Parkinson's Disease Society

Secondary Care and Medication: Involving the User

The experience of people with Parkinson's disease in hospital

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Background

The 2000 NHS Plan puts the patient at the centre of clinical care and says that: '*the NHS of the 21st century must be responsive to the needs of different groups and individuals within society... [and] will treat patients as individuals, with respect for their dignity. Patients and citizens will have a greater say in the NHS, and the provision of services will be centred on patients' needs.*'[1]

In the summer of 2002 the Parkinson's Disease Society (PDS) commissioned a survey to assess the standards of care that patients with Parkinson's disease received in hospitals two years after the publication of the NHS Plan. The survey interviewed 256 people with Parkinson's who had experienced care in hospital throughout the UK.

Parkinson's is a progressive, neurological disorder affecting learned voluntary movements such as walking, talking, writing and swallowing. There are three main symptoms: tremor, rigidity and slowness of movement, many go on to develop postural instability. However, not everyone will experience all three. Parkinson's results from the loss of the chemical messenger, dopamine, within the brain. The cause is as yet unidentified and there is no known cure.

The disease is found all over the world. In the UK, one in 500 people – around 120,000 individuals – have Parkinson's. Although often perceived as an older person's condition, many are affected during their working lives; of the 10,000 British people diagnosed each year, one in 20 is aged under 40.

The case studies in this document give both good and bad experiences people with Parkinson's have had in hospital.

Key Findings of the Survey

Attitude and care by staff

The vast majority of respondents, 81%, felt that staff were polite and 69% were given help to dress when required. The majority (65%) said they could access health professionals when required.

Access to medication

Ensuring that patients receive their medication at the correct time to control involuntary movements is critical for the effective management of Parkinson's. The time that a person takes their medication is specific to them and if they miss this specific time it is often difficult to control their symptoms. Failing to meet these individual times may result in staff having to provide more care.

The survey found that on average people took their medication four times a day but some people took their medication 14 times a day.

55% of respondents said they received adequate help from health professionals to take their medication and 94% said they got the correct amount of medication.

However, only 52% said that they received their medication at the correct time and only one-third was allowed to self-medicate (it should be noted that people's motor cognitive skills may have contributed to this figure).

Health professionals' knowledge of Parkinson's

Many people with Parkinson's endure what is known as the on/off syndrome. The on/off syndrome can best be described as an unpredictable shift from mobility – 'on' – to a sudden inability to move – 'off'. A patient is considered 'on' when the symptoms (such as tremor, rigidity and slowness of movement) of Parkinson's are controlled. On and off can occur suddenly and unpredictably.

[1] *Department of Health, The NHS Plan, July 2000, p.4*

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Survey respondents said that 27% of health professional staff understood the on/off syndrome and said if a patient was admitted for a Parkinson's-related illness, 44% of staff understood the problem compared to 22% for non-Parkinson's related admissions.

The lack of knowledge by health professionals may have been exacerbated by two other factors:

- Only 29% of patients were admitted to hospital because of Parkinson's-related illnesses; as a consequence, healthcare staff may not be initially aware that a patient has Parkinson's and the impact it has on daily care.
- Two-thirds of respondents knew that they would not be able to access a Parkinson's Disease Nurse Specialist (PDNS) while in hospital. It would be better if a national PDNS service is available for advice.

Case 1

While reading the instructions for my entrance in to a hospital day unit for a gastroscopy (an examination of the inside of the gullet, stomach and duodenum) I noticed that I was not allowed to take any Parkinson's medication on the day of the visit. I questioned this with about a dozen staff from the hospital, who all informed me I should adhere to the instructions provided.

By 4pm on the day of the gastroscopy, after taking no medication since the previous evening, I was in a terrible state and wondered afterwards how my wife (aged 75) coped. Although I started taking my medication the following morning I had three falls one of which was in a locked bathroom, my neighbour had to break down the door to get to me and I spent a week in hospital recovering.

After taking up this matter with the hospital concerned they changed their hospital guidelines regarding the stopping of medication before surgery. They now advise patients with Parkinson's to continue their medication to 'as close as is considered safe prior to treatment.'

From a letter to the PDS, 2002

People in the survey were asked what single thing would improve the care they receive and improving the overall knowledge of Parkinson's among health professionals came top.

Understanding Patient's Needs

The symptoms of Parkinson's often mean that patients require assistance with communication, have mobility needs and sometimes special dietary requirements. Patients often have special equipment to help manage these problems. The survey showed that for a large number of patients with Parkinson's these needs are not being met while in hospital:

- One-third of patients were not assessed for their equipment needs while in hospital.
- 37% of patient felt that meals were not provided in a way which were easy for them to swallow and 28% felt that their meals were not consistent with their dietary requirements.
- Over 40% of staff felt that staff were unsympathetic when the on/off syndrome occurred.
- 61% of respondents said that staff listened to them and their carers but only 46% said their opinions were acted upon.

One consistent theme through the survey was that where a patient was admitted to hospital for a Parkinson's-related illness staff were much better at managing aspects of their condition than if they were admitted for a non-Parkinson's related illness. For instance:

- Two-thirds of patients said they were given an explanation if their Parkinson's medication was altered if they had been admitted for a Parkinson's related illnesses, compared to one-third admitted for other illnesses.
- 73% of people admitted for a Parkinson's-related illnesses saw a specialist consultant compared to 57% who were admitted for other reasons.
- 45% of patients admitted for a Parkinson's-related illness saw a PDNS compared to 30% admitted for other reasons.

