

Driving improvement on time critical Parkinson's medication: webinar Q&A

This document summarises the question and answer session which took place during the Driving improvement on time critical Parkinson's medication webinar on 26 February 2025.

Questions were answered by Chair and panellists: Dr Jonny Acheson, Dr Fionnuala Johnston, Clare Addison, Nick Bryden and Emma Kirk.

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Questions and answers

Question: What are the critical signs and symptoms of a patient who may have not well managed Parkinson's?

Answer: There are many different signs. Parkinsonism-hyperpyrexia syndrome is the biggest risk, this can present as increased rigidity, high temperature, reduced consciousness or stiffness. Speech and mobility can be affected and anxiety can increase. People will deteriorate quickly.

Ask when the patient last had their medication.

Q: Fionnuala, what was the biggest barrier when you started your project?

A: Baseline knowledge, people simply didn't know the positive impact that giving medication on time can have and the negative impact of not giving medication on time. Hearing patient voices has been the thing that has made the difference in terms of bringing people on board.

There are clinical pressures and nursing staff can sometimes feel quite overwhelmed with the work that they are being asked to do and so conveying the fact that this is something that will help them and make things easier is helpful. Everybody wants to do a good job for their patient but sometimes the pressures of work can make it challenging to do, so we try our best to give people the tools that they need and make it as easy as possible to do a good job.

Q: Who carries out your capacity assessments and how often are they reviewed?

A: I am taking this question to be specific to whether the patient has capacity to refuse this medicine at this point, capacity is time and medication specific. Our critical medications standard operating procedure (SOP) says that if a patient refuses a critical medication then that triggers a capacity assessment by a doctor, it could be any doctor that is qualified, and a plan has to be put in place.

It isn't that time consuming, these patients need to be reviewed anyway because either they have become delirious or something has changed and they are about to self discharge. If the patient has capacity and does not want to take their medication, bearing in mind that this is not specific to Parkinson's, then they have capacity to do that.

Patients are allowed to make unwise decisions. However if they are delirious and are not able to make decisions around their care then an alternative plan needs to be put in place. That alternative plan might be to let them calm down, bring their relatives in and we will ask them again in 20 minutes. In that situation you are looking for the least worst option and it is very patient specific.

Q: Management of patients presenting to hospital on apomorphine pumps. Any information for HCPs on the newer Duopa gel pumps?

A: Educational videos, such as pump training videos, as well as patient materials can be downloaded from the newly launched [APO-go.com](https://apo-go.com) website. User instructions and set up videos for the pumps and pen, as well as two downloadable guides for the two pumps are available from the [Education Resource pages](#).

Additionally, the phone number for the APO-go® Technical Helpline is **0808 196 4242**. The helpline is available for professionals, carers and patients 24/7.

The pharmaceutical company Abbvie can provide resources about Produodopa pumps directly to healthcare professionals.

Q: How would you deal with managing medication in MDS trays to keep Parkinson's patients independent when taking 5 times a day and over?

A: MDS trays in an acute hospital setting can be difficult because the nurses don't always know what is in them and so there is a reticence to use them.

Lots of MDS trays now have labels explaining that the round blue tablet is this drug, yellow and green capsule is this drug.

I don't think we need this to be a barrier, if you don't have the supply of the Parkinson's medicine on the ward then it is sensible to use it from the MDS tray. Often we wrap ourselves up in what the policy says but what we need to be here is pragmatic, we need to get the medicine for the patient. We don't want to give the wrong medicines so we need to know what it is. Some medicines in that particular slot may have been stopped so we need to assure ourselves that we are giving the right medicine.

I would suggest contacting your pharmacy department, our department has systems where we can work out what the medicines are. We need these to be pragmatic patient centred decisions, what is the best option at this point for the patient? We need policies that are flexible enough that we can bend the rules to get the medicines to the patient. I suggest getting in touch with pharmacy and discussing this from the patient's perspective.

We should be risk assessing and making sure that we always get the medicines to the patient in whatever way we can. I'm not talking about doing a risk assessment on paper, it's about having that thought process and documenting our decisions.

Q: Average length of stay for a patient who has missed time critical medicines within emergency department (ED) delays?

A: A missed dose will increase the length of stay of a patient. Evidence quoted in the Parkinson's UK [Every Minute Counts](#) report shows that missed doses of Parkinson's medication can increase the length of stay in hospital by an average of 4 days, we don't have data which breaks this down specifically for EDs.

The [Parkinson's UK time critical medication dashboard](#) allows health professionals, NHS Trusts, Integrated Care Boards, and Health Boards to estimate the benefits of improving time critical medication (TCM) management for people with Parkinson's in hospitals. [Explore the dashboard](#) and its supporting documentation to learn how your organisation can make a difference.

The Royal College of Emergency Medicine (RCEM) is currently running a [Quality Improvement Programme \(QIP\) on time critical medication](#) which aims to make visits to A&Es safer for thousands of people every year.

Q: Fionnuala, how does the self administration policy work in your area? Is it specific to each ward ?

