

**PARKINSON'S<sup>UK</sup> CHANGE ATTITUDES. FIND A CURE. JOIN US.**



**Key information for  
community pharmacists**

## Introduction

There are 127,000 people living with Parkinson's in the UK<sup>1</sup>. There's no cure yet for Parkinson's, but medication can substantially improve symptoms. However, 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 not enough attention is paid to Parkinson's medication, symptoms can become poorly controlled and people with Parkinson's can subsequently deteriorate.

At Parkinson's UK, we're eager to work with community pharmacists, their teams and pharmacists working within community services to draw attention to the importance of effective medicines management in Parkinson's. You can play a vital role in ensuring people with Parkinson's achieve good control of their symptoms with their medications and so have the best possible quality of life.

## What is Parkinson's?

Parkinson's is a progressive neurological condition. It's predominantly seen in the older population, but one in 20 people who are diagnosed each year are aged under 40<sup>2</sup>. The cause is unknown, but the pathophysiology is the degeneration of dopamine-producing cells in the substantia nigra. Dopamine is a neurotransmitter and linked to a range of neural pathways in the brain. The loss of nerve cells producing dopamine affect these neural pathways and cause the symptoms of Parkinson's to appear.

The symptoms most often associated with Parkinson's affect movement such as slowness of movement (bradykinesia), rigidity and tremor. Most drug treatments aim to ease these motor symptoms.

However Parkinson's is also associated with many non-motor symptoms including mental health issues, sleep disorders, pain, autonomic dysfunction and gastrointestinal problems. These symptoms, which people often say cause them more distress than their motor symptoms, are treated separately but care needs to be taken to ensure medication compatibility.



environments. You can find out more about the campaign at [parkinsons.org.uk/getitontime](https://parkinsons.org.uk/getitontime)

Because of the complexity associated with Parkinson's medication, ensuring an individual is able to maintain their prescribed medication routine in terms of the right preparation, dosage and timing is a challenge. It's also essential to consider issues around adherence as well as the possible adverse effects of medicines and drug interactions.

## Medicines management

The most commonly used medicines are shown in Appendix 1. They compensate for the loss of the dopamine-producing neurons by:

- increasing the levels of dopamine in the brain (levodopa group)
- stimulating post-synaptic receptors that would normally be activated by dopamine (dopamine agonist group)
- blocking the action of enzymes and neurotransmitters that break down dopamine

Parkinson's is a very individual condition in terms of how symptoms present and the speed and nature of its progression. As shown in Appendix 1, the options for treatment are wide-ranging. Therefore medication routines may vary significantly between different people with Parkinson's.

**A key issue with Parkinson's medication is timing.** Medication needs to be taken at specific times to ensure that control of symptoms can be maintained without deterioration. Not getting their medication on time can

mean the difference between someone being able to function independently at work or at home and someone becoming reliant on others for simple everyday activities such as walking and eating. In extreme cases, missed doses may lead to the potentially fatal neuroleptic-like malignant syndrome.

Parkinson's UK launched the Get It On Time campaign to raise awareness of how vital it is that people with Parkinson's receive their medication on time in hospitals and in care homes. This is also just as important when people are in their home

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.



## Your role as a community pharmacist

### Support maintenance of prescribed medication routines

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

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

- ensuring there is no delay in dispensing prescribed Parkinson's medication – 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

- ensuring that you are aware of how and where to source the range of Parkinson's medications without delay so that it is readily available and individual routines can be maintained without disruption
- ensuring that branded preparations are issued where prescribed and not substituted with generic versions (which may

vary in both the level of active ingredients<sup>3</sup> and the effect of non-active components on the absorption of active ingredients<sup>4</sup>) unless absolutely necessary. Where this does occur, explain to the patient and/or carer why a different preparation has been dispensed to help reduce any anxiety or confusion

- ensuring that 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
- printing out timings on the pharmacy label, adding them to any blister packs issued and/

or printing out timings on the MAR (medication administration record) for care homes to help ensure people with Parkinson's get their medication on time

- ensuring care home staff and domiciliary staff that 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. One of the resources developed for the Get It On Time campaign that might help you explain the importance of timing of medication is our *Medicines Management for residents with Parkinson's* DVD. There are also two booklets *Caring for your residents with Parkinson's* and *Parkinson's: a guide for home care workers*. All of these are available to view and order from [parkinsons.org.uk/publications](http://parkinsons.org.uk/publications)

Enabling maintenance of a consistent medication routine will help people with Parkinson's get the most out of their medication.



