The journey: Parkinson's disease

Mary G Baker, Lizzie Graham

To receive a diagnosis of a chronic neurological illness is the beginning of a long journey into the unknown—a journey that may begin in hope, pass through periods of elation and frustration, and finally end in acceptance and resignation. We would like you to come with us part of the way along the journey of Parkinson's disease, seen from the point of view of those who are compelled to make it—the patients and their carers.

The map

When we begin any journey, we need a map. We need to pack and prepare for the journey. We need to know what to expect along the way. The telling of the diagnosis and the explanation of the disease and its treatment form just such a map. And, like the maps of the medieval world, the map of Parkinson's disease is full of unknown territories and nameless threats. Small wonder that the telling of the diagnosis is so difficult. But it is so important and is one of the things that patients repeatedly say could be done better.

Patients tell us that the diagnosis is not always given in such a way that they can take it in, adjust to it, and decipher what it really means. The telling of the diagnosis often has to be repeated—most people are so shocked and confused by what they hear that they may be struggling to make sense of it and too stunned to ask the right questions. In the extremes of distress, people may hear what they want to hear or get the wrong message altogether. In trying to allay patient's fears, professionals may be guilty of misinformation.

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Wilhelm von Humboldt, a famous German academic reformer, humanist scholar, and statesman, in his letters from 1828 until his death in 1835, described the manifestations of Parkinson's disease precisely and more completely than James Parkinson in his "Essay on the Shaking Palsy" of 1817 (illustration from *Leipziger Illustrirte Zeitung*)

People begin the journey with different knowledge and different ways of accepting the disease. The telling must be adjusted to take account of education, intelligence, and cultural background. Not all patients will be well educated, not all will be able to read, and not all will be able to speak well the language of the country in which they are living.

Many patients and their families will have misconceptions about Parkinson's disease that need to be dealt with. One of the best ways to explore the meaning of the diagnosis is to ask patients: "What do you know about Parkinson's disease?" and "What do you want to know?" Among the most common questions are: "Will I die?" "Will I be able to work?" "What will I tell the children?" Then, there are other questions that may not be voiced: "Who will care for me when I can no longer care for myself?" "What will this disease do to my relationships?" Let's look at some of the areas that need to be dealt with if patients are to be able to set out on their journey properly prepared.

Where the map starts and ends

The average age for developing Parkinson's disease is around 65, although up to one in 10 people with the disease develop it in their 40s or 50s. Globally, Parkinson's disease affects 6.3 million people, with one in 10 people receiving a diagnosis before age 50 (www.epda.eu.com).

The symptoms usually appear slowly and develop gradually and in no particular order. It is important to remember that everyone with Parkinson's disease is different and may have a different collection of symptoms and response to treatment from another person with the same diagnosis. The symptoms may take years to progress to a point where they cause major problems, and when they do, many of these symptoms can be treated.

But telling a patient that Parkinson's disease is treatable and leaving him or her with the impression that this means "curable" will do a great disservice to the patient. Honesty is essential—it does not have to be brutal. Although Parkinson's disease has no cure, it is the only neurodegenerative disorder with a range of medical and neurosurgical treatments that substantially reduce symptoms. Having said that, patients need to know that these treatments sometimes lead to disap-

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Kailua, Mayford, Woking, Surrey GU22 0SH
Mary G Baker
president, European Parkinson's Disease Association

European Parkinson's Disease Association, Sevenoaks, Kent TN13 3NJ
Lizzie Graham
project manager

Correspondence to: L Graham
lizzie@epda.eu.com

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Box 1: Professionals who can help with the management of Parkinson's disease

- General practitioner
- Neurologist
- Gerontologist
- Psychologist
- Nurse specialist
- Occupational therapist
- Physiotherapist
- Dietician
- Speech and language therapist
- Pharmacist
- Social worker
- Chiropodist

pointment and may have side effects in the long term that prove more troublesome than the disease.

Parkinson's disease by itself does not directly cause people to die. With the treatments now available, life expectancy for someone with Parkinson's disease is fairly normal. However, for people who are seriously disabled (usually those who have had the disease for many years), their general physical and mental condition can either cause or exacerbate other illnesses and so contribute to the final cause of death.

The period of adjustment to the diagnosis will vary—in some cases, it may take years for people to come to terms with their situation, during which time everyone in the family will suffer and relationships will change. Ultimately, each patient will make his or her own way along the journey, but, hopefully, he or she will not have to make it alone.

Travelling companions

The patients and carers who embark on the journey should be aware from the outset that they do not have to travel alone. Neither should the doctor be the only person who is there to help them carry their physical and emotional baggage. The burden is much better shared among a multidisciplinary team (box 1).

