

PARKINSON'S<sup>UK</sup>

# Every minute counts:

Time critical Parkinson's medication on time, every time

September 2023



## Foreword

**People with Parkinson's rely on their medication: not only to take it, but to take it on time. A delay as little as 30 minutes can mean the difference between functioning well and being unable to move, walk, talk or swallow.**

Missing doses can lead to severe and irreversible harm to their health. People with Parkinson's need to get their medication on time, every time.

It is deeply concerning, then, that 58% of people with Parkinson's admitted to hospitals in England last year did not receive their medication on time, every time.

As the leading charity for people with Parkinson's in the UK, our community has been sharing their experience of this problem with us. And we've been monitoring Parkinson's healthcare services through our service audits to understand what's going on.

In May 2023, we sent a Freedom of Information request to every NHS Trust in England to find out what steps they are taking to address this wholly avoidable problem.

This report, *Every Minute Counts*, brings those insights together to reveal the true extent of missed medications for people with Parkinson's. We show that almost half (48%) of NHS trusts do not provide the right training on time-critical medication. We show that one in four NHS trusts does not enable people with Parkinson's to manage their medication themselves in hospital, despite being able to do so. We also highlight that NHS trusts are not required to monitor or report missed or delayed doses of Parkinson's medication.

The NHS, in its 75th year, has made extraordinary progress in providing life-saving and life-changing healthcare for the nation. And the staff in the NHS go above and beyond every day to meet our needs as patients. However, the NHS is a system under intense pressure from staff shortages, record-high waiting lists and disputes over pay and working conditions.

Healthcare professionals want to help people with Parkinson's get their medication on time, every time when in hospital. But they need help to do that.

In *Every Minute Counts* we describe practical solutions for the NHS in England to:

- Empower people with Parkinson's to take their own medication in hospital,
- Harness the power of e-prescribing to assist, monitor and report on the issue, and
- Train hospital ward staff to give them the knowledge and confidence to ensure people with Parkinson's get their medication on time every time.

As a UK-wide charity, we also describe our work in Scotland, Wales and Northern Ireland to highlight and tackle the problem of missed medications in hospital.

No person with Parkinson's should fear coming out of hospital feeling worse than when they went in. It is time to act now.



A handwritten signature in black ink, appearing to read 'Juliet Tizzard'.

**Juliet Tizzard,**  
**Director of External Relations,**  
**Parkinson's UK**



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## Executive summary

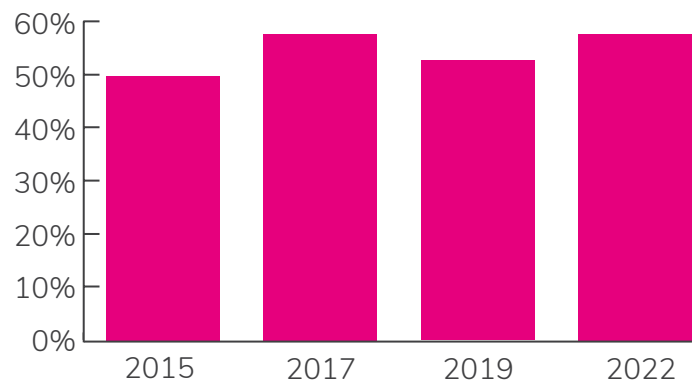
**When people with Parkinson's don't get their medication on time, it can leave them unable to move, get out of bed, swallow, walk or talk. In the most severe cases, this can lead to Parkinsonism-hyperpyrexia syndrome (muscle rigidity, fever, reduced consciousness and impacts aspects of the nervous system), which can be fatal.**

### Key findings

The UK Parkinson's Audit 2022 (the most comprehensive dataset on the quality of health care for people with Parkinson's across the UK) found:

- Only 42% of people with Parkinson's admitted to hospitals in England always got their medication on time every time.

Yet, we know from the 2022 UK Parkinson's Audit that 58% of people with Parkinson's admitted to hospital do not receive their medication on time every time. Scant progress has been made over the best part of the last decade (2015- 50%<sup>1</sup>, 2017-58%<sup>2</sup>, 2019 - 53%<sup>3</sup>, 2022 58%<sup>4</sup>).



**Percentage of Parkinson's patients not receiving timely medication throughout hospital stay.**



## Not getting my medication on time has delayed my recovery and left me traumatised”.

A person with Parkinson’s

Given the serious risk of harm to the health of a person with Parkinson’s and the numbers affected, we believe this should be a priority patient safety issue for the NHS. Yet time critical medication in hospitals fails to register on the health policy landscape.

We sent Freedom of Information (Fol) requests (May/June 2023) to NHS Hospital trusts in England asking about key measures to help ensure people with Parkinson’s get their medication on time in hospital\*. We found:

- One in four NHS trusts does not have policies that allow people with Parkinson’s to take their own medication in hospitals.
- Shockingly, only around half (52%) require staff responsible for prescribing and administering medication to have training on time critical medication (including Parkinson’s).
- Despite 81% of NHS trusts having e-prescribing, only 58% are using it to report on whether people with Parkinson’s receive their medication on time or not.

The significant deterioration in Parkinson’s symptoms due to missed or delayed medication adds to pressures on a health and social care system facing workforce shortages, sky-high waiting lists and social care services struggling to keep up with demand.

