



PARKINSON'S AUSTRALIA INC.

2010 FEDERAL POLICY INITIATIVES

A New Approach to Parkinson's Disease

Substantial savings for government
Substantial services for people living with Parkinson's

A Message from the President and CEO

Across Australia people with Parkinson's disease, their families and carers currently face four major challenges:

1. There are limited services focused specifically on Parkinson's disease;
2. A lack of awareness and knowledge, of the condition and its impact exists in the health, aged care & general community;
3. People with early onset Parkinson's lack appropriate services; and
4. There are cost restrictions on access to effective treatment options.

This submission by Parkinson's Australia, the national peak body representing over 300,000 Australians, their families and carers, is based on the 2007 Access Economics Report, *Living with Parkinson's Disease, Challenges and Positive Steps for the Future*.

Parkinson's disease is a chronic, progressive, incurable, complex and disabling neurological condition that often includes other co-morbidities.

Parkinson's disease is the second most prevalent neurological disease in Australia. Currently twenty five people with Parkinson's are diagnosed every day in Australia and the number of people with Parkinson's is expected to treble to approximately 240,000 by 2033. This data aligns with the Federal Health Minister's estimation that one of the key challenges to the health system will be the additional cost of the anticipated 280% increase in neurological disorders over the next 25 years, where Parkinson's is a major contributor to this increase.

In 2005 the total financial cost of Parkinson's disease per annum was around \$527.7 million (the total economic costs per annum was \$6.8 billion) with the Federal Government bearing 40.5% of the financial costs and the household of a person with Parkinson's disease bearing 20% of the financial costs.¹ The prevalence of Parkinson's disease is expected to grow by 4% per annum due to demographic ageing.²

This submission proposes a strategy to begin addressing these challenges whilst limiting the financial costs to the Australian Government of Parkinson's disease and the disease burden for people with Parkinson's, their families and carers. The proposals in this document are designed to achieve two outcomes:

- Improve the quality of life for all Australians with Parkinson's disease and enabling people to continue in employment, to live at home longer and require less hospitalisation.
- Produce substantial downstream savings in hospital and aged care costs as well as productivity benefits for government.

Parkinson's Australia proposes a four point strategy; a new national approach to Parkinson's disease which complements the current focus of *Ageing well, ageing productively*.

We request a public commitment to Parkinson's Australia's policy initiatives from all those seeking to be elected to Federal Government in 2010.

Mr Roger Norton
President

Mr Norman Marshall
CEO

¹ Access Economics Pty. Ltd, *Living with Parkinson's Disease, 2007, p.90-91*

² Access Economics Pty. Ltd, *Living with Parkinson's Disease, 2007, p.ii*

National Policy Initiative – Executive Summary

Parkinsons Australia recommends that the Commonwealth Government immediately address the following challenges facing people with Parkinsons disease, their carers and families. Implementing programs which address these four challenges will save the Government millions of dollars in the long run³.

1. Limited services are focused specifically on Parkinson’s disease

Australia, currently has a poor reputation for service delivery specific to those with Parkinson’s disease. This challenge can be addressed with a cost neutral, potentially cost saving, national strategy that helps not only people with Parkinson’s but also other neurological conditions.

It is proposed that the Federal Government, over four years, provide funding to employ 50 Specialist Neurological Nurse Educators across Australia. This would 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 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.

The challenge of service gaps for those with neurological conditions (like Parkinson’s) is exacerbated in regional and remote areas, where Parkinson’s is more prevalent (20% higher), as there are no neurologists based in these areas, neurological nurses would provide an essential service to those who cannot afford to travel regularly to the city.

It is envisaged that an initial 50 specialist nurse educators (phased in over 4 years) would cost \$1.5m in the first year rising to \$7.5m in the fourth year), total of \$17.55 over 4 years

2. Aged Care – A lack of Parkinson’s awareness and its impact

There is a lack of awareness in the general community, and in many parts of the health services community, of the challenges and needs of those suffering from this complex and disabling condition. There is a consequential community stigma and constraints in the delivery of quality health and social support services.⁴

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.⁵ 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 PWP⁶. Consequently it is proposed that 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.

