

# Consensus statement for the optimisation of Parkinson's medicines in hospital

“Whilst my mum was admitted for reasons other than her Parkinson's, the fiasco of not getting her medications when she needed them meant that she was in hospital a lot longer than she needed to be. Unfortunately it's now too late to make things right for her so I'm passionate about wanting to make sure these things do not happen to others.”

Anne Ferrett, a member of the consensus statement development group, whose late mother had a difficult and extended stay in hospital due to poor management of Parkinson's medications.

For the vast majority of people with Parkinson's, medication is the only means of controlling their symptoms. If medication is not given in accordance to their routine, this may result in people being:

- unable to swallow (increasing the risk of aspiration)
- unable to speak and/or move (increasing their dependence on staff)

At worst, [Parkinsonism-hyperpyrexia syndrome](#) (also called neuroleptic-like malignant syndrome) may develop which can be fatal.

Poor management of Parkinson's medications during a hospital admission can lead to poor outcomes during an admission for patients and their families that may continue following discharge. **Good optimisation of Parkinson's medications will not only lead to a more successful admission, but also reduce the stress and anxiety experienced by the patient and their families.**

## What is this statement?

This statement aims to answer the question:

For inpatients with Parkinson's who need medication to manage their symptoms, what are the key issues that need to be addressed throughout their hospital admission and how can these be best managed?

## Who is this statement for?

This is aimed at all staff involved in the management of medications for patients with established Parkinson's during a hospital admission with specific reference to doctors, nurses and pharmacists. It is particularly directed towards staff working in areas in which people with Parkinson's may be admitted as an emergency (such as A&E and acute assessment units) as well as areas in which people with Parkinson's may stay during an admission. It is also relevant for when the specialist Parkinson's team is unavailable (eg out-of-hours or during weekends).

**If you can answer yes to this question – 'Is it possible that I will see an inpatient who has Parkinson's?', this statement is for you.**

## How to use this statement

It is intended that this consensus statement will support local guideline development and encourage discussion and learning through local service improvement activities. It has been developed so that you, your team and your organisation will take ownership and make the necessary arrangements and changes that will mean that people with Parkinson's receive the best possible care (including getting their medication when they need them) when admitted to your hospital.

Some of the links included in this document lead to restricted access publications. Please speak to your medical librarian about getting access to these.