Despite the real risk of harm, the data and evidence presented in this report shows that a large proportion of people with Parkinson’s don’t get their medication on time in hospital. Leaving people with Parkinson’s fearing that they will come out of hospital worse than when they went in.

We have outlined clear recommendations for changes on self-administration of medication, e-prescribing and training, that we believe can

- achieve a step change in the number of people with Parkinson’s getting their medication on time in hospital
- reduce length of stay and
- most importantly improve the experience of people with Parkinson’s admitted to hospital

We have also shown examples from Derby and Ayrshire and Arran that demonstrate it is possible to make changes that improve outcomes for people with Parkinson’s.

We believe that no-one with Parkinson’s should fear going into hospital, and we want to work with the NHS to make sure people with Parkinson’s see hospital as a safe place to be.

**Report written by Sam Freeman Carney. Health Policy and Improvement Lead, Parkinson’s UK.**

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\*The statistics used in this report in relation to these freedom of information requests are based on responses from 91% of NHS Hospital Trusts in England. At time of publication responses from the remaining 9% of Trusts had not been received and were beyond the 20 working day statutory period for response.



## Recommendations

At Parkinson's UK, we will keep supporting, guiding and campaigning across the four nations of the UK to help build a service where people with Parkinson's in hospital get their

medication on time, every time. But we also need action from NHS England, Integrated Care Boards (ICBs) and NHS trusts in England to make that happen.

1. **NHS England** should ensure all ICBs in England have a self-administration of medication policy and appropriate facilities in their hospitals to enable people with Parkinson's who can, and are safe to, take their own medication in hospital.
  - › **NHS England and partners** should develop a nationally agreed self-administration of medication policy template and supply this to ICBs to adapt for their hospitals.
  - › **NHS trusts** should monitor the implementation of the self-administration of medication policy template and ensure that the policy is reviewed every two years.
2. **NHS England** should boost the roll out of e-prescribing across all NHS trusts to harness its potential for improving the performance of hospitals to deliver Parkinson's medication on time to people with the condition who are inpatients.
3. **NHS England** should use e-prescribing to monitor and track progress of missed or delayed doses of Parkinson's medication at the NHS trust, ICB and national levels.
  - › In 2023/24 pilot monitoring of this data using the sites where e-prescribing has been rolled out.
  - › In 2024/25, implement a national rollout and publish these figures through NHS Digital as a data set at NHS trust, ICB and national levels.
4. **NHS England** should ensure every hospital trust in England implements training on time critical medications, including Parkinson's medication.
  - › **NHS trusts** should ensure all hospital staff watch the three-minute [video](#)<sup>35</sup> by NHS Leicester Hospital Trust and Surrey and Sussex NHS Trust and record on staff Learning & Development records for audit purposes.
  - › **NHS trusts** should require hospital ward staff who provide care for people with Parkinson's to complete either [Parkinson's UK's 15-minute guided presentation](#)<sup>36</sup> on medication management or [watch the Lancashire NHS Trust's 60-minute video](#)<sup>37</sup> every 3 years and record on staff learning & development records for audit purposes.
5. **NHS trusts in England** should make the changes outlined in '[Time critical medication, on time, every time. Ten recommendations for your hospital](#)'<sup>38</sup> and benchmark progress made against each recommendation.
6. **Each ICB lead on patient safety** should ensure all NHS trusts in their area implement the recommendations outlined in 'Time critical medication, on time, every time. Ten recommendations for your hospital' and benchmark progress made against each recommendation.

# Living with Parkinson's

**Parkinson's is a progressive neurological condition for which there is currently no cure. It is the fastest-growing neurological condition in the world<sup>5</sup>. In the UK, around 153,000 people are already living with Parkinson's<sup>6</sup>. With population growth and ageing, this will increase by a fifth, to around 172,000 people in the UK, by 2030. While thousands of working age people are also affected, the majority of people develop symptoms after the age of 65.**

There are over 40 symptoms of the condition, including freezing, tremor, painful muscle cramps, difficulties speaking and swallowing, anxiety, and depression. The condition develops when nerve cells that are responsible for producing a chemical known as dopamine die. Dopamine allows messages to be sent to the parts of the brain that coordinate movement. With the loss of dopamine-producing nerve cells, these parts of the brain are unable to work normally, causing symptoms of Parkinson's to appear.

People with Parkinson's rely on medicines to control their symptoms. They are often prescribed medicines to replace their lost dopamine (either levodopa, a dopamine agonist or an MAO-B inhibitor) helping with movement related symptoms including tremor (shaking), slowness of movement and rigidity (muscle stiffness)]. Whilst they are able to manage their medication well at home, this is not the case when someone with Parkinson's is admitted to hospital. According to emergency admissions data, 33% of people with Parkinson's in England are admitted to hospital each year<sup>7</sup> (average emergency admissions per annum 2019/20-2021/22.). This is usually

because of a trip or fall, an infection or a cardiac or gastrointestinal problem. Because they are usually cared for by non-specialist staff and are not allowed to manage their own medication, they often lose control over their medication - with devastating effects.

## Timing matters

If people with Parkinson's don't get their medication on time, it can seriously impact their health. They may be unable to move, get out of bed, swallow or walk<sup>8,9</sup>. Some people may never recover and permanently lose their ability to move, or talk.

Even a delay of 30 minutes in taking medication can lead to profound health implications for a person with Parkinson's. In 2017, NICE recognised the importance of levodopa admission as an area for quality improvement within the Parkinson's NICE quality standard<sup>10</sup>.