A: This is the only outstanding amber in our benchmarking document, we aren't there yet. The policy that we have devised is purely for the Parkinson's ward but there is a separate insulin self administration policy which is being delivered now on the endocrine ward and in our intermediate care and rehab hospital, they are also moving towards self administration for all medication with a view to improving independence before home. The plan is for it to be trust wide and to have a unifying policy but there has been a delay due to the issue with cabinets.

Q: Are you able to share your self administration policy, Fionnuala?

A: Yes, I think the trust would be willing to share when it is done.

Parkinson's UK Excellence Network has a [guide to self administration](#) which includes 2 example self administration policies which have been peer reviewed.

This guide is designed to support senior pharmacists and nurses in developing a self administration policy to improve the delivery of time critical medication.

Q: Clare, do patients have a role in this? What can they do to help?

A: Yes, patient education is key and patients need to take ownership of their wellbeing. We are working with Parkinson's UK to think about how we empower patients to prepare for a hospital admission.

Often when patients are admitted as an emergency admission they are less able to advocate for themselves, in this case carers and loved ones need to be upskilled and informed enough to advocate for them.

When an admission is planned there are tools that can play an important role in preparing for hospital. The Parkinson's UK leaflet [Going into Hospital when you have Parkinson's](#) helps patients to understand what to take with them and how to advocate for themselves.

Encourage patients to use the 'term time critical medication' when they arrive in hospital.

Q: Any ideas on how to make sure time critical medications are administered in a busy emergency department? We have specific visual (different colour) care request forms currently.

A: The keys to this are early identification of patients and self administration in the emergency department.

If you can identify early that the patient is on a time critical medication then you have more chance of them getting their medication on time. This is more challenging for emergency departments that are paper based.

Paper based departments can still use the yellow Get It On Time stickers. [Parkinson's UK have produced a specific yellow sticker for emergency departments](#), it asks 3 questions:

- Have you got your medication with you?
- When is your next dose?
- Are you willing to self administer?

People don't present with Parkinson's, they present as a result of

Parkinson's through falls, infection, comorbidities so they are under the radar and you have to discover them.

In April 2025 the Royal College of Emergency Medicine (RCEM) released an [Advisory Statement on Time Critical Medication Self-Administration in Emergency Departments](#). The position statement has four principles that individual hospitals will have to hang the detail on:

1. Does the patient show their medication? So if someone arrives in the ED and is able to take their medication out of their bag or pocket and show it to the staff, that shows that they are on a time critical medication and that they want to take it themselves
2. There will then be an assessment – this will depend on each emergency department
3. The patient will then either be allowed to take their own medication or will be aided to take their own medication
4. Finally, monitoring! The nurse needs to watch the patient take the medication and record this. This empowers the patient.

The RCEM quality improvement programme showed that 10% of patients self administered.

Finally, encourage staff to prescribe not just the patient's first dose but all of their medication, even if they don't know if they are going to be admitted.

Q: With long delays in ambulances and emergency departments, how are EDs flagging these patients as requiring time critical medication? (ie before they've been seen, which can be several hours)

A: In April 2025 the Royal College of Emergency Medicine (RCEM) released an [Advisory Statement on Time Critical Medication Self-Administration in Emergency Departments](#). The position statement says that "Ambulance staff bringing patients into the ED should broadly follow the principles in the position statement guided by their own governance systems." and "Ambulance staff waiting to handover patients to the ED may request clinical support/advice from ED clinicians to AIS TCM prescribing/administration where appropriate."

Q: Fionnuala, you mentioned engagement of senior leaders was key – what persuaded them to take action on this issue? And through your work, did you also see knock on improvements for other TCMs, like insulin or anti-epileptics?

A: I think it helped being able to play the [video](#) to them because that was very relatable to them. But also being able to show that we could do well and now it has become a source of pride in the hospital and that has been very motivating for my senior colleagues.

I've just been back to present this work again at the clinical governance steering group to show them the update since last year on the benchmarking and they asked how we can extend this to insulin and anti-epileptics.

Q: Are these patient story videos available on the Parkinson's UK website at all? It would be great to share these with other healthcare professionals to help their understanding of how important this is.

A: Yes, the patient stories are available now in the Excellence Network section of the Parkinson's UK website, please do share the films with your colleagues to increase their understanding of the importance of Parkinson's time critical medicine: [Time critical medicine patient stories: in their own words](#).

Q: How do I check whether my Trust has pledged?

A: If you want to see if your organisation has pledged [visit the Excellence Network webpages](#).

More than 100 NHS organisations have pledged and are working to improve the delivery of time critical Parkinson's medication. Find out more about their work and how you can join them.

You can read the 10 recommendations for hospitals which Fionnuala and Jonny have talked about here and download the [benchmarking template](#).

These recommendations for hospitals will enable NHS organisations to support timely, safe and appropriate medicine management for people with Parkinson's.

Q: Are there information and resources for care home teams?

