Working together

A well functioning team overseeing the care of a patient with Parkinson’s disease can get results, writes Margaret Richardson

PARKINSON’S DISEASE (PD) is a chronic progressive neurodegenerative disorder that leads to the well-known motor features of bradykinesia, tremor, rigidity and postural instability. Prevalence in Europe is around 160 per 100,000 in the general population.

Medication is the first option of treatment and functional neurosurgery may be indicated for advanced disease or drug-induced complications. In addition to the well-recognised motor disability of PD, neuropsychiatric symptoms such as depression, anxiety disorders and psychosis are common.

In 2002 the Global Parkinson’s Disease Survey identified several factors other than medication and severity of the condition that influenced quality of life for people with the condition.

One major factor highlighted was the importance of a multidisciplinary team approach to managing the care of people with PD, their carers and families. Sometimes management focuses so much on the medical aspects that other issues and the important roles of other professionals in managing PD are often neglected.

Consultant neurologist and GP

The consultant and GP are responsible for the clinical management of PD patients. The GP is often the first port of call for someone who suspects they have PD. The GP will either make a diagnosis or, more likely, refer the patient to a consultant, such as a neurologist, geriatrician or physician to ensure an accurate diagnosis.

The consultant will devise a treatment plan and initiate treatment, keeping the GP informed. The GP will be the main clinical point of contact for PD patients, with the neurologist seeing the patient at longer intervals tailored to the individual.

Nurse specialist/community nurses

The PD clinical nurse specialist (PDNS), where one is available, acts as a co-ordinator of care between the patient, hospital and community services to meet the needs of both patient and carer. The role of the PDNS involves:

- Assessing the patient using the Unified Parkinson’s Disease Rating Scale and planning and documenting care on an individual basis
- Monitoring response to drug treatment and making adjustments where necessary, in liaison with the doctor
- Making recommendations as to when the patient should be referred to another member of the multidisciplinary team
- Providing emotional support, and referring to professional counselling as necessary
- Assessing the needs of carers
- Direct/indirect patient contact throughout the course of the disease, from diagnosis to palliative care.

Other nurses such as public health nurses, community psychiatric nurses and continence advisers may also be involved in assessing PD patients’ abilities. Planning appropriate care particularly with regards to communication, personal hygiene, mobility, elimination, swallowing, diet and psychological problems is essential.

Psychiatrist/psychologist/counsellor

The psychiatrist assists the Parkinson’s patient with mental health problems such as depression, anxiety, dementia and psychosis, if necessary. The psychologist/counsellor can help with cognitive behavioural therapy and talking through any aspect of Parkinson’s disease that is having an emotional effect, including depression, anxiety and communication.

Physiotherapist

The physiotherapist has expertise in the management of mobility problems from the point of diagnosis to the later stages of the disease. The physiotherapist can:

- Maximise functional ability and minimise secondary complications which may include stooped posture, loss of range of movement and reduced dexterity
- Advise on exercises, gait, and strategies for dealing with falls and freezing
- Assist in movements that are no longer automatic, such as turning in bed and getting out of a chair
- Help with pain-relief measures such as heat, cold, specialist equipment and massage
- Maintain or improve effective breathing
- Help to prevent circulatory problems
- Advise carers on care of their own bodies and prevention of harm to the person for whom they are providing care.

Speech and language therapist

The speech and language therapist provides specific information and advice on the management of communication and speech problems, swallowing difficulties and saliva control. They can:
Clinical

- Help to improve overall communication which include the mask-like face, reduced eye blink reflexes, and reduction of body and hand gestures
- Help to improve ability to use the phone and communicate in noisy public places
- Teach techniques to help patients improve voice, speech and respiration
- Assess patients for communication aids if required, eg. an amplifier to increase volume or a communication board to make some words clearer
- Assist with eating and drinking problems
- Give advice regarding posture, head control, psychological attitude and diet
- Help to improve patients’ ability to write
- Give advice and support to carers for communicating with the person with PD.

