral medication, with small amounts of water, for a period of time before their operation.
- Anaesthetists should consider regional anaesthesia rather than general anaesthetic, so that a person's usual medication routine can continue.
- As patients may transfer between areas of the hospital during their admission, it may be necessary for you to advise a range of staff in different wards or departments.

Support people to take control post discharge

- If there have been any changes to a person's medication routine while they've been in hospital, make sure you inform them and their carers of these changes. This includes why these adjustments were needed, and if they should look out for any specific side effects.
- After a person is discharged, it's very important that clear information about their medication is sent to their GP to avoid medication errors.
- Patients who have had their medication changed since going into hospital are eligible to use the NHS Discharge Medicine Service (DMS). This essential community pharmacy service aims to address any errors in medication and resolve these with the GP in the first instance. The patient may also be offered the New Medicine Service (see below) if appropriate.
- Patients who are taking Parkinson's medication for the first time might be eligible to use the NHS New Medicine Service (NMS), depending on local area availability. This service has been set up to help people with long term conditions use their medication as safely and as effectively as possible.
  Visit **psnc.org.uk/national-pharmacy-services/ essential-services/discharge-medicines-service/** and **psnc.org.uk/national-pharmacy-services/advanced-services/nms**

Appendix 1

Non-oral treatments for Parkinson's

Apomorphine (APO-go, Dacepton)

Apomorphine is a dopamine agonist administrated via an intermittent sub-cutaneous injection or a continuous subcutaneous infusion via a pump. It's not morphine-based, and isn't an analgesic or a controlled drug.

Patients who are established on apomorphine need to be continued at the prescribed dose and frequency (injection) or rate (pump). Avoid changing the pump settings unless requested to do so.

For further support, call the APO–go helpline on **0844 880 1327**, or the EVER Pharma (Dacepton) enquiries line on **0800 254 0175**. You can also ask the relevant specialist, for example, a person's Parkinson's nurse or specialist pharmacist, for further advice.

Duodopa infusion

Duodopa is co-careldopa (levodopa and carbidopa) in gel form. It's delivered into the jejunum via a PEJ tube. Patients who are established on a Duodopa routine need to be continued at the prescribed rate – providing gastric emptying is not delayed and the PEJ tube is unobstructed. If not, discontinue and commence on rotigotine patches.

Deep brain stimulation

This involves stimulation of target sites within the brain through electrodes connected to a neurostimulator placed under the skin around the chest or stomach area. Target sites are in the thalamus, the globus pallidus or the subthalamic nucleus. Patients who are established on DBS need to be maintained on the same routine.

For further support, contact the neurological department that implanted the system. The patient should carry a patient ID card listing contact details and the model number of their DBS system.

Appendix 2

Complications with Parkinson's

- delirium (acute confusion due to drugs or infection)
- chest infection, especially aspiration pneumonia
- urinary tract infections
- postural hypotension and falls - check meds and BP lying and sitting, then standing.

Red flags that means a patient needs to be referred to a Parkinson's specialist:

- Fibrotic reactions with ergot-derived dopamine agonists. These include bromocriptine, pergolide and cabergoline, where these have been prescribed. For example, dyspnoea, persistent cough, chest pain, cardiac failure, abdominal pain or tenderness may occur and these patients should be having regular echocardiography and chest X-ray.
- Signs of liver disorder with tolcapone, such as nausea, vomiting, fatigue, abdominal pain, dark urine or pruritis. These patients should be having regular liver function tests.
- Increased falling, especially early in the condition.
- Hallucinations/dementia/depression/cognitive decline, especially early on in the condition.

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**

The helpline can put your patients in touch with a Parkinson's 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 Parkinson's UK 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.

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Our Parkinson's UK Excellence Network works together to drive change, share expertise, learning and improve Parkinson's care across the UK.

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

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