The journey involves not only the patient and professionals but also partners, family, and friends. It is a mistake, however, to assume that suffering always brings people together—sometimes it does not. Not everyone is sustained by happy and loving relationships. A rocky relationship is unlikely to be saved by the crushing blow of chronic incurable illness.

To put it bluntly, not everyone asked to join the journey will want to go. Some will, with great sadness, put down their packs and refuse to go on, either at the start or at some point along the way. This is their right, and we, as professionals should not assume that all partners and families are capable of seeing the journey through.

Parkinson's disease changes relationships between couples in many ways. Not all couples are well equipped to cope; some patients find it very hard to be dependent on their partner, and some partners feel guilty about not wanting to be the main carer. Loss of self esteem, along with the physical problems of general fatigue, shaking, muscle stiffness, and dribbling may lead to sexual difficulties, as will erectile problems. Parkinson's disease may also worsen or be worsened by problems with menstruation, contraception, pregnancy, and the menopause. Yet this is an area that receives scant attention. More practical advice is needed on how to cope with the difficulties from day to day, and more research is also needed—for example, into the interactions of antiparkinsonian medications with the menstrual cycle, with oral contraceptives, and with hormone replacement therapy. Patients rarely voice these concerns spontaneously and may need to be asked sensitively about them.

Hugs and cuddles may be physically difficult for patients with Parkinson's disease to give and receive. This may be particularly difficult to understand for and even be frightening to younger children in the family, who don't know what to make of an impassive face and confusing body language. Generally, children handle honesty far better than deceit, and research shows that children are usually relieved to be told that their mother's or father's strangeness is caused by Parkinson's disease.

The adult offspring of people with Parkinson's disease may have to face the responsibilities of caring for a disabled parent and have to make painful decisions about their own plans for the future and about who will care for their parent.

What travellers need along the way

Patients tell us that there are five things that they need to help them to live better with Parkinson's disease (box 2). They need to be referred to a doctor with a special interest in this disease. They need a better telling of the diagnosis. They need access to the multidisciplinary team. They need continuity of care, and they need to participate in the management of their own illness.

The European Parkinson's Disease Association, in collaboration with the World Health Organization, developed these five principles into a "charter" for people with Parkinson's disease, launched in London on the first World Parkinson's Disease Day, 11 April 1997 (box 2). This charter has been signed and supported by global organisations for Parkinson's disease and by well known celebrities.

Doctors are the chroniclers of the journey. We hope that close collaborations will help us to develop models of integrated care that will draw together the best in modern medical practice, using all the strengths of the multidisciplinary team and involving the patients themselves.

For example, doctors should not forget that many patients value physical therapy as much as, if not more

Box 2: European Parkinson's Disease Association and World Health Organization: charter of rights for people with Parkinson's disease

People with Parkinson's have the right to:

- Be referred to a doctor with a special interest in Parkinson's
- Receive an accurate diagnosis
- Have access to support services
- Receive continuous care and
- Take part in managing the illness.

Declared on this day the 11th Day of April 1997 (cited from www.epda.eu).

than, medication, to help them move and remain active. The Association of Physiotherapists in Parkinson's Disease Europe has developed guidelines for physiotherapy practice in Parkinson's disease, following two Cochrane systematic reviews of physiotherapy and Parkinson's disease, and these are available on the internet (http://appde.unn.ac.uk).

Occupational therapy can also teach patients ways to adapt to their symptoms and continue to do the activities that are important to them. Speech and language therapy may be a great help too, not only for voice training but also to improve and maintain swallowing and to avoid subsequent problems such as choking, undernutrition, and pneumonia.

Health professionals may also find it hard to share their patients' enthusiasm for complementary or alternative therapies. Some of these may have some benefit, even if it is largely psychological. Although it is clearly difficult for health professionals to endorse treatments they do not believe in, there is no reason why they should not take a tolerant and accepting attitude towards measures such as meditation, aromatherapy, yoga, the Alexander technique, osteopathy, and so on. If patients feel better, for any reason, we can only be grateful.

A specialist nurse is often the best person to draw together the strands of multidisciplinary care and to be the key contact for patients and carers, providing the continuity of care those patients have identified as one of their primary needs.