A: There are a range of resources and education opportunities suitable for care home teams:

- **'Get It On Time' stickers** can be placed on a resident's notes as a visible reminder that Parkinson's medication is time critical. These are available to order free of charge from [the Parkinson's UK shop](#).
- **'Get It On Time' clocks** these A5 wipe-clean posters are designed to help staff remember when medication is due. Simply write the dose times on the poster using a whiteboard pen and display it in a prominent place, such as the resident's room door. These are also available to order for free [from the Parkinson's UK shop](#).
- **Booklet for care homes** the [Caring for your resident with Parkinson's](#) booklet provides comprehensive information on Parkinson's and how to best care for residents with the condition.
- **Booklet for domiciliary care agencies** the [Parkinson's: A guide for home care workers](#) booklet offers valuable insights into Parkinson's symptoms, treatments, and their potential side effects.

The Parkinson's UK Excellence Network **Volunteer Educator (VE) programme** offers a free live webinar called [Introduction to Parkinson's](#).

This session is ideal for teams in care homes, nursing homes, and domiciliary care agencies and provides an in-depth understanding of Parkinson's. By the end of the webinar, your team will:

- Have a better understanding of Parkinson's and its impact.
- Be equipped with knowledge of best practices in caring for individuals with Parkinson's.
- Be familiar with the resources available to support people living with Parkinson's.
- Feel confident in evaluating and improving their care for people with Parkinson's.

[Find out more in the Excellence Network Learning Hub.](#)

Q: Any hints and tips about getting better engagement from ward nurses?

A: Yes, read our best practice case studies showcasing work at [Bradford Teaching Hospitals NHS Foundation Trust](#) and [Hexham General Hospital](#).

Q: Breaking the barriers of self medication lockers and self administration. If it works in one Trust why can it not be cloned?

A: Often it is the small practical things like lockers which can be a barrier to self administration. These points will need to be addressed as part of work on your self administration policy but there is best practice which shows that these challenges can be overcome. [Read about self administration at University Hospitals of Leicester \(UHL\) NHS Trust.](#)

Q: We are in the process of finalising our missed dose dashboard, trial ongoing in our Acute Medical Units and some surgical wards, since January. Does anyone have a missed dose dashboard and any guidelines on thresholds etc?

A: A missed dose to me is not administered at all. I'd be more interested in the reasons for missed doses and indeed have they written in nursing or medical notes why it was missed? We have numerous reasons for non-administration e.g. sleeping, medicine not available, etc, if this option is chosen the time is automatically inputted as the time of administration and passes our audit.

Q: Self administration policy? Who led on this, nursing or pharmacy?

A: At South Tyneside and Sunderland NHS Foundation Trust we are still working on this, we have joint medical and nursing leadership for this and pharmacy are supporting us.

Policies require buy in from all parties in order to be successfully implemented.

Q: When patients self administer the time stamp on the dose given will be late even if the patient has taken their medication on time themselves via self administration if we ask and complete the system on our usual drug round. Has anyone found a solution for this to make auditing self administered drugs more accurate?

A: We don't have a self-administration policy in our health board for general medicines or for Parkinson's medicines. It's always best to record when a medicine is given as close as possible to when this occurred, but for self-administration I think the recording time of administration will inherently be less accurate, though more beneficial for patients. Certainly

for auditing purposes, it would be sensible to analyse staff administration and self-administration separately and bear these points in mind.

Some prescribing systems have the ability to record 3 dates for each administration opportunity:

1. Scheduled date and time (prescribed time)
2. Given date and time (time stated by the nurse)
3. Recorded date and time (time nurse was at the computer inputting data)

Don't let EPMA be a barrier to self administration! Recording of doses taken can present difficulties when patients can't record on the system. Be pragmatic.

Q: I'd like to understand how speech and language therapists can support people taking their time critical medication on time when they've got dysphagia.

A: If a person can't safely swallow their medication, then there is a risk they will not be able to take it on time. A patient admitted with dysphagia could be at high risk of aspiration on all consistencies and placed on nil by mouth awaiting further assessment; they might be able to manage certain medications but not others, or may have a non-oral dopamine agonist already, for example, rotigotine.

Only timely screening and assessment will determine the individual's circumstances. This assessment needs to be supported by robust policies that support decision-making. Each Trust should have an administration of medication policy that guides the medical team to the choices available.

The speech and language therapy department can start with an audit, to check how well their own Trust is performing. The NCEPOD recommendation checklist is a good place to start. [Dysphagia in people with PD_Hard to Swallow_Recommendations.pdf](#)

Training needs can be identified at all levels, from those first admitting the patient into the hospital through to the ward staff that manage the patient during their stay. Parkinson's UK Excellence Network provides a quick essential overview of the steps ward leaders need to consider to ensure staff training, screening procedures and supporting policies are in place:

[Screening swallowing problems in Parkinson's: nurse in charge and ward staff guide](#)

Speech and language therapists have a key role in advocating for patients with dysphagia and ensuring senior leaders are aware of this guide and facilitate improvements in care if needed.