## Help people to understand their medication routines and possible side effects

**As pharmacists 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.**

You can help by:

- educating your patients to understand the medication they are taking – this might include how the medication works and what effects they can expect. An example might be the 'on-

off' effects of levodopa leading to difficulty moving. Helpful resources include our *Drug Treatments for Parkinson's* booklet which is available from [parkinsons.org.uk/publications](http://parkinsons.org.uk/publications)

- informing your patients about what side effects to look out for. Side effects with Parkinson's medication may include nausea, vomiting, drowsiness and low blood pressure leading to dizziness and fainting. With some

symptoms. It is also helpful to inform carers and family members of this potential side effect as they might recognise changes in behaviour before the person with Parkinson's does. Helpful resources about impulsive and compulsive behaviour can be found at [parkinsons.org.uk/icbsupport](http://parkinsons.org.uk/icbsupport)

- performing a Medicines Use Review (MUR) or equivalent service (where applicable and appropriate) with your patients with Parkinson's. 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. See Appendix 2 for questions about Parkinson's to use in a medication review

Parkinson's drugs, particularly dopamine agonists and in a small number of cases levodopa, some people experience problems with impulsive and compulsive behaviour. Examples include gambling, compulsive spending, binge eating and 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 side effect they should speak to their specialists about getting their medication reviewed but also not to suddenly stop taking their medication as this may exacerbate their other



## Make sure other medications do not exacerbate Parkinson's<sup>5,6</sup>

**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.**

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. Therefore 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 OTC medicine. Some drugs should be used with caution with close monitoring for worsening of Parkinson's symptoms. In other cases, some drugs should be avoided.

### For hallucinations/ confusion

#### AVOID:

- chlorpromazine (Largactil)
- fluphenazine (Modecate)
- perphenazine (Fentazin)
- 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)
- Domperidone (Motilium) is the anti-emetic of choice 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.

### For coughs and colds

#### AVOID:

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

### Vigilance is particularly required with 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/ Calcard/Dilcardia/Dilzem/ Solzem/Tildiem/Viazem/ Zemtard) and other calcium channel blockers. Note that pharmacy patient medication records systems may support 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<sup>6</sup>.

## Support people with hospital admissions

In 2012/13, people with Parkinson's were admitted to hospital 98,195 times in England<sup>7</sup>. Hospital admissions may be due to Parkinson's, however it may also be due to other health problems which may or may not be related to Parkinson's. In addition, it may be a planned admission, but it may also be as an emergency. 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<sup>7</sup>.

Therefore it is likely that your patient with Parkinson's will have an admission to hospital at some point in their lives. Because of the need to maintain a highly specific medication routine, you could play a worthwhile role in supporting people to prepare for a planned and/or emergency hospital admission as well as supporting their transition back into the community following discharge.

This may include:

- ensuring 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 that is small enough to be kept in a wallet or purse and allows people to record drug names, doses and times. This is available from [parkinsons.org.uk/publications](http://parkinsons.org.uk/publications)
- advising 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/publications](http://parkinsons.org.uk/publications)
- ensuring 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

- signposting your patient to local schemes such as the Lion's Club Message in a Bottle ([www.lionsmd105.org](http://www.lionsmd105.org)) that aim to ensure emergency services are aware of the specific needs of the person they are attending to and the whereabouts of any vital medication
- providing information that will support your patient to self-administer their medication in hospital if they are clinically able to. Hospitals are encouraged to have a self-administration policy and to make an assessment of a person's capacity to self-administer. Supporting people to be

more knowledgeable about their drugs will help them to maintain more control over their medication

- reviewing your patient's medication 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. Therefore it would be appropriate to perform a MUR at this time to ensure continuing effectiveness of all of their medications

## Help people take control

Parkinson's is a lifelong condition for which there is currently no cure. However by looking after themselves, there's no reason why people who have Parkinson's cannot enjoy a fulfilling and enjoyable life. You can play an important role in supporting them to be pro-active in the management of their health and well-being.