**I got 2 pills instead of my usual 13. No-one could tell me what I'd got or where the rest were”.**

**A person with Parkinson's**

People with Parkinson's on levodopa-based medication can take medication up to every two hours<sup>8,11</sup>. The timing of these medications alters from person to person. This is because everyone's Parkinson's symptoms are different, and therefore, each person needs a bespoke medication management regime.





As a result, people with Parkinson's often miss out on their vital medication while staying in hospital for reasons unrelated to Parkinson's. This is linked to several factors including, but not limited to:

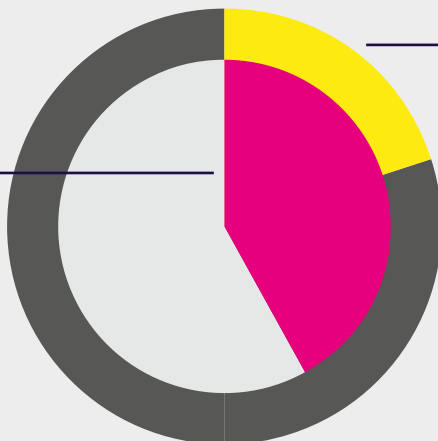
- people with Parkinson's being admitted to a general medical ward without access to a Parkinson's specialist,
- lack of training on Parkinson's medication management of hospital ward staff and
- ward medication rounds not corresponding to a person with Parkinson's specific medication timings<sup>12,13</sup>.

Parkinson's UK has a range of [information and resources for professionals](#), to support them to make sure everyone with Parkinson's in hospital or care homes gets their medication on time, every time.

## The scale of the problem

Our survey of Parkinson's health and care services, the UK Parkinson's Audit<sup>4</sup>, shows that in England:

Only **42%** of people with Parkinson's admitted to hospital received their medication on time - this has got worse since our last audit in 2019.



Of these people, **40%** say the delay had a significant negative or negative impact on their condition.

This means that approximately **24,000 people with Parkinson's<sup>7</sup> did not receive their medication on time**. Evidence shows that missed doses of Parkinson's medication can increase the length of stay in hospital by an average of 4 days<sup>14,15</sup>.

## Joanna's story

Joanna is a nurse from Sheffield whose mother, Jean, was admitted to Darlington Memorial Hospital A&E via ambulance in September 2021. She was taken alone by paramedics despite Joanna's father being her carer. Her mother was experiencing increasing confusion as a result of a urinary tract infection.

Sadly Jean was left alone in A&E for 8 hours, unable to care for herself because she is normally reliant on carers due to her Parkinson's. She was then admitted to the wards and moved twice overnight. No Madopar (Parkinson's medication) appears to have been given during her admission, and her drug Kardex (information about a person's medication) had gone "missing".

Jean was found unresponsive the following morning by the third doctor to review her: the other doctors had assumed she was in a deep sleep and, despite a patch being applied, she did not regain consciousness before her death the

following morning. Whilst the lack of medication was found not to have been the cause of Jean's death, the lack of it will undoubtedly have reduced her motor function, restricting her ability to communicate independently.



**“ I am passionate that more teaching is given to nursing and medical staff of the importance of timely medication administration for people with Parkinson's to stop this happening to anyone else.”**

Joanna

# Policy context England, Scotland, Wales and Northern Ireland

## England

**The issue of time critical medications in hospitals fails to register on England's current health policy landscape, despite the severe risk to the health of a person with Parkinson's through not getting their medication on time.**

We believe this should be a high-priority patient safety issue. Not tackling this issue will hamper attempts to recover elective care services and cut waiting lists. As well as, increasing demand for social care services already under extreme pressure.

The National Institute for Health and Care Excellence (NICE) guidance says that when a person with Parkinson's is admitted to a hospital, their medication should be given at the appropriate times, which may mean people being allowed to self-administer their own medication<sup>16</sup>. NICE recommends that these medication timings should not be changed except

by or following discussion with a Parkinson's specialist. As mentioned earlier, levodopa-based medication must be given within 30 minutes of the prescribed time.

The NHS Patient Safety Strategy<sup>17</sup> aims to deliver continuous improvement in patient safety. However, this strategy does not mention the need for time critical medication management in hospitals. The Medication Safety Improvement Programme (MSIP) refers to getting medication on time in care homes, not hospitals. As a project for the future, MSIP recommends looking at - 'tackling drug omissions, specifically antibiotics, insulin and anti-parkinsonian drugs'; however, we are unaware of any steps to initiate this project.

Recent guidance from NHS England - 'Improving patient safety culture – a practical guide'<sup>18</sup> and the Getting It Right First Time programme - 'Six Steps to Better Care for Older People in Acute Hospitals'<sup>19</sup> are also missed opportunities to address this issue.

In 2021/22:



Emergency admissions for Parkinson's patients totaled **£267 million**<sup>7</sup>, comprising 86% of all admissions of people with Parkinson's.



The average (mean) length of stay for a person with Parkinson's admitted as an emergency in 2021/22 was 10.2 days.



The average cost of non-elective Parkinson's admissions was **£6,395**, compared to the England average of £4,842 per person.

Missed or delayed doses of Parkinson's medication can lead to increased morbidity, mortality, and length of stay, increasing the cost of care for hospitals<sup>15,20,21</sup>.

