The symptoms most associated with Parkinson’s disease are tremor, stiffness and slow movement. But practically everyone who has Parkinson’s disease also has debilitating ‘non-motor’ symptoms such as memory loss, sleep problems, mood changes, dribbling, apathy, concentration difficulties, fatigue and constipation.

‘These non-motor symptoms often have a greater impact on people’s quality of life than the movement difficulties,’ says Professor Ray Chaudhuri who led the development and validation of NMSQuest, a simple questionnaire now used in clinics around the world to help ensure patients get the treatment they need for non-motor symptoms of Parkinson’s disease.

NMSQuest (Non-Motor Symptoms Questionnaire) lists all potential non-motor symptoms and asks patients to indicate which ones they have experienced in the last month. Patients complete the 30 questions before a consultation and then hand their answers over to their specialist doctor or GP.

‘Historically, doctors have chosen to concentrate on the movement symptoms of Parkinson’s disease and have tended to ignore all other symptoms,’ says Professor Ray Chaudhuri. ‘We carried out research that illustrated how often doctors and nurses throughout Europe did not discuss non-motor symptoms – in up to 40 per cent of consultations, they were not asking about them. Patients often didn’t speak about them either because they were embarrassed, or because they thought the symptoms may have nothing to do with Parkinson’s. What NMSQuest does is to empower patients and enable them to declare their non-motor symptoms.’

Other non-motor symptoms include hallucinations, depression and anxiety, poor sense of smell, pain, urinary problems and sexual difficulties. Most people who have Parkinson’s disease experience at least six of them, but some can have up to 30. All non-motor symptoms are treatable as long as doctors know about them.

Patients can download the NMSQuest questionnaire from the Parkinson’s UK website or from the International Parkinson’s and Movement Disorders Society website before visiting a hospital or GP surgery for a regular check or first-time referral. NMSQuest use is now recommended along with use of PDSS by NICE as well as in the Best Practice Tariff criteria for management of Parkinson’s.

Our researchers led the development and validation of two other scales that are regularly used in research studies to measure the effect of new treatments on non-motor symptoms. The Non-Motor Symptom Scale (NMSS) is now used in most clinical trials of new drugs for Parkinson’s.

The second scale, PDSS (Parkinson’s Disease Sleep Scale), was developed to measure sleep disturbances such as insomnia and excessive daytime sleeping and has been translated and validated in nearly 30 countries by the Mapi Institute in France. An updated version (PDSS-2) also measures nocturnal difficulties, including restless leg pain and sleep apnoea.

PDSS-2 was one of the outcome measures used in the ‘RECOVER’ study testing the effectiveness of rotigotine, a Parkinson’s drug administered by skin patch. The results of the research showed the 24-hour patch helped people control their early morning movement symptoms and also improved sleep.

‘Researchers as well as clinicians are now realising how important non-motor symptoms are,’ says Professor Ray Chaudhuri, ‘but before NMSQuest and NMSS, there was no tool available to help record or measure them.’

Research led by Professor K Ray Chaudhuri

REFERENCES


For more in our Making a difference series: www.kcl.ac.uk/difference