### The consensus statement is organised into:

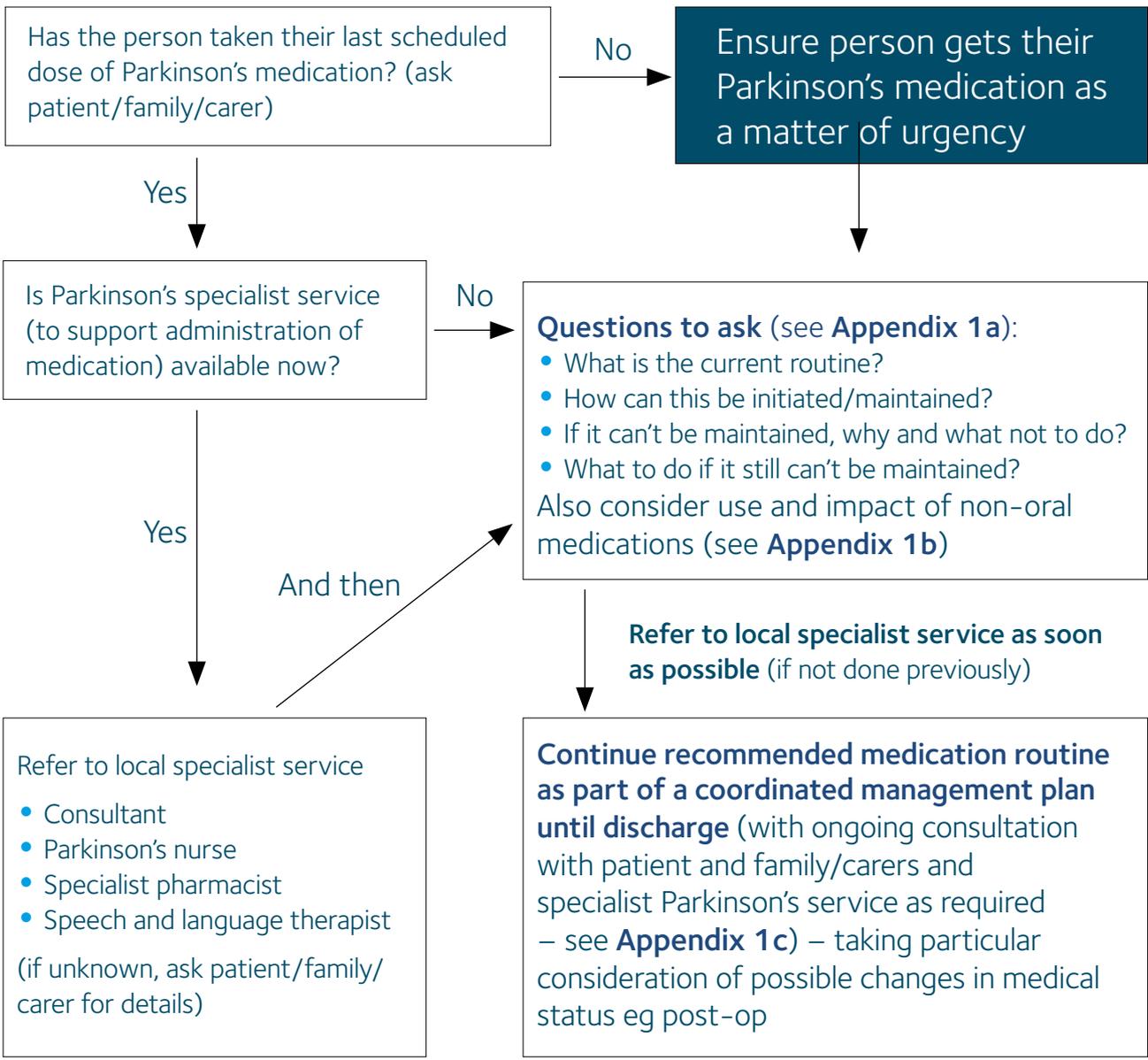
- Medicines optimisation algorithm outlining how to ensure people with Parkinson's get the medication they need – supplemented by:
  - Appendix 1a: Questions to ask on admission
  - Appendix 1b: Management of non-oral medications
  - Appendix 1c: Supporting a good hospital admission for people with Parkinson's
- Appendix 2: Admissions checklist
- Appendix 3: Building the case for medicines optimisation for people with Parkinson's
- Appendix 4: Evaluating practice of medicines optimisation for people with Parkinson's

NB It is **not** intended to support diagnosis of Parkinson's or establishing a new home medication routine (both of which should be performed by a Parkinson's specialist).

# Medicines optimisation algorithm – how to ensure people with Parkinson’s get the medication they need

## Remember

- **Do not** abruptly withdraw Parkinson’s medication – this can lead to life-threatening Parkinsonism-hyperpyrexia syndrome
- **Do not** prescribe centrally-acting dopamine antagonists (ie any medication that blocks dopamine receptors), eg haloperidol
- Each person with Parkinson’s has a unique presentation of symptoms so **maintain their usual medication routine as far as possible** (including supporting self administration of medication)
- **People with Parkinson’s and their family/carers have valuable expertise** about the impact of the condition – make use of their knowledge



## Appendix 1a – Questions to ask on admission

### What is the current routine?

- Speak to patient and their family/carers about the usual medication routine (and sensitively consider asking about any anticipatory care plans that are in place that may influence care)
- Also consult documentation from specialist service or GP (via summary care record/emergency care summary/Welsh GP record/Northern Ireland Electronic Care Record)
- Need to know: medication name (brand/generic), preparation type, dosage, **usual times taken at home**
- Consider pharmacy review for medicines reconciliation within first 24 hours