Travelling alone

One of the hardest things to face in Parkinson's disease is the loss of independence and a sense of isolation or exclusion from normal life. Doctors sometimes advise younger patients to give up work, but this is not a step that should be taken lightly or without proper assessment and support from occupational health services (if available). The impact on the family is not confined to the loss of earnings. The loss of self esteem, the dashing of expectations, and the stress of changing family roles can erode relationships. Not everyone has rich reserves of self worth, or a lively circle of friends and acquaintances, to help them feel that there is a life worth living beyond work. Isolation is often compounded by the patient's introspection and gradual withdrawal from the world beyond the narrow confines of their disease.

Another aspect that patients often mention is having to give up driving—the practical and psychological consequences of depending on others are hard to take. But many people with Parkinson's disease can, and do, continue to drive for many years after the diagnosis, if supported by their doctor. However, in the United Kingdom and many other countries patients have a legal obligation to inform the Driver and Vehicle Licensing Agency (or its local equivalent) of their diagnosis and may need to have a medical examination or take a driving test.

Losing the path

Even if the people who set out are well prepared and have a helpful team of guides and supporters the journey will never be easy. For most patients the journey, after the initial shock of the diagnosis, moves into sunlight. There may be a honeymoon period in which treatment is working well and other people, at work and socially, are unaware of the illness. Slowly, the landscape of the disease changes. The journey becomes dark and difficult, and often lonely. The travellers may lose their way or follow false trails. The dragons of dyskinesia and depression appear, to be fought again and again.

Depression is one the commonest problems encountered in Parkinson's disease and is under-recognised and under-researched. One of the biggest surveys into quality of life, the Global Parkinson's Disease Survey (GPDS), carried out in seven countries in 1998-9, identified that depression reduced quality of life considerably. Half of the people surveyed were depressed, but only 1% had reported this as a problem. It is not clear whether the disease itself causes depression or whether depression is a reaction to the situation in which the patient finds himself or herself. Depression is an equally common problem for carers, although those who feel guilty at not being able to cope may conceal it.

Patients also encounter other problems as the disease progresses: nausea, hot sweats, dilated pupils, nightmares and hallucinations, confusion, and memory loss. Some of these may be due to the disease, others to the side effects of the medication. Whatever the cause, the patient is assailed by the terrifying feeling of being out of control. Instead the disease, or its treatment, is controlling him or her.

Please, as doctors, listen to what your patients have to tell you about medical treatment. The patient's perception of overdose or inadequate dosing may be quite

Box 3: Patient's story

Terry and I had reached the point in our lives when we were established in a nice home, we were financially secure, and life was looking good for our family. But life has the knack of taking you by surprise, and suddenly our lives were turned upside down by a series of events which started with Terry being diagnosed with Parkinson's. Having no knowledge of Parkinson's or any understanding of the condition, I was filled with fear of what the future held for us all. I was utterly convinced that within six months he would be confined to a wheelchair. Then two months later I was diagnosed with cervical cancer and was told that I would have to have a hysterectomy.

I felt there was no one I could turn to, so I shelved any fears I had about me. All I needed was to find out all I could about Parkinson's, so I went to the public library and the information I found there frightened me even more. At night I would lie awake watching Terry to see if his tremor had worsened or spread to another part of his body. My children seemed unable to accept that their father had Parkinson's, which stopped me from discussing it with them, and I felt so isolated. Terry, being Terry, continued to try to live his life as he always had. He had always been the "strong" one, the protector, the provider. But now I felt he was not the same and that he needed my protection. In a few short months, our roles, which had always been secure and constant, had changed.

The telling of a diagnosis whether it be Parkinson's or cancer is crucial. We, the patients, rely on the expertise of the medical profession. If they misdiagnose an illness it can have a catastrophic effect on our lives. We also need easily accessible and accurate information to help us to adjust to the many changes that we have to face.

Our lives have changed, and so have we. I have become more assertive and self assured, and have found strengths within myself which I did not know existed. On reflection, I wonder whether I have made a mistake by taking too much of the burden on to my own shoulders. I honestly feel that people refuse to discuss the most serious problems in their lives at a time when you should express your true feelings. But we rarely do so, as we are frightened to break down and embarrass ourselves as well as our families and friends. Because of my fear I felt a strong need to protect Terry, but perhaps by my actions, I have inadvertently undermined his self confidence. He is after all still Terry, who just happens to have Parkinson's.

different from your own. People may vary widely in the degree of symptoms that they are willing to tolerate. Consultation, not confrontation, is the way to achieve compliance and concordance. Remember that one of the five things that the patient needs most is to take some of the responsibility for their own management.

Travellers' tales

Often patients and carers learn new ways of coping with Parkinson's disease by sharing experiences with others in the same position (see box 3 for patient's story). This is where the Parkinson's disease organisations come in, such as the European Parkinson's Disease Association (box 4).