Over the last 18 months, a campaign launched by a group of health professionals who live with Parkinson's, the Professionals with Parkinson's group, has raised the profile of time critical medication across the UK. The group, led by emergency doctor Jonny Acheson and nurse Clare Addison, has written to every NHS trust/health board, encouraging them to pledge to take action on time critical medication in hospitals.

110 NHS organisations have pledged to take action and many are adopting recommendations developed by the Professionals with Parkinson's group, in collaboration with the Parkinson's Excellence Network (a network of health and social care professionals interested in improving the quality of Parkinson's health and care services). The recommendations list 10 steps NHS organisations can take to solve the issue of delayed and missed doses of Parkinson's medication in hospital.

The campaign has received support from the Chief Nursing Officers (CNOs) in each of the four nations. Dame Ruth May, Chief Nursing Officer in England, has written to all regional CNOs to take action locally and hosted a NHS England webinar on time critical medication for nurses, which over 500 health professionals attended. A similar webinar hosted by the NHS Specialist Pharmacy Service also saw around 500 health professionals attend.

We have also seen action taken by the Royal College of Emergency Medicine. The college is committing to a 3-year quality improvement

project on time critical medications (including Parkinson's). This commitment is welcome and much needed, as our analysis revealed that 47% of NHS trusts in England with an Accident and Emergency department (A&E) do not have a system for people with Parkinson's to get their medication on time while waiting in the A&E.

The analysis and recommendations in this report are for England. However, Parkinson's UK is actively influencing decision makers in Scotland, Wales and Northern Ireland. Here's what we're doing in the devolved countries to make sure that people with Parkinson's get their medication on time, every time, wherever they live in the UK.



**Number of people currently living with Parkinson's in the UK**

## Scotland

**There are about 12,900 people with Parkinson's in Scotland. In a typical year, about a quarter of them will be admitted to hospital at least once. Data from an NHS Scotland board shows that on a typical ward, fewer than half of all Parkinson's medicines are administered within 30 minutes of their prescribed time in hospital<sup>22</sup>.**

We estimate that more than 100,000 Parkinson's medications are given more than 30 minutes outside their prescribed time or missed each year in Scotland's hospitals<sup>23</sup>. Yet, only a handful of adverse incidents and complaints are reported, despite the harm that Parkinson's medication errors can cause.

Before the lockdown, Parkinson's campaigners met with the then Chief Pharmacist in Scotland to discuss the need for urgent change. Working with the Professionals with Parkinson's group, we met with Scotland's CNO in October 2022 and won their support for the Parkinson's pledge. The CNO also cascaded the group's ten recommendations for time critical medicine in hospital<sup>24</sup> to all lead nurses in Scotland.

In April 2023, we teamed up with the Scottish Ambulance Service, and launched a resource for ambulance crews to enable them to support people with Parkinson's to get their medication on time when they're going to hospital and during transfer. This has been even more important in light of recent pressures on ambulance response times and waiting times to admit people to A&E on arrival at hospital.

Despite some excellent initiatives by local Parkinson's specialist teams, the uptake of learning about Parkinson's medication by

general ward staff is still very low in Scotland. We continue to hear that while some people are supported to self-administer their medication while in hospital, many are denied the opportunity. Many boards do not have a supported policy in place.

We've been highlighting the potential of electronic prescribing - also known as Hospital Electronic Prescribing and Medicines Administration (HEPMA) - to improve time critical medicines delivery in hospitals. NHS Ayrshire and Arran has used its HEPMA data to continuously audit Parkinson's medicine administration times for many years. We are keen to see this intervention used in other NHS Scotland hospitals. HEPMA has been slow to roll out but it is now in 12 of 14 Health Boards in Scotland with the remaining two, NHS Fife and NHS Borders, expected to have HEPMA in place until 2024.

We will be publishing a new report in Autumn 2023, including full and updated information about what needs to happen for people in Scotland to get their medication on time, every time, in hospital.



## Wales

**Around 8,300 people in Wales live with Parkinson's. With population growth and ageing, we estimate this will increase to about 9,200 by 2030.**

In November 2022, the Welsh Government published its Quality Statement for Neurological Conditions<sup>25</sup>, which sets out what good quality services for neurological conditions should look like.

On 1 April 2023, the NHS Wales Executive was established to provide a new national support function to drive improvements in the quality and safety of care, and achieve better healthcare outcomes for the people of Wales. Part of the role of the NHS Wales Executive will be to scrutinise health board action against the Quality Statement for Neurological Conditions.

This backdrop provides clear opportunities to bring time critical Parkinson's medication to the attention of national policymakers.

We are working alongside NHS professionals in Wales to benchmark current practice around time critical medications in their organisations against

the recommendations made by the Professionals With Parkinson's group in collaboration with the Parkinson's Excellence Network. Through this benchmarking exercise, we will work collaboratively with NHS teams to identify opportunities for service improvement and play our part in making change happen.

We hope to open a conversation with Health Education and Improvement Wales about increasing awareness of time critical medications for people with Parkinson's and ensure that NHS learning resources that are needed to achieve improvement are widely available.

We are involved in innovative work at Swansea Bay University Health Board (SBUHB) to assess the effectiveness of e-prescribing in improving the timely administration of medication for people with Parkinson's. If successful, we will look to promote the introduction of this platform in other health boards across Wales.