Things you can do include:

- encouraging your patients to access the information and support offered by Parkinson's UK. We have a confidential helpline (**0808 800 0303**) or can be contacted at [hello@parkinsons.org.uk](mailto:hello@parkinsons.org.uk). A range of information including all of our free publications for people affected by Parkinson's can be ordered from [parkinsons.org.uk](http://parkinsons.org.uk)

- advising your patients about health promotion activities such as stopping smoking, eating a balanced diet, maintaining a healthy weight, moderating alcohol intake and participating in physical activity. It may be helpful to signpost them to local initiatives that support these activities

- advising your patients of the need to inform relevant authorities of their condition, such as the DVLA (DVA in Northern Ireland) and their car insurer at the time of diagnosis

## Know and utilise your local Parkinson's experts

The medical specialist managing your patient 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.

Parkinson's UK also offers support locally across the UK. Our information and support workers can offer one-to-one information and emotional support to people with Parkinson's, their families and carers. In addition, our network of local groups enables people with

Parkinson's and their carers to meet others and get involved in activities.

Our website has information about local support teams and our local groups at **[parkinsons.org.uk/localtoyou](http://parkinsons.org.uk/localtoyou)**.

**Find out more about Parkinson's** Parkinson's UK not only provides information and support to people affected with Parkinson's, we also provide specific support to professionals.

Our online Professionals' Network allows you to keep up-to-date with our activities relevant to your work and to engage in learning

opportunities such as Q&A sessions with renowned experts. We provide direct education and training to professionals in your local area. We also develop resources specifically for professionals. More details can be found at **[parkinsons.org.uk/professionals](http://parkinsons.org.uk/professionals)**

We also work with partners to provide education to different audiences. 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 **[www.cppe.ac.uk](http://www.cppe.ac.uk)**

There are also pharmacy networks with a special interest in Parkinson's and/or neurology. For instance, the United Kingdom Clinical Pharmacy Association has a Neurosciences group. More details can be found at **[www.ukcpa.net](http://www.ukcpa.net)**

### Key contacts

Parkinson's nurse.....

Parkinson's UK local contact.....

Local pharmacy tutor.....

Nearest pharmacist with specialist interest with Parkinson's.....

.....

## Appendix 1 Drug treatments for Parkinson's

Note that some people might require different preparations of the same drug, e.g. standard release levodopa medication during the day and a modified release version at night.

LEVODOPA			
Carbidopa and levodopa (Co-careldopa) <b>DUODOPA</b> (Intestinal gel)			 100ml per cassette containing 2000mg levodopa and 500mg carbidopa monohydrate
Levodopa and benserazide (Co-beneldopa) <b>MADOPAR</b>			<ul style="list-style-type: none"> <li> 50mg/12.5mg</li> <li> 100mg/25mg</li> <li> 200mg/50mg</li> <li> CR** 100mg/25mg</li> <li> 50mg/12.5mg (dispersible)</li> <li> 100mg/25mg (dispersible)</li> </ul>
Levodopa and carbidopa (Co-careldopa) <b>SINEMET</b>			<ul style="list-style-type: none"> <li> 25mg/100mg</li> <li> 12.5mg/50mg</li> <li> 25mg/250mg</li> <li> 10mg/100mg</li> <li> CR** 50mg/200mg</li> <li> Half-CR** 25mg/100mg</li> </ul>
Levodopa, carbidopa and entacapone <b>STALEVO</b>			<ul style="list-style-type: none"> <li> 50mg</li> <li> 75mg</li> <li> 100mg</li> <li> 125mg</li> <li> 150mg</li> <li> 175mg</li> <li> 200mg</li> </ul>
Carbidopa and levodopa (Co-careldopa) <b>LECADO</b>			<ul style="list-style-type: none"> <li> 100/25mg</li> <li> 200/50mg</li> </ul>
Carbidopa and levodopa (Co-careldopa) <b>CARAMET</b>			<ul style="list-style-type: none"> <li> 25/100mg</li> <li> 50/200mg</li> </ul>