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The Need for Action

Going into hospital can be an anxious time for anyone but for people with Parkinson's thinking about how the symptoms will be managed (or not managed) can add further anxiety. The survey clearly shows that for many patients their needs are not being met during their stay in hospital.

Many people with long-term conditions are experts in the impact of their condition and should be viewed as a resource to be utilised rather than a problem to be overcome.

The Department of Health in its *Expert Patient Initiative for Chronic Disease Management for the 21st Century* has stated 'the challenge for the NHS... is to bring about a fundamental shift in the way in which chronic diseases are managed – a shift which will encourage and enable patients to take an active role in their own care.'[2] The report shows that there is a lot of work to do.

It is critical that people with Parkinson's, their carers, health professionals responsible for their care and the PDS work together to improve the standard of care being delivered. Below are some practical recommendations about how that care could be improved.

Case 2

My husband, who has had Parkinson's for 13 years, recently fell and broke his hip. We knew the PDNS was not based at the hospital, so we put the importance of the drug regime to the ward's senior staff nurse and found her very knowledgeable on Parkinson's, and my husband received his drugs, as requested, every two hours. Even during staff changeovers this was always carried out efficiently.

Although he spent two weeks in hospital, his Parkinson's symptoms were kept under control, which, of course, makes so much difference.

From a letter to the PDS, 2002

Case 3 (Daughter's Diary)

During a fall in the kitchen Dad broke the top of his leg. He was admitted to hospital for three months.

Everyday needs

I informed the staff that Dad had not been to the toilet for four days. Three days later the nurses gave him some medication for his bowels, but they gave him too much and he developed diarrhoea. The following day Dad asked for the commode but, by the time a nurse had arrived, he had messed himself.

On another occasion, when Dad needed the commode, due to a lack of staff, I had to wipe his backside. I was shocked at how degrading it was for a private man to have his daughter perform this task. After 10 days of having diarrhoea Dad was eventually given some medication that made it a little better.

A hospital care assistant (HCA) came to help Dad onto the commode. However, she put Dad back in to bed on her own. When I returned to the room his legs were twisted to one side. I asked if she would straighten his legs. When I returned again, she had put the trough support on the wrong leg.

Four weeks after admission, Dad developed a wound infection despite my previous unheeded suggestions to nursing staff that his dressings needed changing.

Specialist staff

I phoned the physiotherapist and asked if there were any exercises that Dad could do by himself, to prevent his legs wasting away. She said that she would leave a leaflet. However, when I arrived that evening no leaflet was there.

Equipment

Dad developed pressure sores on his scrotum. An occupational therapist recommended a pressure cushion to ease this problem, however it didn't materialise for two weeks. By which time the condition had worsened.

Attitude

A month into my father's stay, the dinner was wrong again. I asked for it to be changed. The HCA started shouting and insisted that we'd filled in the form incorrectly. I disagreed and repeated that it should be changed.

Medication

One day, when I arrived, Dad was very weak and would not eat. He was having trouble swallowing. I noticed his Parkinson's medication was still in the tablet dispenser.

Adapted extracts from a diary received by both the PDS and the hospital concerned (April 15th -18th July 2001).

[2] *The Department of Health, The Expert Patient, A New Approach to Chronic Disease Management in the 21st Century, 2001, p.6*

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RECOMMENDATIONS

Care

- Patients with Parkinson's should be placed, where possible, on wards where the staff have knowledge and understanding of Parkinson's and its symptoms.
- Ward staff should be aware of a patient's medication needs especially the correct time that patients take their medication.
- Health professionals should, where possible, liaise, listen to and act upon, where appropriate, the views of people with Parkinson's and their carers with regards to equipment needs, medication and other aspects of care.
- Where possible a PDNS or key worker with an understanding of Parkinson's should work with the ward staff to supervise and advise on treatments, care and medication.
- Leaflets on Parkinson's, such as the PDS's *Going into Hospital* (for patients, code FS61), *Hospital Stays and Parkinson's* (for staff, code FS62), *Parkinson's and the Nurse* (for staff, code B24) and *Meeting Your Health and Social Care Needs* (for patients, code B49) should be held at ward level to inform staff. (All available from the PDS.)
- Patients being admitted should be given details of the hospital drug policy (whether self-medication is allowed) and the availability of equipment.
- Contact details for the nearest PDNS should be posted in the ward office.

Medication

- Wherever possible, patients should be allowed to self-medicate.
- Where patients cannot self-medicate, every effort needs to be taken to ensure that medication is given to patients at the correct time.

Equipment

- Patients should be able to use their own equipment while in hospital if assessed as appropriate in the hospital setting.
- Wards must be equipped with the necessary equipment to give as much independence and dignity to patients with Parkinson's as possible.
- Hospitals should produce guidance on the standards for equipment that can be used in hospitals appropriate for people with Parkinson's.

Information

- As part of the hospital admission process, staff should check whether patients have Parkinson's, and what their needs are in that respect. (See PDS information sheet *Going to Hospital, FS61.)*
- Information on medication, equipment and care needs should be recorded in patient records and discharge notes.

Suggested Reading

Read more in the PDS leaflets, *Going into Hospital* (for patients, code FS61), *Hospital Stays and Parkinson's* (for staff, code FS62).

To find out more please contact:

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