In line with the principles of the Quality Statement for Neurological Conditions, we'll consider how we can most effectively work with NHS professionals to improve data collection and monitoring of time critical medication issues in Wales.

By working closely with Parkinson's UK colleagues and the Parkinson's Excellence Network, we'll look at improving the induction process for NHS Wales staff, so that there is greater awareness and understanding of the importance of time critical medication for people with Parkinson's and the tools available to support service improvement.

## Northern Ireland

**Around 4,200 people in Northern Ireland (NI) live with Parkinson's. With population growth and ageing, we estimate this will increase to around 4,580 by 2030. As of March 2023, 18,804 patients were waiting for a consultant-led neurology appointment in NI.**

The median wait time is 1 year and 26.6 weeks. While 1 in 20 patients have been waiting for over 5 years<sup>26</sup>. This is due to significant staff shortages and resources available for people with Parkinson's, as reflected in the Regional Review of Neurology Services<sup>27</sup>, which has been tasked with identifying the optimal service configuration for neurology services through to 2035. NI currently has 21 consultant neurologists, 3 of whom work part-time. This is less than half of the recommended 44<sup>28</sup>.

Political instability and lack of a NI Executive have made this a challenging policy context to work in. The Department of Health budget for 2023/24 } is around £470 million short of estimated funding requirements.

We will work with a dedicated contact within each trust to identify the steps and resources needed to ensure everyone with Parkinson's gets their medication on time.

We believe there is a need to introduce a regional NI self-administration of medication policy to

enable people with Parkinson's to take their own medication in hospital where it is safe to do so. We will continue our engagement with the Lead Pharmacist for Medication Safety and Chief Pharmaceutical and Nursing Officers for NI to help achieve this.

We want a Parkinson's specialist professional to be alerted when a person with Parkinson's is admitted to hospital as an inpatient. They will provide information about that person's medication management (including specific timings) and advise other healthcare professionals caring for the person with Parkinson's. We will work with decision-makers to ensure this happens.

We will also ask health and social care trusts to ensure training on Parkinson's is embedded in ward staff inductions.

We will continue to raise awareness of time critical medications with health and social care staff. This has already started with Parkinson's UK volunteer-led educators planning to deliver Parkinson's training to nursing and residential homes across Belfast in Q3 2023. We are also developing an awareness-raising campaign with the Parkinson's community around the importance of taking their medication on time.

There is an opportunity with the new Electronic Care Record (encompass<sup>29</sup>) in late 2023 to ensure that Parkinson's medication is flagged as time critical as part of the rollout.

It is crucial that there is a funded delivery plan and resources to support the implementation of recommendations made by the Review of Neurology Services report, including creating a sustainable workforce and that outpatient waiting times in neurology services are prioritised in waiting list initiatives.



## Self-administration of medication - empowering people with Parkinson's

**Many people with Parkinson's can and do take their own medication daily. We believe that people with Parkinson's who want to manage their own medication in hospital, if they are well enough, should be allowed to, provided they have been assessed as safe to do so.**

The NICE Quality Standard for Parkinson's states that people with Parkinson's admitted to hospital should be assessed for self-administration of medication<sup>10</sup>. NHS Specialist Pharmacy Service (SPS) says the benefits of self-administration schemes include:

- making care more person centred and improved patient satisfaction

- empowering people who can take their medication to do so where appropriate promotes independence and self-care in a safe place whilst reducing the risk of incorrect administration
- improved understanding of a person's own medication, improved adherence with their medication schedules, decreasing the chances of a future medication related admission
- helps people and their care partners to prepare for leaving hospital, helping decide what is needed by the person when they return home.

Our survey of people with Parkinson's found that 48% of people with the condition who are admitted to hospital want to manage and take their own medication<sup>4</sup>.



For people with Parkinson's to administer their medication themselves, the hospital needs to have a self-administration of medication policy in place. Self-administration policy documents set out the processes and safeguarding that must be followed to assess if a person can take their medication safely.

Our analysis of freedom of information requests of NHS hospital trusts in England found that:

- **1 in 4** NHS trusts in England do not enable people with Parkinson's to administer their own medication when admitted to hospital.
- **16%** of hospitals do not have a self-administration of medication policy.
- **12%** of NHS trusts with a self-administration of medication policy do not apply it to people with Parkinson's.
- Of the NHS trusts with a policy in place, only **56%** apply it to all inpatient hospital wards.

A policy alone will not allow people to take their own medication. Hospitals need the correct facilities (including lockable cupboards to store medicine) and trained staff to assess whether people with Parkinson's can take their own medication safely.

Our analysis of freedom of information requests shows that **17% of NHS trusts in England do not have the facilities and resources to enact their self-administration of medication policy.**

There needs to be a consistent policy across all hospitals and inpatient wards in England to enable all people with Parkinson's to take their own medication in hospital if they wish to and it is appropriate.



**I just wanted to be at home, where I was in control of my meds.”**

**Person with Parkinson's**

## Recommendation

1. NHS England should ensure all ICBs in England have a self-administration of medication policy and appropriate facilities in their hospitals to enable people with Parkinson's who can and are safe to take their own medication in hospital.
  - › NHS England and partners should develop a nationally agreed self-administration of medication policy template and supply this to ICBs to adapt for their hospitals.
  - › NHS trusts should monitor the implementation of the self-administration of medication policy template and ensure that the policy is reviewed every 2 years.