Co-careldopa also available in generic form.

## CATECHOL-O-METHYL TRANSFERASE INHIBITORS (COMT inhibitors)

Entacapone <b>COMTESS</b>			 200mg
Tolcapone <b>TASMAR</b>			 100mg

## DOPAMINE AGONISTS

Apomorphine <b>APO-go PEN</b> (Intermittent injection)			 3ml (10mg/ml)
Apomorphine <b>APO-go PFS</b> (Pre-filled syringe)			 10ml (5mg/ml) Crono APO-go pump 
Apomorphine <b>APO-go</b> (Ampoules)			 5ml amp (10mg/ml) Crono APO-go pump 
Bromocriptine <b>PARLODEL</b>			 1mg  2.5mg  5mg  10mg
Cabergoline <b>CABASER</b>			 1mg  2mg
Pergolide			 50mcg  250mcg  1000mcg

## DOPAMINE AGONISTS CONTINUED

Pramipexole <b>MIRAPEXIN</b>			 0.088mg base/ 0.125mg salt  0.35mg base/ 0.5mg salt  0.18mg base/ 0.25mg salt  0.7mg base/ 1mg salt
Pramipexole <b>MIRAPEXIN PROLONGED RELEASE</b>			 0.26mg base/ 0.375mg salt  2.1mg base/ 3.0mg salt  2.62mg base/ 3.75mg salt  0.52mg base/ 0.75mg salt  3.15mg base/ 4.5mg salt  1.05mg base/1.5mg salt  1.57mg base/ 2.25mg salt
Ropinirole <b>REQUIP</b>			 0.25mg (in starter pack only)  0.5mg (in starter pack only)  1mg  2mg  5mg
Ropinirole <b>REQUIP XL</b> (Prolonged release)			 XL 2mg  XL 4mg  XL 8mg
Rotigotine <b>NEUPRO</b> (Patches)			 2mg/24h  4mg/24h  6mg/24h  8mg/24h

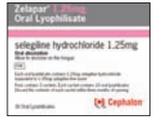
Apomorphine, ropinirole, pergolide, cabergoline, bromocriptine and pramipexole also available in generic form. Be extra vigilant about dispensing the correct strength of pramipexole (note that the dose is expressed in terms of the salt and the base).

## ANTICHOLINERGICS

Procyclidine hydrochloride <b>ARPICOLIN</b>			2.5mg/5ml  5mg/5ml 
Orphenadrine hydrochloride <b>DISIPAL</b>			 50mg
Orphenadrine hydrochloride (Generic)			 50mg/5ml

Also Procyclidine (Kemadrin). Procyclidine hydrochloride and trihexyphenidyl are available in generic syrup and tablet form.

## MONOAMINE OXIDASE B INHIBITORS (MAO-B inhibitors)

Rasagiline <b>AZILECT</b>			 1mg
Selegiline <b>ELDEPRYL</b> (Tablets or syrup)			 5mg or 10mg  10mg/5ml
Selegiline <b>ZELAPAR</b>			 1.25mg

Selegiline also available in generic form.

## GLUTAMATE ANTAGONIST

Amantadine <b>SYMMETREL</b> (Capsules or syrup)			 100mg  50mg/5ml
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- Please note the images of the tablets and capsules are not representative of their actual size.
- The poster does not give an exhaustive list of products used to treat Parkinson's.

\*details current for August 2013.

