Parkinson's Disease Society

A TIME TO CARE IN SCOTLAND

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

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Background

Over 10,000[1] people in Scotland have Parkinson's disease and over 500[2] of these people are aged under 40. By 2011 in Scotland, there will be 12% (120,000) more people aged 60 and over[3] and there are expected to be an additional 1,200 people with Parkinson's by this date.

Parkinson's in Scotland: meeting people's needs?

The Parkinson's Disease Society (PDS) has welcomed the formation of the Scottish Parliament and the opportunities it has provided for better healthcare in Scotland. The Society believes this has contributed significantly to bringing the needs of patients much closer to policy making and we welcome and support policies such as the increased support for carers and older people.

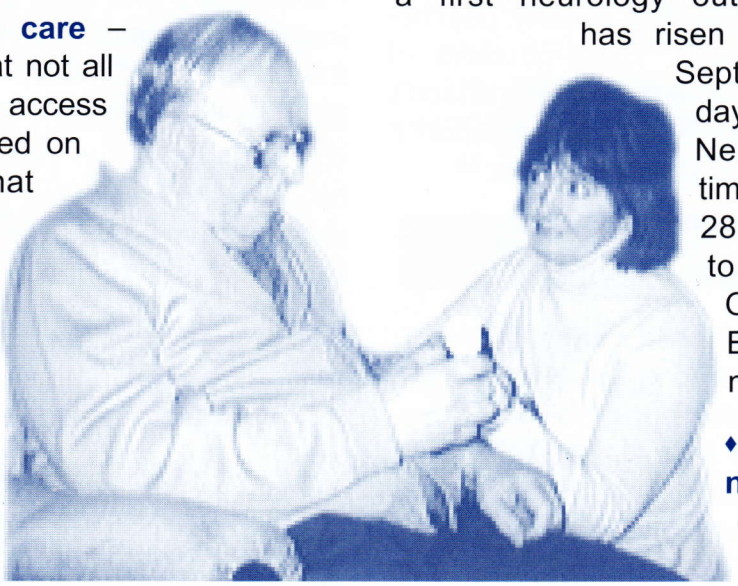
Combined with this we welcome the additional investment in services promised by the Scottish Parliament over the next few years. However, despite considerable evidence of good practice in health and social care there are several issues that are having a detrimental impact on the quality of care and support for people with Parkinson's and their carers:

- **Access to long-term care** – There are concerns that not all people will be able to access free personal care based on their needs and that where they live may determine the level and funding of care they receive. Some local authorities have already threatened to restrict eligibility for free personal and nursing care.[4] Further, there have been concerns that some local authorities may have to cut other important services to fund their legal requirements. Access to long-term care is important for people with Parkinson's and their carers as in the advanced stages of the condition people often require significant support at home or in a residential setting.

- **Reduction in care home places** – The net capacity of the independent care and residential sector in Scotland has fallen by 1,900 places (a reduction of 5.3%) since 2001 (care market analysts Laing and Buisson).[5] This is significant as the independent sector provides over 30,000 places for residential and nursing care in Scotland. At the same time the occupancy rates in nursing and residential homes have been steadily rising from 86% in 1999 to 90.8% in 2002.[6]

- **Increasing hospital waiting lists** – The average length of time people are waiting for a first neurology outpatient appointment has risen from 63 days[7] (30 September 2000) to 79 days[8, 9] (latest figures). Neurological waiting times also vary between 28 days in Lothian to 120 days in Orkney.[10] The Scottish Executive's target is nine weeks (63 days).[11]

- **Low priority given to neurological services** – Neurological services in Scotland are regarded by many people with neuro-



There are currently 12 specialist nurses for Parkinson's in Scotland; the PDS believes six more are needed urgently.

Parkinson's Disease Society
A TIME TO CARE IN SCOTLAND

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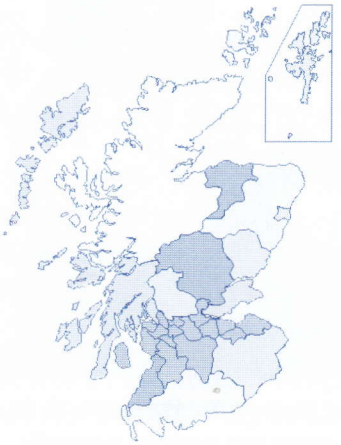
logical conditions and their carers as the 'Cinderella' services of the Scottish NHS. They point to the fact that there is no equivalent to the national service framework that is under development in England and Wales, no clinical guidelines are under development for Parkinson's and the fact that few health boards have a co-ordinated, coherent approach to long term neurological conditions.

- **The lack of awareness of Parkinson's among health and social care staff** – Research suggests that many health professionals have little knowledge of many neurological conditions because they see relatively few people with them (e.g. 65% of GPs see less than five patients each year with Parkinson's[12]). This means that many staff may be unaware how to optimise treatment management for people with Parkinson's leading to a poor quality of care. For instance there are many instances of people with Parkinson's in hospital not getting the correct medication in the correct dose at the correct time.

- **Support for people who care for those with Parkinson's** – It is estimated in Scotland there are 40,000 carers looking after someone with Parkinson's. Carers play a vital role in providing support and care for people with Parkinson's and caring can be demanding socially, psychologically, and physically. Three-quarters of carers who look after someone with Parkinson's report a health problem[13] and many report a lack of support from the statutory sector.[14]



Neurological waiting times also vary across Scotland: the wait is 28 days in Lothian, but 120 days in Orkney. The Scottish Executive's target is 63 days.

A Time to Care – The Way Forward in Scotland

The Parkinson's Disease Society (PDS) believes the following steps should be taken now to improve the quality of life for people with Parkinson's disease and their carers in Scotland.

