

Parkinson's Disease Society

A TIME TO CARE IN NORTHERN IRELAND



Improving quality of life for people with Parkinson's and their carers

Background

Around 3,300 people in Northern Ireland have Parkinson's disease¹. Around one in 20 is under 40 years old and around 270 people in Northern Ireland are diagnosed each year with the condition².

By 2013 in Northern Ireland, there will be an increase of 18.2% (49,000) in the number of people of retirement age (60 for women, 65 for men)³ and there are expected to be around 500 additional people with Parkinson's disease by this date.

It is estimated that there are over 2,200 people with Parkinson's disease who have a significant level of disability.⁴

Parkinson's in Northern Ireland: meeting people's needs?

The Parkinson's Disease Society (PDS) recognises that there is much good practice in health and social care, but there are also some important issues that are having a detrimental impact on the quality of care people with Parkinson's disease and their carers receive:

♦ **Waiting for diagnosis or treatment** – Large numbers of people are waiting unacceptably long times for treatment and waiting lists are increasing⁵. According to the latest figures, there are still 422 people waiting over 12 months for a first neurological outpatient appointment⁶.

♦ **The lack of specialist neurological staff** – There are currently four nurse specialists in Northern Ireland and it is believed that another three are needed urgently.

♦ **Meeting future needs for residential care provision** – The

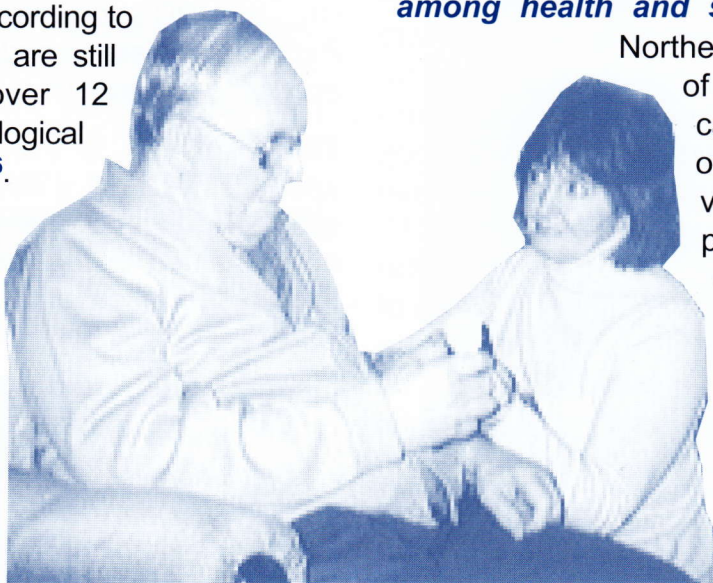
number of places in residential homes has declined by 300 to 6,408 in 2001 (latest figures)⁷. Also, the number of residential places for older people aged 75 and over has declined by 5% since 1999⁸.

Against this, the number of people of pensionable age (60 plus for women and 65 plus for men) will rise by 8% by 2008⁹ and the number of those aged 75 and over is expected to increase by 22% by 2013¹⁰.

♦ **Lack of awareness of Parkinson's disease among health and social care staff** – In

Northern Ireland a proportion of patients with neurological conditions have their out-patient care supervised by general physicians and 20% of emergency admissions have a neurological condition¹¹.

Research suggests that many health professionals may have little knowledge of many neurological conditions because they see relatively



A further three Parkinson's Disease Nurse Specialists are urgently needed in Northern Ireland



Parkinson's
Disease Society

Parkinson's Disease Society

A TIME TO CARE IN NORTHERN IRELAND

Improving quality of life for people with Parkinson's and their carers

few people with them (e.g. 65% of GPs see less than five patients each year with Parkinson's 12). This means that staff may be outdated in the current management trends and best practice treatment options. They could therefore be unaware of how best to provide and manage effective treatment of people with Parkinson's disease with which will have a negative impact upon their quality of care.

The Parkinson's Disease Society (PDS) is concerned, for example, about the many instances of people with Parkinson's in hospital, often admitted for a non-Parkinson's related problem, find that their medication is inappropriately timed and altered from the stable drug regime they have achieved at home. Adjusting the timing of the medication a patient receives in hospital to accommodate drug rounds may adversely affect that patient's ability to maintain their usual level of independence and co-operate in movement, personal care, or swallowing (i.e. when the drugs wear off). This in turn has a resource implication in terms of time for the hospital staff and avoidably disempowers the patient.

