



Parkinson's Australia

Submission to

**Senate Community Affairs References Committee**

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**Inquiry into Planning Options and Services for People Ageing with a  
Disability**

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28 May 2010

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# Table of Contents

1. Introduction .....	3
2. Summary of Recommendations.....	5
3. Priority Needs.....	6
3.1 Support for specialist Neurological Nurse Educators and a pathway to support.....	6
3.2 There is a critical need for education and training programs on Parkinson's disease in the Aged Care Sector.....	10

# 1. Introduction

There has been a lot of research and much written about Australia's ageing population and the increasing health demands that this phenomena will have on future budgetary outcomes.

This submission seeks to establish a number of constructive and pragmatic proposals aimed at improving the quality of life for Parkinson's sufferers, their families and carers and at the same time identify long term cost savings. These proposals aim to reduce the anticipated explosion of costs in the aged care sector, reduce the burden of disease faced by people with Parkinson's and other neurological conditions as well as reduce discrimination and at the same time enable people to remain in employment longer, require less hospitalisation and most importantly continue living at home longer. Of note, to this review is the importance of Parkinson's as its sufferers have a much higher probability of nursing home placement than the general population due to functional impairment, drug complications (such as hallucinations) and comorbidities associated with Parkinson's such as dementia and incontinence<sup>1</sup>.

This submission is made by Parkinson's Australia, the national peak body representing over 300,000 Australians, their families and carers affected by Parkinson's disease.

Parkinson's Australia is a non-profit community organisation made up by a confederation of six State and Territory bodies. These bodies reach out to people with Parkinson's by delivering specialist information advice, counselling services (which include carers and families), education and support services.

## What is Parkinson's disease

Parkinson's is a chronic, progressive, incurable, complex and disabling neurological condition. It is the most common neuromuscular disorder in Australia and also remains one of the least understood in terms of its cause and management.

PD sufferers and their carers are confronted with major issues of disability including:

- tremor (trembling in hands, arms, legs, jaw and face)
- rigidity and stiffness of limbs and trunk
- sudden slowness and loss of spontaneous movement and impaired balance and coordination.

PD also results in impaired speech and various mental health issues, such as depression and anxiety arising from both the impacts of the disease on individuals, the pathology of the disease and side effects of medications. Other symptoms include sleep disruptions, difficulty with chewing and swallowing and urinary and constipation problems.

PD has a community stigma and is under resourced in terms of the delivery of health and social support services. To change this predicament Australia needs to assist the health and general community to comprehend better the challenges and needs of those suffering from this long overlooked, complex and disabling condition.

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<sup>1</sup> Living with Parkinson's Disease ó Challenges and Positive Steps for the Future, Access Economics, June 2007, p10

Parkinson's Australia recently commissioned Access Economics to conduct a systematic and in-depth report<sup>2</sup> into the extent and scale of the costs and disability burden faced by People with Parkinson's disease (PWP), their families and the community at large.

The report, *Living with Parkinsons Disease: Challenges and Positive Steps for the Future 2007*, found that there was a lack of awareness and understanding regarding this illness. Misdiagnosis is common preventing patients receiving treatment and intervention at an early stage.

The key to the new national approach is early intervention, based on effective health interventions, as this improves quality of life, slows disability, reduces growth rate in the future costs of PD and allows sufferers to continue to be productive in the workplace.

### **“Living with Parkinsons Disease: Challenges and Positive Steps for the Future 2007”**

The significant findings of the report are:

In 2005 approximately 73,000 Australians have PD – a conservative figure due to misdiagnosis and under-diagnosis.

- People of working age (15-64 years) comprise 18% of PWP – this is not just an old person's disease.
- There were around 8,900 new cases of PD in 2005 – with one new case being diagnosed every 56 minutes or 25 new cases every day in 2005.
- PD is more prevalent than a number of diseases and injuries considered National Health Priority Areas. These including some cancers and injuries, homicide and violence, suicide and self inflicted injuries, fires, burns and scalds, and machinery accidents.

### **Economic Costs of the disease**

The total financial cost of PD per annum was around \$527.8 million in 2005

- The financial costs of PD are incurred over many years. While the median years living with PD is 12.2 years, many live with the condition for well over 20 years.
- The lifetime financial cost of a PWP living with PD for 12 years (around \$100,000) is on par with the average lifetime financial cost of cancer (\$114,500).
- While lower than many childhood cancers, it is significantly higher than prostate and breast cancer (both around \$64,000).

