



To stop their condition getting out of control, people with Parkinson's need their medication on time – every time

Ideas for action: healthcare professionals

The Parkinson's Disease Society's (PDS) 'Get it on time' campaign aims to ensure all people with Parkinson's in hospitals get their medication on time – every time. When they don't their Parkinson's symptoms become uncontrolled and they become very ill. This can lead to unnecessary extended hospital stays, using up vital resources.

Whether you are a hospital pharmacist, doctor or nurse, this good practice guide will help you to help people with Parkinson's to get their medication on time – every time.

We want...

- all staff working in hospitals and care homes to have a better understanding of Parkinson's and why the timing of drugs is so crucial
- hospital and care home staff to listen to people with Parkinson's, their carers and families
- hospital pharmacies to make sure they always stock a broad range of Parkinson's medication which is also easily accessible
- people with Parkinson's to have the option to self-medicate, (control their own medication) if they are able to
- people with Parkinson's to have their medication on time

What the experts say:

Deputy Chief Pharmacist

"The support and advice of local people with Parkinson's has been essential to developing an effective medicines management scheme from admission to discharge."

Stephen Cook
Hinchingbrooke Hospital

Consultant Neurologist

"People with Parkinson's have varying needs and require their medication at individually prescribed times at a number of points in the day. It is essential this flexibility is allowed in hospital."

Dr Ray Chaudhuri
King's College Hospital

Consultant Geriatrician

"Unfortunately we still see Parkinson's patients coming into hospital and not getting the correct medications at the correct times, as they would at home. There is still a lack of knowledge in this area among medical staff."

Dr Belinda Kessel
Princess Royal University Hospital

Parkinson's Disease Nurse Specialist (PDNS)

"Medication is an important part of patients' lives; and one they're getting increasingly vocal about."

Liz Morgan
Rookwood Hospital

Why on time – every time?

If a person with Parkinson's is unable to take their prescribed medication at the right time, the balance of chemicals in their bodies can be severely disrupted – and this will lead to their Parkinson's symptoms becoming uncontrolled.

With an uneven release of dopamine, a person may suddenly be unable to move, get out of bed or walk down the corridor. Other problems can occur too – sleep can become disturbed, bowel and kidney function and digestion can be affected. Hallucinations and mood swings can also be triggered.

What is Parkinson's?

Parkinson's disease is a progressive, fluctuating neurological disorder. It occurs when the cells in the part of the brain that controls movement are lost.

These cells produce dopamine, a chemical that enables people to perform smooth co-ordinated movements. Without enough dopamine in the brain, everyday activities including walking, swallowing and even smiling are affected.

Parkinson's and medication

The main treatment for Parkinson's is medication and there are specific drugs which work by replacing or mimicking the actions of dopamine. Often people will be on a number of drugs, each of which must be taken throughout the day at specific times. These stimulate a carefully-timed release of chemicals into the brain to allow a person with Parkinson's to control their movement.

The symptoms and progression of Parkinson's is unique to each individual. It may have taken a long time for the patient and specialist to establish the best individualised drug regimen.

Impact on patient care

Once a medication regimen is disrupted it may take hours, days, or even weeks for a person's Parkinson's to stabilise. This can have serious consequences for ward management and the treatment for which the person was originally admitted.

The patient is likely to require a higher level of care and an extended hospital stay, at a significant cost in both time and resources. There is an increased risk of accidents and falls, and in some cases the originally planned treatment may no longer be possible. The patient may also feel a loss of dignity and independence, as well as the ability to communicate and exercise choice in their care.

The National Institute for Health and Clinical Excellence (NICE) guideline on the management of Parkinson's disease (June 2006) stated:

- *Anti-parkinsonian medication should not be withdrawn abruptly or allowed to fail suddenly due to poor absorption (for example gastroenteritis, abdominal surgery) to avoid the potential for acute akinesia or neuroleptic malignant syndrome.*
- *In view of the risks of sudden changes in anti-parkinsonian medication, people with PD who are admitted to hospital or care homes should have their medication:*
 - *given at the appropriate times, which in some cases may mean allowing self-medication*
 - *adjusted by, or adjusted only after discussion with, a specialist in the management of Parkinson's disease.*

A checklist of standards relating to the medicines management of people with Parkinson's in hospitals in England and Scotland is available from the PDS.