³ The 2007 Intergenerational Report highlighted the three major spending pressures for the next 40 years will be health, aged pensions and aged care. Any prudent investment today in these areas will reduce these pressures in the future.

⁴ Access Economics Pty. Ltd, *Living with Parkinson’s Disease, 2007, p.i*

⁵ M.Makoutonia & R Iansek , *Optimising Care of residents with Parkinson in supervised facilities p.2*

⁶ M.Makoutonia & R. Iansek, *Optimising Care of residents with Parkinson’s in supervised facilities, p3*

The cost for this national program would be \$1.8m over 4 years.

3. People with early onset Parkinson's lack appropriate services

Being diagnosed younger is different. These are the foundation years for forming relationships and rearing children, career development, asset acquisition, active leisure and recreation, and planning for a secure future. Young onset people with Parkinson's have to learn to live with a severely disabling condition for many decades.

It is proposed that the Federal Government provide assistance of \$400,000 over two years to establish a National Young Onset Project Centre that will support younger people with Parkinson's disease. This Centre aims to maximise the young onset group's independence and well being, reduce emergency and high cost service requirements by accessing services and training, such as employment and financial assistance, counselling, mental health and specific health services, as well as peer support.

The costs of providing this Centre would be offset by:

- 1) An increase in workplace productivity as people with young onset Parkinson's remain longer in the workplace
- 2) A reduction in hospital admissions used to stabilize health crises due to medication issues, falls and depression;
- 3) An anticipated delay in the progression of the disease through appropriate self management strategies.

4. There are cost restrictions on access to effective treatment options

In Australia, there are a number of very effective treatment options for people with Parkinson's. Unfortunately some of these options are expensive and whilst the drug may be listed on the Pharmaceutical Benefits List, the consumables and infusion devices are not and as a result, some people are unable to afford these treatments and benefits.

It is proposed that the Federal Government implement a comprehensive Patient reimbursement system for consumables and continuous infusion devices used to deliver Parkinson's disease medication.

The initial cost of the program would be \$1.6m per year, \$6.4m over 4 years.

Introduction

Parkinson's Australia is seeking a commitment from the Commonwealth Government to a new set of policy initiatives for Parkinson's disease (PD). A national approach is needed that recognises the current challenges facing people with PD and sets clear strategies that:

- enable people with PD to have a better quality of life, continue living at home longer and require less hospitalisation;
- reduce the levels of discrimination in Aged Care;
- assist young onset Parkinson's to live their lives to their optimum capacity;
- enable all equitable access to effective treatment options

The cornerstone of the approach is a commitment to better health for People with Parkinson's (PWP) through intervention, care and support. Given the emphasis on the need to better manage chronic illness outlined in the *Intergeneration Reports since 2002*, Parkinson's disease deserves a more equitable share of funding for initiatives that cover health, ageing, disability and community services.

PD is a chronic, progressive, incurable, complex and disabling neurological condition. PD is one of the most common neurological disorders in Australia and one of the least understood in terms of its cause. There are over 300,000 Australians affected by this chronic illness – many of whom are not receiving the services and support that people in most European, North American and UK countries are receiving.

Australians with Parkinson's 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.

Parkinson's Australia recently commissioned Access Economics to conduct a systematic and in-depth report⁷ into the extent and scale of the costs and disability burden faced by PWP and the community at large.

The report, *Living with Parkinson's 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, equitable access to services, as this will improve quality of life, slow disability development, reduce growth in the future costs of PD and allow PWP to continue to be productive in the workplace.

⁷ Access Economics, "Living with Parkinson's Disease: Challenges and Positive Steps for the Future" June 2007

In the report "*Living with Parkinsons Disease: Challenges and Positive Steps for the Future*" the significant findings were:

In 2005 approximately 73,000 Australians had PD – a conservative figure due to 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.