### **Burden of Parkinsons Disease**

The total economic cost of PD was \$6.8 billion in 2005. Furthermore, these costs are set to rise substantially given the anticipated 20% increase in the proportion of older Australians over the next 5 years.

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<sup>2</sup> Access Economics, *Living with Parkinsons Disease: Challenges and Positive Steps for the Future* June 2007

## **2. Summary of Recommendations**

Parkinson's Australia seeks the support and commitment of the Federal government to improve the quality of care of people with Parkinson's and their families starting from diagnosis and continuing throughout the whole progress of this disabling condition. This submission includes recommendations to improve the quality of life for all Australians Ageing with Parkinson's disease both whilst living in the community and in residential care for those whose disability deteriorates to a point where such care is inevitable.

### **1. Support for a Parkinson's community model of care using a pathway to specific services and Specialist Neurological Nurse Educators**

Currently Australia's poor reputation for specific services on Parkinson's disease could be addressed with a costs neutral, potentially cost saving, national strategy that helps not only Parkinson's sufferers but also other neurological conditions.

A. Over four years provide funding to employ 50 of the needed 200-300 Specialist Neurological Nurse Educators across Australia to significantly improve the quality of life for people with Parkinson's, Motor Neurone Disease and other neurological conditions whilst reducing government health care costs. These nurse educators can substitute for some of the specialist care, contribute to better management of treatment, and through information and referrals reduce the impact of symptoms, and hospital and aged care admissions. There are potential savings of up to \$100,000 per annum for every person who remains in the community rather than residing in an aged care facility. There are also potential savings of \$20 million to \$ 40 million in hospital costs through prevention of unnecessary hospital entry. In Australia there is a lack of services for people suffering from neurological conditions like Parkinson's. This situation is exacerbated in regional and remote areas where Parkinson's disease is more prevalent (20% higher) and there are no neurologists based in these areas.

B. Provide funding for a position in each state to be a link for people with Parkinson's and their families to access the best and most appropriate care at any stage of the condition. These link workers will be expert in understanding disability and ageing and will have an expert knowledge of what people need as their disability increases. This position would be a first point of call and then available for people as their Parkinson's progressed and their symptoms worsened.

Cost:

In the first 4 years, it is envisaged that an initial 50 specialist nurses (established at a rate of 10-20 per year) would cost of \$1.5m in the first year rising to \$7.5m in the fourth year = \$17.55m over 4 years.

The cost of providing a link worker in each state and territory @ \$0.45m each year for four years would be \$1.8m per annum.

### **2. Increase awareness and training in the Aged Care Sector of the challenges and needs of those suffering from this complex and disabling condition.**

There is a lack of awareness in the health and general community of the challenges and needs of those suffering from this complex and disabling condition, as well as community

stigma and constraints in the delivery of health and social support services.<sup>3</sup> This proposal begins to address the impact of this lack of awareness on the care needs of the most vulnerable in the Parkinson's community, those in aged care facilities, who are often most at risk of cognitive decline.

People with Parkinson (PWP) in residential facilities are usually elderly, cognitively impaired, physically disabled with poor quality of life and a high mortality rate.<sup>4</sup> Most staff in aged care facilities have limited or no training in Parkinson's disease. Research shows that basic training in Parkinson's specific knowledge can produce a significant and clinically meaningful improvement in the care of PWP<sup>5</sup>.

C. Over three years a national training program be developed, trialled and evaluated by Parkinson's Australia to provide training in all aged care facilities in the management of advanced Parkinson's disease.

Cost: \$1.8m over 4 years.

### 3 Priority Needs for people with Parkinson's

#### 3.1 Specialist Neurological Nurse Educators and a pathway to support

**There are currently limited services focusing specifically on Parkinson's disease and people with the condition and their families and carers do not know where to seek specific help.**

The National Health & Hospitals Reform Commission (NHHRC) stated that effective management of people with chronic illness requires continuity of care, and the use of multidisciplinary team, which needs to work effectively together with defined care pathways and is a powerful framework to catalyse action on health improvement (p84).

Our proposal aims to strengthen services for people with Parkinson's and their families using a similar framework.