\*\*CR (controlled release) drugs are complete doses. Tablets and capsules should not be broken or split.

## Appendix 2

### Questions about Parkinson's to ask in a medication review

The following 'traffic light' questions were developed as part of a project between Greater Manchester Movement Disorder Group, Salford Royal NHS Foundation Trust and Parkinson's UK<sup>8</sup> (funded by an educational grant from GlaxoSmithKline). It aimed to increase collaboration between community pharmacists and local Parkinson's nurses, highlighting the benefits of establishing a partnership with your patient's Parkinson's nurse.

#### 1. When was your last hospital appointment with a Parkinson's specialist?

- Within the last 6 months ..... (0)  
Within the last 12 months ..... (5)  
More than 12 months ..... (15)  
Have never seen a specialist for the management  
of my Parkinson's ..... (20)

#### 2. How would you rate the control of your Parkinson's symptoms at the moment?

- Well controlled ..... (0)  
Somewhat controlled ..... (5)  
Poorly controlled ..... (15)  
Not controlled ..... (20)

#### 3. Do you remember to take your medication every time?

- Yes ..... (0)  
Misses the occasional dose (1 a week) ..... (5)  
Misses regular doses (1 a day) ..... (15)  
Not compliant – I do not have a clear understanding  
of my medication regime ..... (20)

#### 4. Do you ever take additional Parkinson's medication over and above what your specialist has advised?

- No, never ..... (0)  
Infrequently ..... (5)  
Most of the time ..... (15)  
All of the time ..... (20)

#### 5. Are you experiencing any new motor symptoms, eg freezing, increased tremor or gait problems, since your last hospital appointment?

- No ..... (0)  
Not sure ..... (5)  
Occasionally ..... (15)  
Yes ..... (20)

#### Total score from assessment questions = outcomes of total score

<b>0 – 15</b>	Satisfactory review. No action necessary.
<b>15 – 30</b>	Direct to local Parkinson's nurse. See Key contacts box on page 15 for contact details.
<b>30+</b>	Intervention required. Referral to GP for onward referral to Parkinson's specialist.
<b>50+</b>	URGENT intervention required. Patient to see GP as soon as possible for referral to Parkinson's specialist.

- Record outcome on local documentation
- Give copy of assessment questions to the patient after consultation

## Other 'red flags' that need referral to Parkinson's specialist<sup>9</sup>:

- Fibrotic reactions with ergot-derived dopamine agonists (including bromocriptine, pergolide and cabergoline) eg dyspnoea, persistent cough, chest pain, cardiac failure, abdominal pain or tenderness.
- Signs of liver disorder with tolcapone eg 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. Therefore it is important to allow sufficient time to conduct a medication review and to ensure the environment supports your patient 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 the side-effects of taking the medication outweigh their benefits from the point of view of the person. 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.

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Paul Hughes, Senior Pharmaceutical Advisor, NHS Kernow Clinical Commissioning Group

Alastair Buxton, Head of NHS Services, Pharmaceutical Services Negotiating Committee

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Parkinson's UK is working with pharmaceutical companies to improve information and standards of care for people affected by Parkinson's. Our partners have no editorial control over the content of the material we produce.

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## Every hour, someone in the UK is told they have Parkinson's. Because we're here, no one has to face Parkinson's alone.

We bring people with Parkinson's, their carers and families together via our network of local groups, our website and free confidential helpline. Specialist nurses, our supporters and staff provide information and training on every aspect of Parkinson's.

As the UK's Parkinson's support and research charity we're leading the work to find a cure, and we're closer than ever. We also campaign to change attitudes and demand better services.

Our work is totally dependent on donations. Help us to find a cure and improve life for everyone affected by Parkinson's.

### Parkinson's UK

Free\* confidential helpline **0808 800 0303**.

Monday to Friday 9am–8pm,

Saturday 10am–2pm. Interpreting available.

Text Relay **18001 0808 800 0303**

(for textphone users only)

\*calls are free from UK landlines and most mobile networks.

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