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).

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

Four Key Strategies

The proposed national approach is designed to establish a set of constructive and pragmatic steps, interlinking government, non-government, clinical research and community services to:

1. enable people with PD to have a better quality of life, continue living at home longer and require less hospitalisation;
2. reduce the levels of discrimination in Aged Care;
3. assist young onset Parkinson's to live their lives to their optimum capacity;
4. enable equitable access to effective treatment options

These strategies will significantly decrease the economic and social costs of this disease for PWP, the Government and to the community. Each strategy is described below and costed.

1. A Greater Focus on Specific Services for Those with Parkinson's disease through the Introduction of Specialist Neurological Nurse Educators (SNNEs)

The provision of health care services for patients and families affected by PD like other neurological conditions are currently concentrated around neurological specialists within metropolitan centres with a marked deficiency in other regions (finding a neurologist in rural areas is very difficult). Thus, the challenge of obtaining appropriate services is exacerbated for those in regional areas, where Parkinson's is more prevalent (20% higher). SNNEs would provide an essential service to those who cannot afford to travel regularly to the city. The proposed strategy is an excellent example of what the National Health & Hospitals Reform Commission referred to as the effective management of people with chronic illness through continuity of care, and the use of a multidisciplinary team working effectively with defined care pathways (p84).

United Kingdom (UK) guidelines on PD specialist nurses are based on case loads of approximately 300 patients per nurse. If these guidelines were applied to Australia it would equate to a requirement of 200 specialist nurses. The model proposed by Parkinson's Australia, strategically targets rural and remote communities as well as benefitting a number of other neurological conditions besides Parkinson's, such as Motor Neurone Disease.

It is proposed that the Government provides funding for 50 SNNEs over 4 years, with the remainder being funded after year 4. The initial 50 positions would be established throughout Australia, at the rate of: 10 positions in Year 1, 12 in Year 2, 13 in Year 3 and 15 in Year 4. **Costs: \$1.5m in year one (\$150,000 pa per nurse) rising to \$7.5m in year 4 (Total \$17.6m over 4 years).**

Savings: The potential net savings to government from 50 SNNEs could be as high as \$7.5m. The UK National Institute for Health and Clinical Excellence (NICE) Guidelines estimated that access to specialist nursing care and therapy services would reduce hospital inpatient admissions by 50% and hospital outpatient attendance by 40%⁸. The Australian Federal Health Minister recently stated that 500,000 preventable hospital admissions occur each year, and the Productivity Commission argue that 100,000 deaths could be avoided by 2030 through health promotion and disease prevention⁹. Evidence from Parkinson's specialist nurses in West Australia as well as in the UK¹⁰ clearly show that a large number of these hospital admissions are Parkinson's related and are preventable. (See attachment 1).

The UK figures indicate that there is potential for a net saving of around \$150,000 per annum per specialist nurse through clinical outpatients services alone¹¹. This saving is likely to be an underestimation as further cost savings would arise from health promotion and domiciliary visits. In addition, it is reasonable to assume that regular access to SNNEs will improve self medication management thereby reducing the incidence of complications and thus hospital admissions. That service, combined with regular therapy services, reduce the need for unnecessary hospitalisation, outpatient appointments, GP attendances and nursing home admissions. Given that total annual hospital costs for PD in 2005 was \$74.4m¹², the estimated potential savings on hospital admissions is \$20 million to \$40 million per year. In addition, the 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 2020¹³.

Recommendation: That the Federal Government, over four years, provide funding to employ an initial 50 Specialist Neurological Nurse Educators across Australia.