## E-prescribing - assist, monitor and report

**Despite the devastating consequences, there is no requirement for NHS hospital trusts in England to record, monitor or publish data on missed or delayed doses of Parkinson's medication in their hospital. The only data we have is collected by Parkinson's UK, not the NHS.**

Without this data, trusts cannot identify the issue, know the scale of the problem or track progress in tackling it. Without this data, regulators and NHS managers can't act.

### How e-prescribing can help

Electronic prescribing and medicines administration systems (referred to here as e-prescribing systems) are digital systems to

replace paper based systems for managing the prescribing and administration of medications in hospitals.

We believe e-prescribing systems support health professionals in delivering Parkinson's medication on time by identifying people with Parkinson's in their ward and indicating when their medication is due. It also holds huge potential to record and report missed or delayed doses of Parkinson's medication.

NICE recommends that Parkinson's levodopa-based medication is administered within 30 minutes of the prescribed time. Where e-prescribing systems have the functionality to record medication administration at half-hour intervals, it is possible to determine if a person's medication was delayed, missed or given on time.

## Can NHS electronic systems be used to improve Parkinson's medication administration?

A project lead by Nick Bryden, a Parkinson's Nurse in NHS Ayrshire and Arran, using e-prescribing to improve timely administration of Parkinson's medication in hospital shows that not only is it possible, but it also leads to better patient outcomes and shorter lengths of stay in hospital.

Hospital admissions can fill people with Parkinson's with fear and anxiety over not "getting my medication on time" and "they didn't have my medication".

The underlying problem was that Parkinson's professionals were not informed by ward staff or families when their patients had been admitted to hospital. They learnt of the admission within a few days, several weeks or not at all. They tried promoting their service by visiting wards, but unfortunately, they found that staff were "busy" and some did not engage. They could also only speak to the staff on the ward that day. Knowledge of Parkinson's was highly variable. This was not restricted to nursing staff but all disciplines within ward areas.

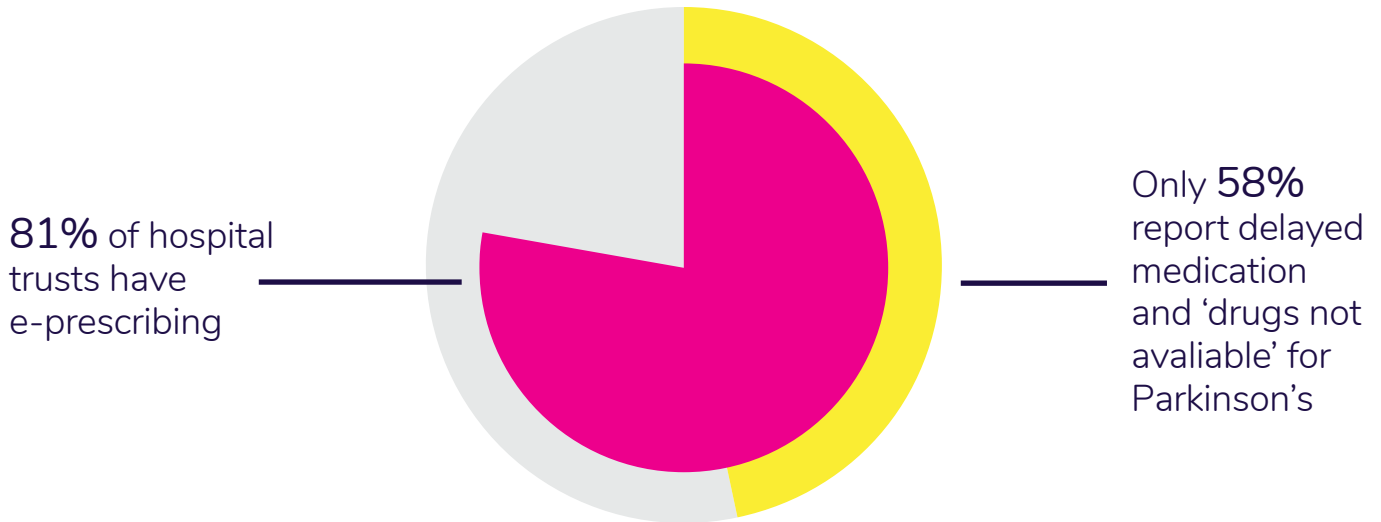
Nick, working in collaboration with Richard Cottrell, Principal Pharmacist Digital Health and Electronic Prescribing and Michelle McLuckie, Head of Systems in Digital Services identified electronic prescribing as a system that could produce a daily report that would alert them when a person with Parkinson's had been admitted to hospital and also audit all administration of

Parkinson's medication every month. The reports meant that patients were identified within 24 hours of admission to hospital. It enabled monitoring of prescribing practice and timely administration of all Parkinson's medication over the previous 24 hours. Wards not administering medication on time could be quickly identified and offered support.

Since beginning the initiative there have been clear improvements in both the proportion of timely administrations given, overall reduction in time between scheduled and administered time of medications, improved patient satisfaction, increased staff education and more effective working.

- Up to 87% of people with Parkinson in targeted wards now receive time critical medications on time or within 30 minutes (in line with NICE guidance). Before the system was introduced in 2018, rates were consistently below 50%.
- 64.7% of people with Parkinson's have received medication on time board-wide in the last 12 months.
- Patient feedback confirms satisfaction and confidence in staff during hospital admissions.