### How can this be initiated/maintained?

- Assess for ability to self-administrate medication (with possible assistance from carers) and communicate to relevant staff – note status may change during an admission so any changes must be documented and communicated to all relevant staff
- Check if any medication brought in original packaging is suitable for use
- Ensure access to medication maintained (use emergency drug cupboard or contact on-call pharmacist if necessary) – Parkinson's medication should be on the critical medicines list so that supplies can be accessed at all times ([National Patient Safety Agency \(2010\) Rapid Response Report on reducing harm from omitted and delayed medicines in hospital](#))
- Ensure **timings of routine maintained at all times** – even where these do not coincide with times of usual drug rounds
- Utilise **free resources** from Parkinson's UK's [Get It On Time campaign](#) to ensure all staff maintain the medication routine the person needs – these include:
  - A4 laminated clock poster which give a discreet reminder to staff of the need for timely medication
  - Get It On Time stickers which can be put on patients' notes to prompt staff
  - [Medicine optimisation for patients with Parkinson's DVD](#) with a 14 minute film explaining how staff can help people with Parkinson's get their medication on time
  - Also see [Drug treatments](#) for a brief overview of common Parkinson's medications and the [Emergency management of patients with Parkinson's pocket guide](#)
- Consider timing and nature of interventions (e.g. investigations, operations) to enable maintenance of the medication routine – patients can still take prescribed medication with clear fluids up to two hours before elective surgery ([Brennan and Genever, 2010](#)); also consult with anaesthetist regarding use of regional (which would allow continuation of usual medication routines) versus general anaesthesia
- Avoid switching between branded and generic preparations because of potential impact on symptom control ([Go et al, 2011](#)) – where this does occur, explain to the person and/or their carer why this has been done to reduce anxiety
- See **Appendix 1b** about maintenance of non-oral medications

## If the current routine can't be maintained, why and what not to do?

Is the person experiencing **swallowing difficulties**?

- Where possible, refer to speech and language therapy for urgent swallowing assessment and advice
- Ensure all staff encourage posture that enables effective swallow (sitting upright with chin neutral)
- Consider using thickened fluids or soft foods to assist
- **NEVER** crush/split modified release preparations (labelled CR, MR, XL or PR)
- Consider dispersible or liquid versions of drug preparations (see [Appendix 2 – admissions checklist](#)) however ensure that patients consume all the medication and do not leave a residue

Is the person experiencing **nausea/vomiting**?

- Consider possible underlying cause (e.g. gastric disturbance, intestinal obstruction\*) and treat accordingly
- **AVOID** metoclopramide (Maxalon®) and prochlorperazine (Stemetil®) due to anti-dopaminergic action
- Consider domperidone (Motilium®) – NB A [review in 2014](#) found a small increased risk of serious cardiac side effects with domperidone and so advised it to be contraindicated for people with known cardiac conditions. However the advice also highlighted the need to consider the overall safety profile with the clinical need for its use with particular reference to Parkinson's.

Is the person experiencing **confusion/agitation/hallucinations/altered level of consciousness**?

- Check for history of cognitive impairment
- Check for underlying cause (e.g. infection, dehydration, constipation\*) and treat accordingly
- Check impact of non-Parkinson's medication (e.g. opiates) and medications contributing towards [anticholinergic burden](#) (linked to increased cognitive impairment ([Fox et al, 2011](#))) and consider reducing these (NB these also include amantadine, orphenadrine and trihexyphenidyl which may be used in the management of Parkinson's – consult with specialist before altering these)
- **AVOID** haloperidol (Serenace®/Haldol®) and chlorpromazine (Largactil®) and other anti-psychotics with anti-dopaminergic action
- Consider benzodiazepines such as lorazepam (Ativan®)

\*See [Appendix 1c](#) for more information about the impact of gastrointestinal function in Parkinson's

## What to do if the current routine still can't be maintained?

Objective is to enable **short-term** management of Parkinson's with most appropriate therapy (prioritising dopaminergic medication) considering available access and to return to usual medication routine (and route of administration) **as soon as clinically possible**

As the dosages are being administered by mechanisms not usually used, the patient might tolerate these differently in comparison to their usual routine. So it is important to treat and monitor each person individually and adjust doses accordingly (particularly if dementia or delirium noted).