Presently, the provision of health care services for patients and families affected by PD like other neurological conditions are concentrated around pockets of specialist neurologist care within metropolitan centres with a marked deficiency in rural and remote regions. Strategic targeting of the general community with innovative initiatives offers a clear opportunity to improve the efficiency of interventions for this target group. Following diagnosis people are not routinely given information on what services there are in the community or how to access them.

#### *Neurological Specialist Nurse Educators*

The failure to provide adequate services outside larger clinical centres is by no means unique to Australia. Other universal systems of health care around the world have had to address this dilemma. Probably the most successful model that has been formulated exists in the UK and in Europe where there has been the widespread introduction of Parkinson's disease specialist nurses. In particular, the role of specialist nurses has been effectively

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<sup>3</sup> Access Economics Pty. Ltd, *Living with Parkinson's Disease, 2007, p.i*

<sup>4</sup> M.Makoutonia & R Ianseck, *Optimising Care of residents with Parkinson in supervised facilities p.2*

<sup>5</sup> M.Makoutonia & R. Ianseck, *Optimising Care of residents with Parkinson's in supervised facilities, p3*

rolled out in the UK. In particular, the National Institute for Health and Clinical Effectiveness (NICE), who are the UK's independent organisation responsible for providing national guidance on promoting best practice health care and preventing and treating ill health, have included Parkinson's specialist nurses in their model for the management of the disease, recognising the vital function they perform.

The role of Neurological Specialist Nurse Educators is to provide access to specialist care, particularly for:

- i) Monitoring clinical indicators (e.g. the development of falls and dementia);
- ii) Overseeing and assessing adjustments in medication in consultation with the neurologist and GPs;
- iii) Coordinating access to other essential services (e.g. speech pathology, physiotherapy), particularly for those in regional and remote areas;
- iv) Providing an effective integrated primary care service including health and social support via community and home-based care;
- v) Providing practical support and education for the unpaid carers of people with Parkinson's;
- vi) Working collaboratively with GPs, neurologists, Parkinson's clinic staff, pharmacists, aged care nursing staff, physiotherapists and occupational therapists to case manage the long term needs of people with Parkinson's, their family and carers; and
- vii) Reducing the impact of hospitalisation by educating all medical and clinical staff (including surgeons) on the problems associated with the interaction between Parkinson's medication and hospital treatments.

The Minister for Health and Ageing, The Honourable Nicola Roxon MP has already demonstrated her support for the augmented role of specialist nurse practitioners and in particular, highlighted her desire to see these skills increasingly implemented within the primary health care setting. The Minister has also recognised that there are many barriers that exist when attempting to expand and integrate the nursing profession within the community and rural setting. Parkinson's Australia believe that the time has come to work through partnership with the Commonwealth Government to attempt to remove these obstacles and improve the lives of Australians living with PD and other neurological conditions.

The model of national Parkinson's specialist nurses in the setting of rural and remote Australian communities would be expected to have even greater impact, particularly as it is estimated that the prevalence of Parkinson's in regional and remote Australia is 1.6 times the rate in metropolitan areas<sup>6</sup>.

To support the concept of a community based specialist nurse position in Australia an innovative pilot project in the Shoalhaven area, NSW has been funded. This project provides a two year examination of the benefits of a Neurological Specialist Nurse Educator in a rural and remote setting is currently in its first year. Following the expected success of this project, Parkinson's Australia proposes that this model be rolled out throughout Australia.

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<sup>6</sup> Peters C, Gartner C, Silburn P, and Mellick G (2006) Prevalence of Parkinson's Disease in Metropolitan and rural Queensland: A general practice survey in *Journal of Clinical Neuroscience* 13: 343-348.

## Health Care Savings

One of the major benefits from the establishment of specialist Neurological nurse educators will be to assist in the reduction in the growth in the health and ageing expenditure over the coming decades. This would be achieved by avoiding unnecessary hospital admissions through falls and other conditions, and delayed entry into aged care facilities through the provision of better integrated care services and community and home-based care.

In addition, the nurse educators can improve drug management and reduce the incidence of complications – both of which reduce not only hospital admissions, outpatient attendances but also nursing home admissions and disease burden<sup>7</sup>. For every 12 months that new entrants into aged care facilities are delayed, the savings to Governments are between \$8m and \$24m per year rising to between \$24m and \$75m per year in 2033. The longer people can remain living independently in their own homes (which is what most people want) the greater the potential savings to governments.