1. Establishment of a National Strategy for Neurological Services

As with stroke, cardiac and cancer services, a national plan should be prepared and introduced for the development of neurological services in Scotland.

2. Each health board to develop and implement a co-ordinated approach to services for people with Parkinson's/ neurological conditions

Each health board should be required to develop a co-ordinated approach to neurological services (along the lines outlined by Greater Glasgow Health Board[15]) to complement the national strategy, help highlight gaps in services and develop holistic systems of support for people with long term conditions and their carers.

3. Ensuring that all people with Parkinson's and their carers have much improved access to a nurse with a special interest in Parkinson's throughout Scotland

Building on the already successful introduction of specialist nurses in parts of Scotland, the PDS believes that as many people with Parkinson's and their carers should have access to a specialist nurse as soon as possible. This could be a Parkinson's Disease Nurse Specialist, a neurological nurse, a nurse specialising in movement disorders or a qualified nurse trained in the care and management of Parkinson's. Introducing more specialist nurses gives people access to specialist care and advice relatively quickly. There are currently 12 specialist nurses in Scotland and that initially six additional specialist nurses with an interest in Parkinson's are urgently needed.

Parkinson's Disease Society

A TIME TO CARE IN SCOTLAND

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4. The Scottish Executive to commission SIGN guidelines for Parkinson's

They will set out clear standards and treatment guidelines for people with Parkinson's.

5. Planning adequate nursing and residential care

The number of people with Parkinson's is forecast to increase for demographic reasons over the next few years and additional places in appropriate residential and nursing care will be required.

6. Initiation of a professional development programme for staff in hospitals, nursing and care homes and primary care on Parkinson's and other neurological conditions and their treatments.

This would include the creation of an information bank for health professionals which could be accessed by health service staff, care home staff and GPs. This may help to reduce pressure on these staff and increase the quality and speed of diagnosis, care and treatment of those with Parkinson's. Secondly, the introduction of a continuing professional development and awareness programme for key groups of professionals who have regular contact with people with Parkinson's and their carers.

7. Developing expert patients in Scotland

The Society is currently participating in the expert patient programme (EPP) initiated by the Department of Health in England and the National Assembly for Wales. The EPP aims to empower people with Parkinson's and other long term conditions to take more control of their treatment and communicate more effectively with healthcare professionals in the management of their care.[16] The Society plans to evaluate how effective it is for people with Parkinson's. There are currently no plans for the Scottish Executive to deliver the EPP in Scotland, although some voluntary organisations do run programme courses in Scotland, such as Arthritis Care. If the EPP proves to be effective, the Society will explore the idea of delivering the programme itself in Scotland and work with the Scottish Executive and Scottish Parliament to start to initiate a Scotland-wide programme.

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

8. Wherever possible, patients should be allowed to self medicate

Where patients cannot self medicate, supported medication schemes should be encouraged and if this is not possible, every effort needs to be taken to ensure that medication is given to patients at the correct time.

9. Better support for carers

Including accurate up-to-date information covering the nature and impact of Parkinson's, its treatment options, their side effects, in addition to which carers should be supported in learning more about accessing 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.

A Time to Care in Scotland

The PDS calls on all Members of the Scottish Parliament and prospective Members to join us in challenging Parkinson's by supporting these proposals and agreeing to look at all practical ways of implementing better services for people with Parkinson's, their carers and families.

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1 *The incidence of Parkinson's disease is one in 500 and 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 *Scottish Executive, Fair Care for Older People, Chapter 5. Taken from http://www.scotland.gov.uk/library3/health/cdgr-06.asp.*

4 *BBC Online, Council rejects free care curbs, 13 November 2002, http://news.bbc.co.uk/2/hi/uk_news/scotland/2446019.stm.*

5 *Laing & Buisson's , press release Launch of Care of Elderly People Market Report 2002, http://www.laingbuisson.co.uk/News/lost%20elderly%20care%20places.html.*

6 *Scottish Executive, Occupancy Rate and Bed Complement in Private Nursing Homes 1999 – 2002, Statistics Release Vacancy Monitoring in Residential Care Homes and Nursing Homes, Scotland 2002, Table 2d, http://www.scotland.gov.uk/library5/health/00225-05.asp.*

7 *Written Scottish Parliamentary answer from Susan Deacon MSP to a question tabled by Margaret Smith MSP, S1O-2756.*

8 *Written Scottish Parliamentary answer from Malcolm Chisholm MSP to a question tabled by Christine Graham MSP, 5 June 2002, S1W-26119.*

9 *Written Scottish Parliamentary answer from Malcolm Chisholm MSP to a question tabled by Linda Fabiani MSP, 13 May 2002, S1W-25467.*

10 *Written Scottish Parliamentary answer from Malcolm Chisholm MSP to a question tabled by Christine Graham MSP, S1W-26119.*

11 *Written Scottish Parliamentary answer from Malcolm Chisholm MSP to a question tabled by Linda Fabiani MSP, 13 May 2002, S1W-25467.*

12 *Working Together, Parkinson's Disease Society, March 2001, p.2.*

13 *Yarrow, S, Survey of Member of the Parkinson's Disease Society, Policy Studies Institute, 1999, p.64.*

14 *Yarrow, S, Survey of Member of the Parkinson's Disease Society, Policy Studies Institute, 1999, p.64.*

15 *Greater Glasgow Health Board, Board Paper on the Development of Services for People with Long-term Neurological Conditions, 16 April 2002.*

16 *Department of Health (England), The Expert Patient: A new approach to chronic disease management for 21st century, August 2001.*

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