This is a guide to actions you can take to ensure people with Parkinson's get their medication on time, every time in hospitals.

Dealing with emergencies

A number of hospitals have set up systems to promote good practice when people with Parkinson's are admitted to hospital in an emergency.

Dr Belinda Kessel, Elderly Medicine Physician with a special interest in Parkinson's disease, at Bromley's Princess Royal University Hospital, has been working with the local PDNS to devise a set of emergency guidelines for when people with Parkinson's are admitted.

These are available for all staff on the hospital's computer system and can be printed off and incorporated into the patient's notes.

The guidelines summarise the range of Parkinson's drugs available with their brand and generic name and dosages, where to get them out of hours, and alternative drugs that can be used in an emergency. They also advise on drugs for common medical complaints to avoid inappropriate prescribing of contra-indicated drugs.

In addition, the Chief Pharmacist at the hospital has developed a system to encourage patients going into hospital by ambulance to take all their drugs with them. This is particularly useful for people with Parkinson's who may be on medication that is not immediately available on all wards.



Elderly Medicine Physician

"Unfortunately we still see Parkinson's patients coming into hospital and not getting the correct medications and at the correct times, as they would at home. There is still a lack of knowledge in this area by medical staff and these guidelines are there to aid them when specialists are not available to give advice."

*Dr Belinda Kessel
Princess Royal University Hospital*



Before a patient is admitted

For planned admissions encourage people with Parkinson's to bring with them to hospital:

- a list of their medications with their dosage and timings
- their own medication in its original packaging.

If there is a PDNS assigned to the hospital it is a good idea to contact them in advance.

At Southend Hospital, PDNSs Sue Freeman and Maggie Stannard conduct an eight-week patient education course twice a year. This covers all aspects of Parkinson's, including the importance of medicines management. The course involves sessions run by physiotherapists, occupational therapists, and speech and language therapists, as well as local PDS branch members.

Sue and Maggie make sure they repeat the importance of medication timings at all patient consultations and encourage people with Parkinson's and their carers to let them know in advance of any planned hospital admissions.

PDNS

"One of the key things we stress to people with Parkinson's and their carers is that the onus is really on them to tell us about any planned hospital stays. We then remind staff on the relevant wards about how important it is going to be for these patients to get their medication on time."



*Sue Freeman
Southend Hospital*

Alerting staff that a patient has Parkinson's

To minimise the risk of medication-related incidents involving people with Parkinson's, all members of the multi-disciplinary team should be alerted that a patient has the condition.



PDNS

"Now there's no excuse for staff not to know about a patients' Parkinson's because it's on the intranet."

*Anne Martin
Bromley NHS Trust*

Anne Martin, a PDNS at Bromley NHS Trust, has introduced a system on the Trust's intranet which flags up all people with Parkinson's. When the patient is admitted, staff can see from the icon that they have Parkinson's. Clicking on the icon leads to guidelines for how to deal with patients with Parkinson's admitted in an emergency.

Anne said: "Patients with Parkinson's were experiencing problems resulting from not getting their drugs on time; or not getting them at all. Because there was no system for highlighting patients with the condition, they could go 24 or 48 hours before I knew they were there and was able to alert other staff to their needs."

In other hospitals across the UK, staff have been using 'Get it on time' campaign materials to inform colleagues that a patient has Parkinson's and that medication timings are important. Actions include attaching campaign stickers or posters to patient notes.

Parkinson's and professional development

Four out of five PDNSs surveyed by the PDS felt there was a lack of understanding about Parkinson's medication. Raising awareness among ward staff about Parkinson's can be challenging. Here are some examples of how it can be done:

In Northern Ireland so far, 168 nurses have been taught the importance of medicines management in a joint PDS and Royal College of Nursing project. The PDS-funded project has to date included a series of workshops to teach nursing staff about Parkinson's, whether they work in hospitals, people's homes, GP surgeries, hospices or nursing homes.

The project will continue for the next two years, building up a network of nurses across the region who have an interest in Parkinson's, and can drive forward the measures needed to create a first-class service.