UK National Institute for Health and Clinical Excellence (NICE) Guidelines have estimated that access to specialist nursing care and therapy services would reduce hospital inpatient admissions by 50% and hospital outpatient attendance by 40%<sup>8</sup>. In Australia, the Federal Health Minister recently stated that 500,000 preventable hospital admissions occur each year in Australia and that the Productivity Commission argue that 100,000 deaths could be avoided by 2030 through health promotion and disease prevention<sup>9</sup> - the evidence from specialist nurse educators in WA and in the UK<sup>10</sup> clearly show that a large number of these hospital admissions are Parkinson's related and are preventable.

In the Australian setting this would equate to a net saving of around \$150,000 per annum per specialist nurse in consultant clinical outpatients alone<sup>11</sup>. This saving is an underestimation as other cost savings arise from education, health promotion, research and development, specialist drug intervention and domiciliary visits.

In addition, the involvement of specialist Neurological Nurse Educators in improving drug management for people with PD will reduce the incidence of complications thereby reducing hospital admissions, outpatient attendances, nursing home admissions and disease burden. It is therefore, reasonable to assume that regular access to specialist nursing and therapy services will reduce the need for unnecessary hospitalisation, outpatient appointments and GP attendances. Total annual hospital costs for PD in 2005 was \$74.4m<sup>12</sup> - much of these costs can be provided cheaper and out of the hospital system.

UK guidelines on PD specialist nurses are based on case loads of about 300 patients. This translates to a requirement of around 200 specialist PD nurses in Australia, each with a similar case load of about 300 patients. The Australian model goes further and could

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<sup>7</sup> Access Economics Report, "Living with Parkinson's disease: Challenges and Positive Steps for the Future", (2007) p 113.

<sup>8</sup> "Parkinson's disease: diagnosis and management in primary and secondary care", National cost-impact report, UK National Institute for Health & Clinical Excellence (NICE) Guidelines No 35, June 2006

<sup>9</sup> Speech by the Hon Nicola Roxon MP, Minister for Health & Ageing to the Committee for Economic Development of Australia, Health: the National Priorities Forum, Melbourne 30 April 2008

<sup>10</sup> Commissioning Parkinson's services: the clinical and financial value of Parkinson's Disease Nurse Specialists (attached)

<sup>11</sup> "What is the Economic Utility of Introducing a PNS Service?", S Roberts, Conway and Denbighshire NHS Trust (see attached)

<sup>12</sup> P47, Access Economics "Living with Parkinson's Disease", June 2007



include a number of other neurological conditions such as Motor Neurone Disease.

In addition, there would be flow-on effects where the increasing demand for aged care facilities would be slowed. Currently, the cost of aged care facilities for people with PD is over \$170m pa and is predicted to double by 2020<sup>13</sup>.

**Recommendation A: That the Senate Community Affairs References Committee requests the Federal Government to consider funding the introduction of the Specialist Neurological Nurse Educator Program.**

Cost: In the first four years, it is suggested that the Government provides initial funding for 50 specialist Neurological Nurse Educators with the remainder being funded after 4 years. These positions would be established progressively throughout Australia with 10 positions in the first year, an additional 12 in the second year, an additional 13 in the third year and an additional 15 in year 4.

This would cost \$1.5m per year in year one (\$150,000 pa per nurse) rising to \$7.5m in year 4 adding up to \$17.55m over 4 years.

However it is important to note that total net savings to governments from this initiative of 50 Specialist Neurological Nurse Educators could be \$7.5m by year 4, making the positions at least cost neutral.

**Recommendation B: That the Senate Community Affairs References Committee supports the concept of a community Link Worker in each state (most appropriately located in the offices of the state or territory Parkinson's Association) to be an initial and ongoing resource for people with Parkinson's and their families to access the best and most appropriate care and services at all stages of their disability, including referral to Specialist Neurological Nurse Educators.**

Cost: to provide the equivalent of one Link Worker position in each state per annum: 6 x \$75,000 = \$4.2m per annum.