Journey's end

Not everyone starts the journey from the same point, in terms of knowledge and expectations. Better telling of the diagnosis is needed. Patients need clear maps and signposts along their journey, to help them cope with treatment; physical problems; the world of work, family, and relationships; and the depression they may encounter along the way. Patients do not undertake their journey alone, but not every member of their family may be willing or able to travel with them. Doctors do not have to carry all the burden of supporting the patients—the multidisciplinary team and patients' organisations are there to help.

Further reading for patients, carers, and doctors

A series of six information leaflets for patients, produced in 2004, is a helpful and accurate resource for people with Parkinson's, their families, and healthcare professionals. To date they have been translated into eight languages, with more translations planned throughout the year—www.epda.eu.com

Anderson S. *Health is between your ears. Living with a chronic disease.* Hornslet, Denmark, Parkinson Info, 2002. This book, by a Danish psychologist diagnosed in 1989, was written for people with Parkinson's and their families, to regain optimism, and to show that despite the disease, life can still be good—www.epda.eu.com

Aho K. *Parkinson's disease: my constant companion a neurologist's experiences as a patient.* Brussels: European Parkinson's Disease Association, 2002. Successful treatment of Parkinson's disease is an art. In addition to a good doctor-patient relationship, the patient's own activity and initiative have a central role. Alongside medical treatment, the right type of nutrition often brings added help

Baker MG, Marsden CD, Oxtoby M, Williams A, Moore L, Woodroffe D, et al. *Parkinson's at your fingertips.* 2nd ed. London: Class Publishing 1999. Clear and helpful information on Parkinson's, written in a very accessible question and answer format—www.parkinsons.org.uk

Parkinson's Disease Society. *Parkinson's aware in primary care.* London: PDS, 2003. Written mainly by general practitioners, for general practitioners and the wider primary care team, this is a guide for the best management of Parkinson's disease. As well as information on Parkinson's and the drug treatment available, the leaflet gives guidelines on procedure at four key stages: diagnosis, maintenance, complex and palliative—www.parkinsons.org.uk/shared_asp_files/uploadedfiles/{31E42B83-775B-414F-B3C4-8708E9DC0B2C}_PDAwarePrimaryCareSept03.pdf

Infopark (www.infopark.uwcm.ac.uk)—Brought together academics, clinicians, and user groups to explore the information needs of older people with disabilities in Europe. The research project involved partners from the United Kingdom, Spain, Portugal, Estonia, Germany, Greece, and Finland. Information sheets in six languages on Parkinson's disease have been developed based on the results of patients', carers', and professionals' concerns

www.parkinsonpoly.com—The need for education and information for people with Parkinson's disease and their carers has been the driving force behind this innovative program, which uses the web and visual mnemonics. In 2004, it is being translated into many languages

www.besttreatments.co.uk—Has brought together the best research about Parkinson's disease and weighed up the evidence about how to treat it. People with Parkinson's disease can use the information to talk with their doctor and decide which treatments are best for them

Box 4: European Parkinson's Disease Association

The European Parkinson's Disease Association was formed in Munich in 1992 with a membership of nine European organisations for Parkinson's patients, and its membership has since increased to 35, with nine associate members including the Movement Disorder Society, the Association of Physiotherapists in Parkinson's Disease Europe, the European Federation of Neurological Associations, and the Tremor Foundation. The association's purpose is to develop a dialogue between science and society and to effect change by shaping European policy and education, resulting in improved quality of life for people with Parkinson's disease. The association is committed to ensuring that people with Parkinson's disease, their families, and their friends do not have to make the journey alone but have the best possible support from the healthcare professions, from the social and welfare agencies, and from each other.

The association is a non-political, non-religious, and non-profit making organisation concerned with the health and welfare of people living with Parkinson's disease and their families. It has provided an important forum to work in collaboration with international organisations, both patient and neurological. These include the European Commission, the World Health Organization, the World Federation of Neurology, and the pharmaceutical industry. This partnership has enabled the development of research projects into quality of life issues, production of validated information on Parkinson's disease, its medication and how to manage the complexities of its management, and biannual conferences for multidisciplinary teams and people of any age with Parkinson's disease.

The right information is crucial for any journey to be successful; without it, people end up going in the wrong direction. The European Parkinson's Disease Association is very well aware how important it is to provide validated information, for people to be able to access this and to make their own choices as to whether or not to use it. The association's website, www.epda.eu.com has been developed to provide such information and include information not only about Parkinson's disease, its management and medication, but also on magazines and on books written by people with Parkinson's disease and professionals, and links to other websites about holidays and organisations that could be of help.

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