Nick's fantastic work has been recognised though being shortlisted for a 2023 Nursing Times award for use of technology and data in nursing<sup>31</sup>. Demonstrating the huge value of Nick and his colleague's solutions to the care of people with Parkinson's.



Our analysis shows that many hospitals have the e-prescribing systems in place with functionality that could improve inpatient medication management for people with Parkinson's who are admitted to hospital:

- **81%** of hospital trusts have e-prescribing.
- **96%** of those that do have e-prescribing can use it to record when medication is administered at 30 minute intervals.
- **79%** can alert hospital ward staff when medication is due.
- **79%** can alert hospital ward staff when a patient's medication is late.

However:

- only **37%** can alert hospital ward staff to patients needing time critical medication.
- and only **58%** use an e-prescribing system to regularly run reports of delayed medication doses and 'drugs not available' for Parkinson's medication.

The NHS needs to go much further, and faster. We believe it must harness the full potential for e-prescribing systems to help ensure people with Parkinson's can get their medication on time in hospital no matter where they live. It is also vital that this data is made publicly available so that decision-makers can be held accountable and inform public policy on patient safety.

## Recommendations

2. **NHS England** should boost the roll out of e-prescribing across all NHS trusts to harness its potential for improving the performance of hospitals to deliver Parkinson's medication on time to people with the condition who are inpatients.
3. **NHS England** should use e-prescribing to monitor and track progress of missed or delayed doses of Parkinson's medication at the NHS trust, ICB and national levels.
  - › In 2023/24 pilot monitoring of this data using the sites where e-prescribing has been rolled out.
  - › In 2024/25, implement a national rollout and publish these figures through NHS Digital as a data set at NHS trust, ICB and national levels.

# Training - understand and act

Health professionals need to understand the importance of people with Parkinson's getting their medication on time to control symptoms, especially for staff responsible for prescribing or administering medication in hospital inpatient wards.

That's why we are concerned that training on time critical medication is mandatory for just 37% of NHS trusts in England for this staff group.

Our analysis found that:

- Only around **half (52%)** of NHS trusts in England require inpatient hospital ward clinical staff to complete training on time critical medications (including Parkinson's).
- Only **40%** of NHS trusts in England make it mandatory for inpatient hospital ward clinical staff with responsibilities for prescribing or administering medication to complete training on time critical medications (including Parkinson's medication).
- Of trusts that require staff to complete training only **16%** repeat it annually, **15%** every 2 years, and **18%** every 3 years. **34%** of trusts only require staff to do the training once or at induction. **16%** did not know if the training was repeated.

Evidence shows improved outcomes for people with Parkinson's where training on medication management is implemented<sup>31</sup>.

## Derby Parkinson's Service training ward staff on Parkinson's and medication management

The Derby Parkinson's Service wanted to understand the impact of suboptimal management of Parkinson's medication in hospital, by introducing an in-patient Parkinson's unit for those emergency admissions of people with the condition with general medical problems. To assess the unit's impact they looked at the data on medication management, length of stay in hospital and patient experience.

The unit was led by staff from the Derby Parkinson's Service, ensuring readily available Parkinson's drugs, guidelines and support for ward staff. Four mandatory 1-hour sessions on Parkinson's symptoms, medications, therapy, communication and swallowing were provided to all staff on the ward.

Using an electronic prescribing and administration system they were able to retrieve accurate data on times of administration, so they could compare outcomes before and after introduction of the unit.

This saw missed medication fall on the ward from 20% to 13% and more medication was given on time rising from 50% to 64%<sup>32</sup>. The median length of stay decreased from 13 days to 9 days. Patients reported an improved experience of care.

We strongly believe that a step change is needed in the number of healthcare professionals trained in Parkinson's medication management if we are to get a grip on this issue.

“

I was so upset by the lack of care and understanding that I called my family and tried to self discharge from the hospital”.

Person with Parkinson's

## Recommendations

4. **NHS England** should ensure every hospital trust in England implements training on time critical medications, including Parkinson's medication.
  - › **NHS trusts** should ensure all hospital staff watch the 3-minute video by NHS Leicester Hospital Trust and Surrey and Sussex NHS Trust and record on staff Learning & Development records for audit purposes.
  - › **NHS trusts** should require hospital ward staff who provide care for people with Parkinson's should complete either Parkinson's UK's 15-minute guided presentation on medication management or watch the Lancashire NHS Trust's 60-minute video every 3 years and record on staff learning & development records for audit purposes.

# What can be done locally to ensure people with Parkinson's get their medication on time every time?

The Professionals with Parkinson's group, in collaboration with the Parkinson's Excellence Network, have developed 10 recommendations<sup>33</sup> to support health professionals in implementing time critical medication management in their hospitals.

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## Time critical medications - Ten recommendations for your hospital

1. Parkinson's medication is time critical medication. Time critical medications must be given within 30 minutes of when they are due, highlighted as a risk to patient safety and added to every hospital risk register. Compliance is audited and any dose over 30 minutes reported as an adverse event.
  - a. [Parkinson's UK 15 minute Educational Video](#)
  - b. [Parkinson's UK Medication Educational Module produced by Lancashire Teaching Hospitals](#)
  - c. [Parkinson's medication for staff who don't administer medications](#)

[2019 Get It On Time report](#)  
[NICE quality statement](#)
2. All staff within hospitals are made aware of time critical medication. Make this 3 minute video [Time Matters : It's Critical](#) mandatory viewing for all staff.
3. Hospitals identify which staff are to undertake further Parkinson's medication training. Recommended online training courses are available in the Parkinson's Excellence Network's learning hub:
4. Hospitals develop, maintain and update a self-administration policy for those patients who can administer their own medication. The Policy should be reviewed regularly. [See NHS Guidance](#).  
[NHS Specialist Pharmacy Service](#).
5. Hospitals identify all patients on Time Critical Medication when they arrive in the Emergency Department (ED) or through an elective or emergency admissions unit.

