



Parkinson's
Disease Society

get it
on time

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

'Get it on time' campaign

The Parkinson's Disease Society's (PDS) 'Get it on time' campaign aims to make sure that people with Parkinson's in hospitals and care homes 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.

Mr Jones

When Mr Jones went into hospital for a hernia operation he explained the importance of getting his prescribed Parkinson's medication on time to ward staff and was reassured that he would not face any problems.

He was expecting to stay in hospital for two days. He was in for a fortnight.

Late and missed doses of his Parkinson's medication resulted in hallucinations at night and it was only when his well-established drug regime was reinstated and kept to, that Mr Jones was well enough to go home.

Because Mr Jones didn't get his medication on time, a routine hospital stay turned, quite literally, into a nightmare.

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 complex, carefully timed release of chemicals in the brain and as a result allow a person with Parkinson's to control their movement.



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 becoming uncontrolled.

With an uneven release of dopamine, a person may suddenly not be able 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 and mood swings can also be triggered.

Once this balance of chemicals has been upset it may take hours, days or even weeks for a person's Parkinson's to stabilise, enabling them to get on with life again.

When circumstances change

Because people with Parkinson's and their carers are so aware of the importance of taking medication on time, their drug regime is easily managed when they are at home or at work. However, if they are admitted to a hospital or care home it can be difficult to maintain the timing of their drugs.

If you know anyone with Parkinson's, tell them about the 'Get it on time' campaign and encourage them to contact the PDS to find out more.

Help spread the word and put up a 'Get it on time' poster.

The current situation

There is no single reason why people with Parkinson's don't get their medication on time in hospitals and care homes. It may be that staff don't understand the condition and how important it is to stick to a prescribed drug regime. Or maybe the hospital has inflexible drug rounds on the ward.

It varies from hospital to hospital. In a small-scale study, 19 out of 20 Parkinson's patients who went into hospital as a planned admission had problems getting medication on time. The only person who had no difficulties was in charge of his own drugs.

In a different hospital, 70% of people with Parkinson's admitted as an emergency case had a substantial delay in receiving their first dose of Parkinson's medication. Some patients experienced a wait of up to 62 hours (over two-and-a-half days) before receiving their Parkinson's medication.

The Department of Health has set standards on medicines management and it is unclear how many hospitals are actually meeting these. People with Parkinson's deserve better.

If you work in a hospital...

Tell your colleagues about 'Get it on time' and how important the timing of Parkinson's medication is.

If you are the Chief Executive of a hospital then you are responsible for implementing a plan for medicines management - is there one in your hospital? And is it working?

Hospital pharmacies should have an accessible stock of Parkinson's medication - does yours?

If you have Parkinson's...

Contact your Parkinson's Disease Nurse Specialist (if you have one) in advance of a hospital stay and ask them to explain your drug regime to the ward staff.

Don't give up if you wish to self-medicate and are not allowed to - keep talking to the nurses and doctors and consider asking your consultant or GP to support you.

"It didn't seem to me that the fact I had Parkinson's was ever passed on between ward staff. I had to explain things every time a shift changed." Graham, 45

"The nurse didn't understand how I could be fine one minute and not able to move the next. They didn't make the link that I needed my drugs." Rajeev, 70

"A nurse witnessed me 'freezing' in the corridor. I had seized up and was completely unable to move. She was horrified. She thought I'd had a heart attack." Eileen, 54

The way forward...

By listening to patients and their carers, a few hospitals are gradually realising the importance of people with Parkinson's getting their medication on time. For example, pill timers have been bought by some hospital trusts for their patients with Parkinson's. Nurses carry the timers and, when the alarm sounds, they know it is time for a patient's medication.

A number of people with Parkinson's have been able to self-medicate when they are in hospital, using lockable bedside cabinets – a practical, safe way of allowing this to happen.

One hospital has highlighted all the people with Parkinson's in their area on their patient computer database, so that if they are admitted as an emergency, the staff know immediately to check that the pharmacy has an adequate stock of Parkinson's medication.

What the Department of Health says should happen

- Within 24 hours of being admitted to hospital patients need to have a complete medication review. The PDS knows that for people with Parkinson's this must happen as soon as possible.
- Patients' own medication should be used after the review if this has been considered suitable. At this point patients to be given the opportunity to self administer (if appropriate).
- All staff training programmes, including inductions for agency and locum staff, must contain information about medicines management.

"I had a miserable stay in hospital three years ago because I was unable to self-medicate. Things had to change – so I kicked up a fuss and wrote numerous letters. I was really pleased that the next time I was in hospital, secure drugs lockers and understanding staff meant I got my Parkinson's medication on time."

The Parkinson's Disease Society

The Parkinson's Disease Society is the UK's leading charity dedicated to supporting everyone affected by Parkinson's. We campaign for a better quality of life for people with Parkinson's and provide expert information on all aspects of living with the condition. We are the 11th biggest funder of medical research in the UK and have invested £35million in research into the cause, cure and treatment of Parkinson's since 1969. The PDS also provides information, local support staff and maintains over 330 branches and support groups across the UK. We are almost entirely funded by voluntary donations.

For further information please contact:
Free Helpline: 0808 800 0303 Textphone: 0207 233 5373
(The Helpline is a confidential service. Calls are free from UK landlines and some mobile networks)
www.parkinsons.org.uk



The Parkinson's Disease Society
of the United Kingdom
215 Vauxhall Bridge Road
London SW1V 1EJ
Telephone: 020 7931 8080

Charity registered in England and Wales No. 258197
and in Scotland No. SC037554
A company limited by guarantee
Registered No. 948776 (London)
Registered office as above.