- ♦ **Support for people who care for those with Parkinson's disease** – It is estimated that in Northern Ireland there are some 9,000 carers and family members supporting people with Parkinson's disease. Carers play a vital role in supporting and looking after people with Parkinson's disease and caring can be demanding socially, psychologically, and physically. Three-quarters of carers who look after someone with Parkinson's disease have been identified as having a health problem 13, which is frequently overlooked because of the burden of their caring and many report a lack of support from the statutory sector 14. The time and commitment involved in providing care on a long-term basis can also have financial implications for the carer, of course.
- ♦ **Shortage of home care assistants and domiciliary-based care** – There is a lack of home care assistants to prevent avoidable admission to hospital and care after discharge.

A Time to Care – The Way Forward in Northern Ireland

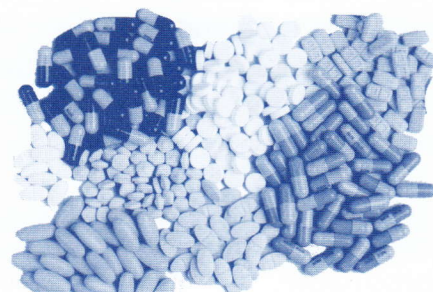
The Parkinson's Disease Society believes the following steps should be taken now to improve the care and support for people with Parkinson's disease and their carers in Northern Ireland.

1. Giving a high priority to the implementation of the recent review of neurology services 15. The Northern Ireland Assembly commissioned a review of neurology services that was published in 2002. The recommendations of this review should be implemented as rapidly as possible to expand the number of neurology outpatient clinics held and continue to develop the neurological clinical network in Northern Ireland.

2. Ensuring that all people with Parkinson's disease and their carers have much improved access to a specialist nurse with an interest in Parkinson's disease throughout Northern Ireland. Building on the already successful introduction of specialist nurses in all parts of the UK, the PDS believes that all people with Parkinson's disease and their carers should have access to a specialist nurse as soon as possible.

This could be a Parkinson's disease nurse specialist (PDNS), a neurological nurse, a nurse specialising in movement disorders or a qualified nurse trained in the care and management of Parkinson's disease. Introducing more specialist

*The PDS
believes
that wherever
possible,
patients should
be allowed to
self-medicate.*



Parkinson's Disease Society

A TIME TO CARE IN NORTHERN IRELAND

Improving quality of life for people with Parkinson's and their carers



nurses gives people access to specialist care and advice relatively quickly. A recent study in Wales demonstrated that one PDNS was able to save around £50,000 worth of consultant time¹⁶.

There are currently four specialist nurses in Northern Ireland and the PDS believes that another three posts should be funded as an immediate priority.

3. Funding additional posts for neurological consultant staff. The PDS would like to see 16 neurologists in post by 2008 as recommended in the recent review of neurology services in Northern Ireland¹⁷.

4. Initiating a professional development programme for staff in hospitals, nursing and care homes and primary care focusing on Parkinson's and other neurological conditions and their treatments. The creation of an information bank for health professionals which can be accessed by health service staff, care home staff and GPs. This may greatly reduce pressure on these staff and increase the quality and speed of diagnosis, care and treatment of those with Parkinson's disease.

The PDS has a professional development programme for health and social care professionals. This programme should be incorporated into the primary care protected learning initiatives. There should also be continuing professional development and awareness programme for key groups such as general physicians¹⁸ and other professionals who have regular contact with people with Parkinson's disease and their carers.

5. Increasing the number of residential and nursing care home places. The number of people with Parkinson's disease is forecast to increase for demographic reasons over the next few years, supported accommodation places will be in greater demand and there will be additional need for home support staff.

All staff involved in these settings should have access to accredited professional development that is focused firmly upon the needs of people with Parkinson's disease in their terms.

6. Wherever possible, patients should be allowed to self medicate. Where patients are not permitted to administer their own medication, supported medication schemes should be encouraged and if this is not possible every effort must be taken to ensure that medication is given to patients at the correct time.

