

Parkinson's: the wrecker of lives

Most people are aware of, or indeed know first-hand, someone who is affected by this crippling condition. It is the fastest growing neurological condition in the world and in the UK there are 150,000 people afflicted. It is no respecter of age and although it mostly affects people over the age of sixty, many aged fifty or under fall victim. It is estimated that 1 in 37 people will be affected at some point in their lives. It affects men more than women by a factor as high as 50%. We do not understand the causes and, although advances in medication continue, there is no cure. The following account brings home the awfulness of Parkinson's:

'John is a 52-year-old, married man. He is a self-employed electrician. His wife works in the local council offices, and they have no children. They are able to pursue a comfortable lifestyle which includes their own house, regular holidays abroad, some hobbies and a plan to retire to Spain at the age of sixty.'

John gradually becomes aware of a tremor affecting his right hand. Week by week it becomes more noticeable and is accompanied by a weakness of his arm and a tendency to trip up. He and his wife look up possible causes on the internet and when they go to see his GP their worst fears are confirmed. The doctor diagnoses early Parkinson's and starts him on treatment while referring him to a neurologist. Their world is shattered. But they are a resilient, loving couple and after the first shock and many tears, informed by websites and literature, they come to terms with what lies ahead. The medication makes a big difference, and John manages reasonably well for the time being. His tremor is well controlled, and he is able to carry on working.

Gradually the symptoms – particularly his tremor, arm weakness and unsteadiness – increase, and respond less well to medication. After the first year or two, more frequent and stronger doses of medication are required. It is clear he must give up his business and he is forced to retire at the age of fifty-six. Fortunately, the mortgage insurance relieves some of their financial worries, although money is now tight. He, his wife, and his GP work together to manage the dose and frequency of his medication but the local health services are under strain and there are long waits between appointments for specialist advice and services.

During the next few years, John ages more rapidly than would be expected. His face becomes increasingly immobile and expressionless. He doesn't smile and his speech gradually becomes hesitant, slow, and slurred. He cannot get out of bed or walk without help. He is supported by outreach services, but his wife must give up her job as her husband becomes increasingly incapacitated. Other symptoms emerge as the years pass. Frequent painful muscle cramps, insomnia, constipation, and urinary incontinence reduce his quality of life still further. By the age of 65 he is spending much of his time sitting or in a wheelchair

Patrons

Colonel Edward Bolitho OBE, Lord-Lieutenant of Cornwall
David Fursdon Lord-Lieutenant of Devon
The Rt Hon Lord David Owen CH FRCP
Angela Rippon CBE
Barbara Vann

with an indwelling catheter. It is little wonder that he becomes depressed, and his wife worn out with coping. They manage independently for a few more years, supported by outreach care teams, but by the age of 67 John is totally incapacitated, mentally and physically. His quality of life is negligible, and he passes away from pneumonia at the age of seventy.'

This account illustrates how Parkinson's typically presents. Mild at first, often the first sign is a certain clumsiness, weakness or tremor affecting a limb. Those close may notice the face becoming increasingly expressionless and speech slow or slurred. Other early symptoms include a limp or a dragging foot. As the condition progresses, there may be numerous other, less well known, problems. Constipation, impotence, poor balance, walking problems, incontinence, painful cramps, and inability to think clearly ('brain fog') are just some of the challenges which may be encountered as the condition progresses.

A major sadness is the bleak outlook. Although hugely variable in severity and the way it affects different individuals, Parkinson's is a life sentence. The average life expectancy is reduced, but not by more than a few years, meaning that patients and families must learn to cope with their distressing symptoms for many years. Whether rapid or slow, there is an inevitable, steady decline in abilities and an increase in unpleasant symptoms as the nervous system degrades. Limbs become painful, stiff and incapacitated. Brain function degrades making communication difficult and not infrequently progressing to dementia. Parkinson's takes away futures, destroys dreams and places a lifelong burden on family and carers. It is a truly miserable condition.

Access to advice and therapy must be rapid

So, what can be done? Well, the answer is 'a great deal', particularly in the early stages and if specialist help is at hand to assess, advise and treat. There is a huge range of drugs and physical therapies available many of which can control unpleasant symptoms and enable patients to live a full life including work. But herein lies a problem: no two patients experience the same symptoms, disabilities or time-line. Effective treatment is dependent on rapid access to expert assessment as and when necessary. Once established, changes become irreversible. Delay is failure.

Plymouth's University Medical School and Hospitals made the decision some years ago that they would focus on research into neurological conditions of the sort that cause major disabilities and chronic suffering. Professor Carroll, consultant neurologist and scientist has worked steadily to build a team which researches new ways of understanding, treating, and managing Parkinson's. It is now achieving international recognition for its work, particularly for its pioneering approach utilising modern, technical innovations to monitor the well-being of Parkinson's patients in Devon and Cornwall.

<https://www.plymouth.ac.uk/research/parkinsons/applied-parkinsons-research/home-based-parkinsons-care>

The Peninsula Medical Foundation is proud to be providing support for Professor Camille's team in its quest to improve the care of patients suffering from Parkinson's Disease.

Patrons

Colonel Edward Bolitho OBE, Lord-Lieutenant of Cornwall
David Fursdon Lord-Lieutenant of Devon
The Rt Hon Lord David Owen CH FRCP
Angela Rippon CBE
Barbara Vann