Head of Professional Development, RCN

"Many nurses are likely to care for someone with Parkinson's disease at some stage in their career. It is absolutely crucial that nurses understand the effects of the condition on people who have it, and their families.

We are delighted that there has been such a high level of interest in our workshops and we hope to continue working with the Parkinson's Disease Society to make sure that nurses in Northern Ireland provide the very best care possible."

*Dr Carolyn Mason
RCN Northern Ireland Board*



Alison Monaghan, PDNS at Greasby Clinic in the Wirral, has been working closely with Paula Morgan, Hospital Pharmacist at Wirral NHS Trust, to improve care for people with Parkinson's when they are admitted to hospital. To date, work has included a programme of training sessions to educate staff about Parkinson's and medication and how to use the apomorphine pump. Teaching and information packs have been distributed to all wards, along with a list of useful contact numbers for healthcare professionals, patients and carers.



PDNS

"Raising the awareness of hospital staff to the importance of medication timing for people with Parkinson's was a real challenge. But by working closely with Paula the Hospital Pharmacist, we have really been able to spread the message throughout the hospital."

*Alison Monaghan (left)
Greasby Clinic, Wirral*



Supporting self-administration

Many people with Parkinson's are experts in their own condition. Allowing people to self-administer their medication in hospital can help ensure Parkinson's symptoms are kept under control, enable the individual to maintain their independence, and save staff time.

A number of hospitals around the UK have introduced lockable bedside cabinets onto wards and patients are given keys. This enables them to take their medication at the right time for them.

At Hinchingsbrooke Hospital the Deputy Chief Pharmacist, Stephen Cook, has developed a system for self-administration. Initially piloted for patients admitted to a speciality Parkinson's ward, the scheme has recently been extended to elective surgical wards and a number of other medical wards.

At a medical assessment, prior to admission, patients and carers are given a leaflet explaining what self-administration would involve.

People with Parkinson's wishing to take responsibility for administering their own medicines, either alone or with their carer, are then assessed on admission.

The assessment criteria includes: familiarity with drug names, doses and timings, and both physical and mental ability to take their own medicines.

If the patient or carer fulfils the assessment criteria, they are given a pack containing a dosette box and their medication so that they can take doses in accordance with their defined schedule. Ward staff regularly check the patient's competency to self-administer and that the drug charts have been completed correctly.



Deputy Chief Pharmacist

"Hinchingsbrooke Hospital has developed a very effective medicines management scheme for patients with Parkinson's disease from the point of admission through to discharge. The support and advice from local people with Parkinson's has been essential in its development and is key to its continued success."

*Stephen Cook
Hinchingsbrooke Hospital*



A helpful reminder to give drugs on time

When a patient is not able to self-administer, healthcare professionals can use pill timers or alarm clocks to alert them when a patient's Parkinson's medication is due.

The Scarborough branch of the PDS has bought 25 pill timers for ward staff at Scarborough Hospital to use to remind them of patients' medication timings.

Lynette Bayes, Staff Nurse with a special interest in Parkinson's at Scarborough Hospital, said: "The pill timers are set according to the individual drug regimen of the patient and bleep when a dose is due. Now nurses have no excuse for not giving medication on time.

"Now we have access to pill timers, both patients and staff feel much more relaxed about medication timing."

At Rookwood Hospital in Cardiff, nurses have started to use alarm clocks as a reminder that Parkinson's patients have individual medication requirements.



PDNS

"We're trying to promote ourselves as an area of high standards and I've had very positive patient feedback so far. Medication is an important part of patients' lives and one they're getting increasingly vocal about."

*Liz Morgan
Rookwood Hospital*



Audit services for improvement

Assessing the availability of Parkinson's drugs throughout the hospital is a vital first step to ensuring patients get the right drugs at the right time.

The full range of Parkinson's medication in all formulations and preparations is not likely to be stocked on every ward. So it is vital healthcare professionals know where they can obtain the right medication – and how to get it out of normal hospital pharmacy hours. An audit of prescription and administration practices can help identify any difficulties.

Auditing the experiences of patients who have Parkinson's and their carers after a stay in hospital can also help identify issues that pose challenges to effective ward management and patient care.