7. Better support for carers. This should include accurate up-to-date information covering the nature and impact of Parkinson's disease, its treatment options, their side effects, and in addition, they should be supported in learning more about access to local health and social services and welfare benefits, improved support and assistance for the daily tasks of caring, respite care, and the establishment of networks to share experiences.

To find out more please contact:

PDS Northern Ireland

Northern Ireland Manager
William Canning

Dunsilly Lodge, Dunsilly, Antrim BT41 2JH

Tel/Fax 028 9442 8928

E-mail wcanning@parkinsons.org.uk

PDS National Office

215 Vauxhall Bridge Rd,
London SW1V 1EJ

Tel 020 7963 9307 Fax 020 7233 9908

E-mail tthorpe@parkinsons.org.uk

Web www.parkinsons.org.uk

PDS Helpline 0800 800 0303

(open Monday-Friday, 9.30am-5.30pm)



Parkinson's
Disease Society

Parkinson's Disease Society

A TIME TO CARE IN NORTHERN IRELAND

Improving quality of life for people with Parkinson's and their carers

- 1 The general prevalence of Parkinson's disease is one in 500 people. The incidence increases to one person per 100 in people aged over 65 and this rises to one in 50 in those aged 80 and over. See *Facing the Future*, Parkinson's Disease Society, July 2001, p.2 and CE Clarke, *Parkinson's Disease in Practice*, London: Royal Society of Medicine Press, 2001.
- 2 Five percent of people diagnosed with Parkinson's disease is aged under 40 years old. See *One in 20 An Information Pack for Younger People with Parkinson's*, Parkinson's Disease Society, September 2002.
- 3 Máire Rodgers and Robert Beatty, *Population Projections for Areas Within Northern Ireland*, NISRA Occasional Paper Number 14, December 2000, Annex 2, Table 4, p.44.
- 4 Department of Health, Social Services and Public Safety, Northern Ireland Assembly, *Review of Adult Neurology Services in Northern Ireland*, July 2002, Table 1, p.18.
- 5 Department of Health, Social Services and Public Safety, Northern Ireland Assembly, *Review of Adult Neurology Services in Northern Ireland*, July 2002, p.49.
- 6 Department of Health, Social Services and Public Health, Northern Ireland Waiting Lists, Table 7a, 4 September 2003.
- 7 Department of Health, Social Services and Public Safety, Northern Ireland Assembly, *Key Indicators of Personal Social Services for Northern Ireland 2002*, Appendix 1, Table 34, Column AA01.
- 8 Department of Health, Social Services and Public Safety, Northern Ireland Assembly, *Key Indicators of Personal Social Services for Northern Ireland 2002*, P.114, Table 11.3, Column OA01.
- 9 Máire Rodgers and Robert Beatty, *Population Projections For Areas Within Northern Ireland*, NISRA Occasional Paper Number 14, December 2000, Annex 2, Table 4, p.45.
- 10 Máire Rodgers and Robert Beatty, *Population Projections For Areas Within Northern Ireland*, NISRA Occasional Paper Number 14, December 2000, p.10.
- 11 Department of Health, Social Services and Public Safety, Northern Ireland Assembly, *Review of Adult Neurology Services in Northern Ireland*, July 2002, p.49.
- 12 *Working Together*, Parkinson's Disease Society, March 2001, p.2.
- 13 Yarrow, S, *Survey of Members of the Parkinson's Disease Society*, Policy Studies Institute, 1999, p.64.
- 14 Yarrow, S, *Survey of Members of the Parkinson's Disease Society*, Policy Studies Institute, 1999, p.64.
- 15 Department of Health, Social Services and Public Safety, Northern Ireland Assembly, *Review of Adult Neurology Services in Northern Ireland*, July 2002.
- 16 Hobson, P. *What is the economic utility of introducing a Parkinson's Disease Nurse Specialist service?* Conwy and Denbighshire NHS Trust Academic Unit, 2003.
- 17 Department of Health, Social Services and Public Safety, Northern Ireland Assembly, *Review of Adult Neurology Services in Northern Ireland*, July 2002, p.50.
- 18 Department of Health, Social Services and Public Safety, Northern Ireland Assembly, *Review of Adult Neurology Services in Northern Ireland*, July 2002, p.50.