### **3.2 Education and training programs on Parkinson's disease in the Aged Care sector.**

#### **The impact of Parkinson's disease in the Aged Care Sector**

It was estimated that people with Parkinson's make up between 5% and 7% of the population in aged residential care<sup>14</sup>. This equates to 12,283 people based on the number of residential aged care places in Australia at 30 June 2008<sup>15</sup>

They are usually elderly (79.7 years), dependent, cognitively impaired with a high rate of dementia, depression and associated high falls rate<sup>16</sup>. People with Parkinson's in aged care facilities suffer a high disease burden due to *functional impairment, drug*

<sup>13</sup> P37, Access Economics *Living with Parkinson's Disease*, June 2007

<sup>14</sup> Goetz, C G and Stebbins, G T, *Mortality and hallucinations in nursing home patients with advanced Parkinson's disease* in *Neurology*, 1995, p. 669-71

<sup>15</sup> AIHW *Residential aged care in Australia 2007-2008: a statistical overview*

<sup>16</sup> Buchanan, R J, Wang, S, Huang, C, Simpson, P and Manyam, B V *Analyses of Nursing Home residents with Parkinson's disease using the minimum data set* in *Parkinsonism and Related Disorders* 2002 p.369-80

*complications (such as hallucinations) and comorbidities associated with PD (such as dementia and incontinence).*<sup>17</sup>

The Government has an enormous investment in Aged Care Services and Parkinson's care is an increasing feature of this care. The Access Economics report of 2007 states that the health cost profile for PD was dominated by high care residential accommodation or 'aged care' - \$170.0 million (49.4%)<sup>18</sup>

Whilst Parkinson's Australia is committed to assisting people to remain in their own homes for as long as possible which both increases personal well being and saves on health funding, the reality is that due to the very complex nature of the condition, a percentage will end up in residential care through degeneration of symptoms and increase in carer burden. For these people Parkinson's Australia promotes and seeks best practice in the provision of care.

### **The value of training and the research supporting this proposal**

Training in dementia care goes some way to equipping staff to cope with the needs of people with Parkinson's in residential care but specialist knowledge is needed to manage the complex physical movement symptoms that are also associated with this condition. The government has invested highly in training and care for people with dementia in residential care with positive results and Parkinson's Australia asks that a similar commitment be made towards the training of staff and care of people with Parkinson's in residential care. Parkinson's is the second most common neurological condition after dementia.

A study was conducted by Dr Margarita Makoutonina and Professor Robert Iansek in 2008-09 which involved the delivery of a comprehensive training program to 118 staff members across 9 aged care facilities in Melbourne. As well as showing increased and sustained skill levels in staff, the study demonstrated

*...sustained improvements in residents with Parkinson's over the 12 month period and these improvements were reflected in all measures including impairment, quality of life, mood and falls*

In particular the reduction in falls has the capacity to save costs in hospital and rehabilitation care. The study noted that there was:

*...dramatic improvement in falls rate after staff education which was maintained to 12 months and was mirrored by all resident outcomes which were therapist dependent.*

As numbers of people with Parkinson's in residential care have increased, the demand for training has also increased. The various Parkinson's Associations have been trying to meet this demand, but have neither the resources nor a consistent training package to offer facilities. State Associations also receive requests from training providers of Certificate III in Aged Care to provide specific sessions on understanding and managing Parkinson's disease.

The development of an industry standard package with funding to deliver throughout Australia would provide consistency and expertise, ensuring that all facilities including

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<sup>17</sup> Access Economics Pty. Ltd, *Living with Parkinson's Disease, 2007, p347*

<sup>18</sup> Access Economics Pty. Ltd, *Living with Parkinson's Disease, 2007, p.47*

those in rural and remote areas have access to this level of training and skills development.

**Recommendation C: That the Senate Community Affairs References Committee supports Parkinson's Australia's request of the Federal Government to fund the development of a specific training package for staff in residential aged care, on the care and management of people with Parkinson's. The aim will be to develop a Parkinson's competency to form part of the Certificate III in Aged Care and a DVD for residential care staff focussing on medication management and falls reduction specifically for people with Parkinson's. That this package be trialled and assessed and then provided to all residential aged care facilities in Australia. The consultation process will involve all state and territory Parkinson's Associations, and representatives from DEEWR, Aged Care Sector and Consumers.**

**Development and costs over 4 years:**

Year 1: Development of Competency including consultation of all state Associations, Industry & Training representatives and writing: \$220 000

Year 2: Production of Training Package: \$100 000

Production and distribution of DVD: \$80 000

Trial of Competency: \$50 000

Years 3 and 4: Provision of Training to facilities throughout Australia: \$1,350,000

TOTAL: \$1.8m