Occupational therapist

The occupational therapist enables PD patients to adapt and develop life skills to help with their new or altered capabilities, promoting independence. They can:
- Give advice on the way the course of the disease can affect everyday life
- Assess patients’ ability to carry out activities of daily living such as eating, drinking, bathing and dressing
- Work alongside patients and their carers to plan the most appropriate daily or weekly routines
- Give advice on ways of making homes/ workplaces safer and more manageable
- Advise on appropriate adaptations and aids and provide specialist equipment to assist with activities of daily living
- Advice on leisure activities that will promote physical and mental wellbeing
- Provide information, advice, and support to carers of PD patients.

Dietitian

As the condition affects muscular movement, Parkinson’s has widespread effects on eating and drinking. Inability to swallow affects the nutritional status and there are also oral health issues to consider, thus weight loss appears to be common. The dietitian’s aim is to:
- Detect nutritional inadequacies at an early stage, through in-depth diet history
- Instigate measures to correct deficiencies or nutrition-related problems
- Identify ways to minimise any difficulties associated with eating or swallowing
- Liaison with speech and language therapist in the management of patients with swallowing difficulties
- Prevent undesirable weight gain or loss
- Prevent lean muscle mass
- Reduce the impact of the side-effects of drug treatment on dietary intake
- Provide guidance on ways to promote optimal nutrition and energy balance
- Maintain good general and oral health
- Regularly monitor nutritional status as the condition progresses
- Encourage a diet that is high in fibre and fluid to prevent or manage constipation.

Social worker

The social worker assesses the PD patients’ needs in order to establish the balance between need, risk and resources for intervention. This may make the difference between living independently or in a residential establishment and should be an ongoing process due to the fluctuating nature of PD and the wide variation in symptoms.

Assessment is a two-way process and the social worker needs to empower patients with communication difficulties to fully participate in the assessment process together with their carers.

The social worker’s role is to develop a package of care that supports patients and carers’ choices and needs, while also recognising and negotiating the conflicts that these can create. It is imperative that the social worker provides information and guidance in claiming and accessing all available benefits and entitlements.

Chiroprodist

PD patients are particularly prone to problems because of difficulties they can experience with walking, posture and cramps. They may also have difficulty bending over or in controlling the fine movements of their hands needed to cut toenails safely. The chiroprist often needs to liaise with the physiotherapist in addressing foot-related mobility problems and prevention of falls.

Carer

A vital member of the team, the carer supports or lives with the person affected by PD. Their insight is invaluable and can help all members of the multidisciplinary team do their best for the patient.

Support groups

The Parkinson’s Association of Ireland is a charitable organisation based in Dublin, offering excellent support, advice and information to people with Parkinson’s and their carers. It runs a confidential Helpline service every morning, Monday to Friday, 9am -1pm.

The Association produces a wide range of resources, including information sheets and booklets on issues associated with the condition.

There are a number of local branch support groups countrywide. They are run by volunteers, often people who have PD, their families and carers. Each branch is different in the support it offers, but generally they provide opportunities for mutual support and social activities through monthly meetings and practical help at a local level. They are also involved in fundraising and public awareness.

The Parkinson’s Active Liaison and Support Group (PALS) is a special interest group for younger PD patients and their families. The needs of younger people with PD and their families can be very different to those of older people. These may include family relationships, particularly regarding children; employment and concerns about mortgages and financial matters.

It is important for the multidisciplinary team to identify and work towards the same goals, and that the people with Parkinson’s are aware of and have agreed to these goals. It is important that advice from across the multidisciplinary team is consistent, and that the advice of one member of the multidisciplinary team reinforces, rather than contradicts, advice from other members.

Each member of the multidisciplinary team needs to fully understand and respect other members of the multidisciplinary team and their roles. Above all advice and treatment should be evidence-based.

Parkinson’s disease has a considerable impact on the mental, emotional and physical well-being of an individual as well as their lifestyle and requires access to a wide range of services.

The multidisciplinary team is essential in offering a patient-centred approach and holistic assessment and treatment by working closely with patients and carers to deliver the best possible care in a cost-effective manner. Each person with PD must be treated as an individual, with the multidisciplinary team requiring shared understanding of each other’s roles and any rehabilitation or interventions are in partnership with the PD patient and their families and carers.

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References available from nursinginmedica.ie.
(quote Richardson WIN 2008;16(9): 31-32)