NB Commencement of longer-term, non-oral medications needs to be in consultation with specialist Parkinson's service

### Administration via NG/NJ/PEG tube

- Sensitively speak to the patient and their family/carers about any anticipatory care plans about the use of enteral feeding systems
- Assess for any contraindications
- Insert as per local protocol
- Following administration, flush tube afterwards to ensure complete dosage
- Information about Parkinson's medication used via NG/NJ/PEG tube: see **Appendix 2 – Admissions checklists** (NB Also check organisational policies related to non-licensed use of medications)

### Administration via rotigotine patch (if unable to tolerate NG/NJ/PEG tube)

- Information about conversion calculations: see **Appendix 2 – Admissions checklists**

## Appendix 1b – Non-oral medications

### Apomorphine (APO-go)

- This is a dopamine agonist administered via an intermittent sub-cut injection or a pump – it is **not** morphine-based, is **not** an analgesic and is **not** a controlled drug.
- Patients who are established on an apomorphine routine need to be continued at the prescribed dose and frequency (injection) or rate (pump) – do not change the pump settings unless requested to do so.
- For further information and support, go to the [APO-go website for professionals](#), call the APO-go Helpline on 0844 880 1327 or contact the specialist Parkinson's service.

### Duodopa infusion

- This is co-careldopa (levodopa and carbidopa) in gel form 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 patent – if not, discontinue and commence on rotigotine patches).

## Deep brain stimulation (DBS)

- This involves stimulation of target sites within the brain (either in the thalamus, the globus pallidus or the subthalamic nucleus) through electrodes connected to a neurostimulator placed under the skin around the chest or stomach area.
- Patients who are established on DBS need to be maintained on their usual routine.
- For further information and support, contact the neurological department that implanted the system (the patient should carry a patient ID card listing contact details and model number of the DBS system).

## **Appendix 1c: Supporting a good hospital admission for people with Parkinson's**

Whilst getting the medication they need in hospital is a major issue for people with Parkinson's, there are other key considerations that influence whether or not an admission is a good experience for the person and their families and carers.

### **Staff knowledge and understanding of Parkinson's**

Parkinson's is a complex condition, however with a smaller incidence in comparison to other conditions (affecting 127,000 people in the UK compared to 4.5 million people living with diabetes), many hospital staff may not regularly encounter people with Parkinson's.

Parkinson's UK has a range of **free** resources and educational opportunities to enable staff at all levels learn more about Parkinson's including:

- [Caring for your patient with Parkinson's booklet](#)
- [Parkinson's: Key information for hospital pharmacists booklet](#)
- [Parkinson's awareness](#) – a 15 minute online presentation for ward staff
- [Parkinson's: Foundation modules for health and social care staff](#) – online training
- [Parkinson's: An introduction to caring to someone on your ward](#) – follow-on training after the foundation module for health and social care staff
- [Parkinson's: Foundation modules for junior doctors](#) – online training
- [Parkinson's: Foundation modules for pharmacists](#) – online training

More information about information and support for professionals can be found at [parkinsons.org.uk/excellencenetwork](https://parkinsons.org.uk/excellencenetwork)

## Key clinical features of hospital admissions and people with Parkinson's

Because of the role of dopamine as a neurotransmitter in a number of neural pathways, people with Parkinson's may present with a range of both motor and non-motor symptoms. Of these, a hospital admission may be particularly affected by:

- **Orthostatic hypotension** – defined as a sustained reduction of systolic blood pressure of at least 20mmHg or diastolic blood pressure of 10mmHg within 3 minutes of standing (Freeman et al, 2011). In Parkinson's, this may occur due to impairment of the sympathetic vasomotor neurons. Symptoms include lightheadness or dizziness on standing, syncope, neck and shoulder ('coat-hanger') pain. Management strategies may include non-pharmacological interventions such as increasing fluid intake and pressure stockings, and pharmacological measures (dependent on individual requirements) such as introduction of corticosteroids or cholinesterase inhibitors (Sánchez-Ferro, Benito-León, Gómez-Esteban, 2013)
- **Gastrointestinal problems** – because dopaminergic medication is absorbed in the jejunum, issues that affect the gastrointestinal tract such as blockages and faecal impaction may also influence the uptake of Parkinson's medication (and thus the observed effectiveness of medications). Therefore these need to be addressed as a **matter of urgency**. Constipation is a particular issue for people with Parkinson's. This is due to a direct effect of the condition on the autonomic nerves controlling bowel function and indirectly due to difficulties mobilising and taking in food and drink. Management strategies may include increasing fluid and fibre intake as well as the use of stimulants and laxatives as required (Winge, Rasmussen and Werdelin, 2003)

A review by Low et al (2015) of hospital episode statistics data between 2009 and 2013 showed the main reasons for **emergency admissions** among people with Parkinson's are **pneumonia** (13.5%), **physical deterioration** (9.4%), **urinary tract infection** (9.2%) and **hip fractures** (4.3%) with people with Parkinson's up to **twice as likely to be admitted** for these reasons compared to the general population.

Therefore a successful admission requires management of a person's Parkinson's symptoms, the related issues resulting from the condition and the presenting reason for admission (which may or may not be related to Parkinson's). This is reliant on good communication with other relevant teams to maintain a holistic and coordinated approach to patient management. This will give confidence to both the patient and their loved ones.

## Involvement of carers

Carers often play a vital role in supporting someone to manage their Parkinson's. This may involve practical support such as giving reminders for taking medication and physical assistance with everyday tasks to emotional support as the person they care for deals with a lifelong degenerative condition. However the skills and expertise of carers are frequently undervalued when a person with Parkinson's goes into hospital. Therefore to ensure that a hospital admission is as successful as possible (and this includes a safe and timely discharge from hospital), acknowledging carers as part of the team is essential. Parkinson's UK support John's Campaign which advocates that families and carers of people with significant health issues such as dementia to have the same rights as the parents of sick children, and be allowed to remain with them in hospital for as many hours of the day and night as possible. Enabling carers of people with Parkinson's to do the same could help reduce anxieties for both the person and their loved ones, and assist in ensuring they get the care they need.

## **End-of-life care**

Parkinson's is a progressive condition and they can experience health problems (which may bring them into hospital) that can affect life expectancy ([Willis et al, 2012](#)). Therefore it is possible that end-of-life considerations may need to be taken into account within someone's inpatient management. This is clearly a difficult topic to discuss with patients and their loved ones. However some may have already developed documents such as anticipatory care plans and talking about these with them in a sensitive manner will show the commitment a service has in ensuring these are followed. Resources such as Parkinson's UK's information on [preparing for end of life](#) may help to support a conversation.

## **Safe and effective discharge**

As with all patients, discharge planning should start as early as possible during an admission. For people with Parkinson's, their complex needs may mean that many different professionals will have been involved in their care during a hospital stay and they may need ongoing intervention following discharge. Therefore it is important for their discharge plans to be as coordinated as possible. In addition, it is vital that any information about the management of Parkinson's medication, including any necessary changes, is communicated to the patient's GP (and specialist, if for any reason, they were not involved whilst the person was admitted). This information also needs to be given to the patient and/or family/carer upon discharge.

Parkinson's UK also provides a range of services for both people affected by Parkinson's and those around them, including a free confidential helpline (0808 800 0303) and direct support from Parkinson's Local Advisers and local groups. More information can be found at [parkinsons.org.uk/information-and-support/support-you](https://parkinsons.org.uk/information-and-support/support-you)

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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.**

The tools, education and data it provides are crucial for better services and professional development.

The network links key professionals and people affected by Parkinson's, bringing new opportunities to learn from each other and work together for change.

Visit [parkinsons.org.uk/excellencenetwork](https://parkinsons.org.uk/excellencenetwork)