6. EDs and admissions units develop and update an agreed list of Time Critical Medication visible to patients when they arrive so they feel empowered to inform staff that they take Time Critical Medication. For elective admissions, people with Parkinson's will have prepared themselves. Using the [Parkinson's UK Guidance](#).
7. Hospitals have a designated pharmacist who is responsible for ordering and stocking the Time Critical Medications in the ED and on appropriate admissions units and wards to ensure they are always available.
8. Where appropriate the prescribing of a patient's Time Critical Medication should reflect their normal daily schedule and should continue during the full admission period. Hospital systems, including electronic prescribing where available, should be maximised to support this.
9. Ensure that hospitals have a Standard Operating Procedure / guideline for all Time Critical Medication, including those patients who are nil by mouth (NBM) or require a nasogastric (NG) tube. This should signpost to one of the [NBM medication calculators](#).
10. Ensure hospitals devise and implement a system so that staff can administer all Time Critical Medications outside of the normal medication rounds if self-administration is not appropriate. See a [successful example from Leeds Hospitals](#) and [resources available from Parkinson's UK](#).

These recommendations have been developed by the Professionals with Parkinson's group in collaboration with the Parkinson's Excellence Network to support healthcare professionals in implementing time critical medication management.

See PDF versions for [England](#), [Scotland](#), [Northern Ireland](#) and [Wales](#) for contact information.





The recommendations are clear, tangible and deliverable measures that will help embed sustainable change to enable people with Parkinson's to get their medication on time every time.

The group have contacted NHS trusts and bodies across the UK, with 110 pledging to take action on time critical medication in their hospitals. We plan to benchmark their progress against these 10 recommendations and will follow up with them to offer targeted support to help improve the timely administration of Parkinson's medications in their hospitals.

NHS England's Patient Safety Incident Response Framework supporting guidance<sup>34</sup> states ICBs should appoint a lead for patient safety. Timely administration of Parkinson's medication in hospitals is a major patient safety concern. We believe ICBs have a role to coordinate action across trusts to tackle this issue and spread good practice.

## Recommendations

5. **NHS trusts in England** should make the changes outlined in 'Time critical medication, on time, every time. Ten recommendations for your hospital' and benchmark progress made against each recommendation.
6. Each ICB lead on patient safety should ensure all NHS trusts in their area implement the recommendations outlined in 'Time critical medication, on time, every time. Ten recommendations for your hospital' and benchmark progress made against each recommendation.

# Appendices

## Appendix 1 - Freedom of information request questions sent to all NHS hospital trusts in England (May 2023)

### Self-administration of medication policies

1. Does your hospital have a self-administration of medication policy? Y/N. If yes:

a) Does it enable all people with Parkinson's admitted to the hospital to be assessed to administer their own medication should they wish to do so?

b) Does your hospital have the necessary resources (e.g. lockable cupboards, staff training) to enact the self-administration of medication policy?

c) How many inpatient wards/departments is the self-administration of medication policy operational in out of the total number of inpatient wards/departments?

### Training

2. Do you require inpatient hospital ward clinical staff who prescribe or administer medicine to complete training on medication management in Parkinson's? Y/N. If yes:

a) Is this training mandatory for staff who prescribe or administer medicine ?

b) Please specify the name of this training and course provider?

c) What percentage of staff who prescribe or administer medicine have completed this training?

d) Which types of clinician are required to complete this training?

e) How often do you require staff who prescribe or administer medicine to repeat this training?

3. Do you require inpatient hospital ward clinical staff to complete training on time critical or time sensitive medications (including Parkinson's medication)? Y/N. If yes:

a) Is this training mandatory for staff who prescribe or administer medicine?

b) Please specify the name of this training and course provider?

c) What percentage of staff who prescribe or administer medicine have completed this training?

d) Which types of clinician are required to complete this training?

e) How often do you require staff who prescribe or administer medicine to repeat this training?

### E-prescribing

4. Does your hospital have e-prescribing? Y/N. If yes:

a) Does it have the functionality to record when medication was administered in 30 minute intervals over a 24 hour period?

b) Does it have the functionality to alert hospital ward staff when a patient's medication is due to be administered?

c) Does it have the functionality to alert hospital ward staff when a patient's medication is late in being administered?

d) Does your hospital have an electronic alert system to identify patients requiring time critical medication? If yes, please list the health conditions included as requiring time critical medication?

e) Does your hospital use an e-prescribing system to regularly run reports of delayed medication doses and 'drugs not available' for Parkinson's medication?

#### **Other**

5. Are Parkinson's medications available to clinical staff 24 hours a day, 7 days a week? (E.g. is this medication stocked in an emergency medicines cabinet?)

6. Do you have a system in place to ensure people with Parkinson's get their medication on time while waiting to be seen in the accident and emergency department?

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