Effectively communicating a diagnosis of Parkinson's disease

Each year approximately 10 000 people are diagnosed with Parkinson's disease in the UK. As Schrag et al (2000) have reported, one in every 20 of those diagnosed is under the age of 40 years.

At diagnosis, patients may exhibit some or all of the cardinal signs of the condition, such as rest tremor, rigidity and slowness of movement. However, it is not possible to predict either how quickly the condition will progress or what other symptoms will develop over the course of an individual's life with Parkinson's disease.

It can be difficult for people to deal with the unknown. Encouragingly, in a survey of over 3000 members carried out in 2007, over a quarter were told about the support and information available from the Parkinson's Disease Society (PDS) by a doctor or Parkinson's disease nurse specialist (PDNS) immediately after being diagnosed.

The information patients need

Being told you have Parkinson's disease can be such a shock that patients may not remember what they are told afterwards. This may explain why, in a PDS consultation exercise which took place in 2006, over 60% of our members felt that patients either receive limited or no information at the time of diagnosis.

In order to improve the way information is delivered at diagnosis and better meet the needs of patients, clinicians should listen to what information and support the patients themselves are asking for. In a PDS focus group, people with Parkinson's disease, carers and health-care professionals were asked about the questions they felt needed answering at diagnosis. The main questions people highlighted were:

- What is Parkinson's disease and what causes it?
- What are the primary symptoms?
- Will I develop other (secondary) symptoms?
- What medicines are available?
- How will my condition progress?
- Is there a cure?
- Who gets Parkinson's disease – is it hereditary?
- What help is there? (medical and professional)
- What is the difference between 'progressive' and 'terminal'?
- Is Parkinson's disease the same for everyone?
- Should I expect to see a specialist?
- Is surgery an option for me and what kind of surgery is there?
- Will I get a tremor?
- When should I start medication?
- When do I take my medication?
- Can I do anything for myself, such as exercise?
- Can I continue to work and drive?
- How will I feel emotionally?
- Will I die from Parkinson's disease?

Importance of communication

The importance of communication and patient-centred care has been highlighted by the Department of Health in its *National Service Framework for Long-Term Neurological Conditions* (Department of Health, 2005). Quality Requirement 1, the core requirement underpinning the other quality requirements, is for a patient-centred service. This states that people with long-term neurological conditions 'are to have the information they need to make informed decisions about their care and treatment and, where appropriate, to support them to manage their condition themselves.'

The significance of communication was also emphasized by NICE (National Institute for Health and Clinical Excellence). In its Parkinson's disease guideline, developed by the National Collaborating Centre for Chronic Conditions (2006), NICE states that:

> **'Good communication is essential, supported by evidence-based information, to allow patients to reach informed decisions about their care. Carers and relatives should have the chance to be involved in discussions, unless the patient thinks it inappropriate.'**

Table 1 outlines the recommendations NICE has made about communicating with people with Parkinson's disease and

Table 1. National Institute for Health and Clinical Excellence guidelines for communicating with people with Parkinson's disease and their carers

Aim to empower people with Parkinson's disease to participate in judgments and choices about their own care	
Aim to achieve a balance between provision of honest, realistic information about the condition and promoting optimism	
Because people with Parkinson's disease may develop impaired cognitive ability, depression and/or a communication deficit, provide:	Individually tailored oral and written communication throughout the course of the disease, reinforced as necessary
	Consistent communication from the professionals involved
Give families and carers information about the condition and their entitlements to care assessment and the support services available	
Agree a comprehensive care plan with the person with Parkinson's disease, their family/carers and specialist and secondary health-care providers	
Offer an accessible point of contact with specialist services. This could be provided by a Parkinson's disease nurse specialist	
Advise all people with Parkinson's disease who drive that they should inform the Driver and Vehicle Licensing Agency and their car insurer of their condition at the time of diagnosis	

From National Collaborating Centre for Chronic Conditions (2006) their carers. The PDS welcomes this guidance and hopes that clinicians will make use of the wide variety of pamphlets and information sheets the PDS produces. These can help answer patients' questions and concerns.

In addition to the guidelines on communication issued by NICE, the PDS believes that health-care professionals should inform their patients about the potentially serious side effect of dopamine agonist use – dopamine dysregulation syndrome. Grosset et al (2006) found that more than 10% of people taking certain dopamine agonists to treat their Parkinson's disease developed a problem with gambling. Informing patients about this when prescribing medication should help patients and their families recognize any changes in behaviour (such as pathological gambling) and tackle the situation before it becomes a major problem.

Access to specialist advice

There is evidence to suggest that people with long-term neurological conditions such as Parkinson's disease have improved health outcomes and a better quality of life when they are able to access prompt and ongoing advice and support from practitioners with dedicated neurological expertise, such as specialist nurses. Hurwitz et al (2005) reported that health outcomes were significantly better in patients attended by nurse specialists. Grosset et al (2006) showed, in the PD-LIFE study, that people with Parkinson's disease who were prescribed medication early have a better health-related quality of life. This emphasizes the importance of doctor–patient interaction and a PDNS would play a key role in this dialogue.

Self-care

Many people with Parkinson's disease embrace local expert patient programmes and other initiatives focused on giving them the information they need to manage their condition. As Chaudhuri et al (2006) have reported, when patients have the ability to self-care they make fewer and more appropriate demands on primary and secondary care services.

Resources to help health-care professionals

The PDS wants all health-care professionals involved in the diagnosis and management of Parkinson's disease to direct their patients to the PDS and the information and support they provide. The PDS produces a number of resources which health-care professionals can use during consultations with patients and give to them to take away with them.

A DVD 'Being There' has been launched for people newly diagnosed with Parkinson's disease. This free resource helps answer questions about symptoms, available treatments and managing the condition; and features interviews with both health-care professionals and people who have been living with Parkinson's disease for some time. We encourage specialists to give a copy of the DVD to every person at the time of their diagnosis. We also want this resource to be given to patients by PDNSs and therapists involved in the management of the condition. To order free copies of this DVD call: 01473 212115.

A Parkinson's disease atlas to support clinicians and PDNSs in explaining Parkinson's disease to patients in a language they understand is also available. The atlas covers six illustrated topics, with each topic consisting of two pages with the same content: one for the patient and one for the clinician or specialist nurse. This format makes it simple to use and enables face-to-face discussion of the patient's condition.

Health-care professionals can also direct people with Parkinson's disease to the PDS. Many already advise patients about the information and support the PDS provides and it is hoped that many more will start to do so.

Conclusions

The way in which the diagnosis of a long-term condition such as Parkinson's disease is given can significantly affect the psychological wellbeing of the person and his/her family. Improving this communication should be a goal for all of us. By understanding the information needs of patients and working hard to meet these needs, we can help people manage their condition more effectively and make less demands on limited health resources. **BJHM**

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KEY POINTS

- A diagnosis of Parkinson's disease can leave people feeling alone, confused and isolated.
- The National Institute for Health and Clinical Excellence and the National Service Framework for long-term neurological conditions emphasise the importance of communication and patient-centred care.
- Resources produced by the Parkinson's Disease Society can help clinicians communicate with patients.
- Clinicians can direct patients to the Parkinson's Disease Society.

Further information

www.parkinsons.org.uk

PDS Helpline: 0808 800 0303 (Monday–Friday 9.30am – 9pm and Saturdays 9.30am–5.30pm)

To order the DVD and other resources call 01473 212115

To order a free copy of the Parkinson's disease atlas email: juliet.z.ashton@gsk.com