Dr Rachel Bradley, Specialist Registrar in General and Geriatric medicine at the Royal United Hospital in Bath, conducted an audit to identify how Parkinson's medication was being managed in an acute hospital setting. She performed a retrospective review of prescribing and administration practice using patients' medication charts, followed by interviews with patients to get their views on how their medication had been managed while in hospital.

The audit identified issues with:

- the availability of Parkinson's medication on some wards and at certain times of the day
- medication timings being left off patients' drug charts
- nursing staff forgetting to administer medication on time.

Together with the consultant geriatrician, senior pharmacist and PDNS, Dr Bradley used the audit results to formulate a plan to improve the handling of Parkinson's medication in the hospital. The findings were presented to local medical, nursing and pharmacy staff, and at regional and national meetings. Results were also presented as a poster at the Royal College of Physicians conference on multi-disciplinary care in Parkinson's disease and Parkinsonism in July 2006, and at the British Geriatric Society's autumn meeting in October 2006.

The audit and action plan led to:

- a wider range of Parkinson's medication being stocked and accessible 24 hours a day
- guidelines being drawn up to advise doctors on alternative drug preparations for patients with difficulties swallowing
- teaching sessions for a wide range of hospital staff to highlight the importance of medication timing for patients with Parkinson's and how they can access further information
- the development of a self-administration policy.



Specialist Registrar

"The audit helped us first identify and then tackle the sort of issues that were going wrong when people with Parkinson's were admitted to the hospital. It has been an important driver for change and has helped improve standards of patient care and staff awareness."

*Dr Rachel Bradley
Royal United Hospital*



Patient-centred care: above all, just listen

People with Parkinson's and their carers are experts in their condition and have been managing their treatment successfully at home for years. Asking about their normal medication regimen and listening when they say they need their medication can help avoid unnecessary complications and prolonged hospital stays.

"Not only did I not get my pills on time, I was put on a completely different set of Parkinson's drugs than I normally take. It has taken me and my specialist years to find the right drugs and doses for me. I don't see why this had to change when I went into hospital with a leg infection."
Ray

"The hospital doctor decided to take my Grandad off his Parkinson's medication for 24 hours 'so he could assess him better' - (he had gone in with a broken backbone!). Luckily we found out the next morning and fought to reverse this decision, although the side effects had already begun to kick in."
Alison

Actions to take in your hospital:

- introduce a system of alerting the local PDNS (if there is one) every time a person with Parkinson's is admitted
- highlight to all staff that the patient has Parkinson's as soon as they are admitted by introducing an electronic flagging system or using 'Get it on time' stickers or information sheets in patients' files
- use pill timers or alarm clocks on the ward to remind staff about patients whose medication is due at different times to the standard drug rounds
- introduce a self-administration policy for patients with Parkinson's
- audit the availability of Parkinson's drugs in your hospital, and the experiences of patients and their carers when they go into hospitals
- tell your colleagues about 'Get it on time' and how important the timing of Parkinson's medication is
- organise a training session on Parkinson's and medication
- raise awareness of the campaign by putting up 'Get it on time' posters
- talk to local people with Parkinson's about their experiences and needs

Further information for professionals

- Medication card
- 'Hospital stays: information for professionals' sheet
- 'When your patient has Parkinson's' booklet
- 'Get it on time' materials including posters, leaflets and stickers

All available by contacting the PDS:

Tel: 020 7963 9370

Email: pr@parkinsons.org.uk

The Parkinson's Disease Society of the United Kingdom

The PDS is the UK's leading authority on all aspects of the condition. The charity campaigns for a better quality of life for people with Parkinson's and leads the way in research into the cause, cure and treatment of Parkinson's. The PDS also provides information, local support staff and maintains over 300 branches and support groups across the UK.

For further information please contact:

Free helpline: 0808 800 0303

www.parkinsons.org.uk

Sharing good practice

We hope this information gets you started, or reinforces the care you already give, to ensure people with Parkinson's get their medication on time. We would love to hear how 'Get it on time' is making a difference in your hospital.

Please contact the campaigns team:

Tel: 020 7932 1325

Email: campaigns@parkinsons.org.uk



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