⁸ '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

⁹ 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

¹⁰ Commissioning Parkinson's services: the clinical and financial value of Parkinson's Disease Nurse Specialists

¹¹ "What is the Economic Utility of Introducing a PNS Service?", S Roberts, Conway and Denbighshire NHS Trust

¹² P47, Access Economics "Living with Parkinson's Disease", June 2007

¹³ P37, Access Economics "Living with Parkinson's Disease", June 2007

2. Better Care for People with Parkinson's in the Aged Care Sector.

There is a critical need for education and training programs on Parkinson's disease in the Aged Care sector. It is estimated that people with Parkinson's make up between 5% and 7% of the population in aged residential care¹⁴. This equates to 12,283 people based on the number of residential aged care places in Australia at 30 June 2008¹⁵. The people with Parkinson's in aged care are mainly elderly (79.7 years), dependent, cognitively impaired with a high rate of dementia, and depression with an associated high falls rate¹⁶. People with Parkinson's in aged care facilities suffer a high disease burden due to *functional impairment, drug complications (i.e. hallucinations) and comorbidities associated with PD (such as incontinence)*.¹⁷

The Government has an enormous investment in Aged Care Services and Parkinson's care is an increasing feature of these services. 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.¹⁸ Whilst Parkinson's Australia is committed to assisting people to remain in their own homes for as long as possible which has been shown to increase personal well being, and saves on health funding, the reality is that due to natural progression of the condition, a percentage of People with Parkinson's will need residential care. For these people Parkinson's Australia promotes and seeks best practice in the provision of care.

The research supporting this proposal -

Parkinson's is the second most common neurological condition after dementia. The existing 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.

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".

The development of an industry standard package with funding for delivery Australia-wide would provide consistency and expertise, ensuring that all facilities including those in rural and remote areas have access to this level of training and skills development. Such a project would include development of competencies, production of training package including teaching aids and provision of training to facilities throughout Australia.

Recommendation: That the federal government fund the development of a specific training package for staff in residential aged care, on the care and management of people with Parkinson's. Cost \$1.8m over 4 years.

¹⁴ 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

¹⁵ AIHW *Residential aged care in Australia 2007-2008: a statistical overview*

¹⁶ 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

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

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

3. Coordinated Services for People with Early Onset Parkinson's

There is a critical need for the establishment of a National Support Network for Young Australians with Parkinson's.

Unlike many people diagnosed in later life, younger people typically live for decades with Parkinson's and experience the full spectrum of the condition's debilitating physical, cognitive and emotional effects. This significant sub-group are diagnosed when they have very full lives and when their identities and futures are being shaped by pursuing careers and accumulating assets; forming and maintaining close friendships and partnerships; establishing families and raising children; and engaging in active and social leisure pursuits. This is also the time when they are also laying the foundations for retirement and older age.¹⁹

People with young onset Parkinson's disease therefore have additional to, and very different information, advocacy and community support needs from people diagnosed with Parkinson's in their older years.

North America, Europe and the UK all have established well developed networks for Young People with Parkinson's. These networks have used the internet to disseminate information about Parkinson's and its management and to provide individuals with the opportunity to connect with others through informal peer support. Australia, despite extensive service development for younger people with other progressive and disabling conditions, has not provided Young People with Parkinson's with the same opportunities to access information, services and peer support specifically relevant to their situation.

Parkinson's Victoria collaborated with "Parkies with a Purpose" to research the issues and impact of young onset Parkinson's disease in Australia, leading to a report produced in 2010 by Dr Chris Fyffe & Jeffrey McCubbery. This report identifies the needs of people with Young Onset Parkinson's and their family members.

The first recommendation of this report is the establishment of a national young onset resource centre to provide information, peer support, service development and research on the means for supporting people's lifestyles. Information would be electronically available and in formats relevant to people isolated by language, geography or internet competence. Models of peer support would be varied and available to family members, and friends, as well as people with young onset.

The centre would also be a focal point to enable Young Onset people to access services and training, in areas such as maintaining employment and financial assistance; as well as counselling and mental health and other specific health services.

It is envisaged that an Australian National Young Onset Project Centre would employ a full time Young Onset Project Coordinator to establish information networks and pathways to appropriate services. The coordinator would also train 5 young people to act as mentors for younger people with Parkinson's and in the future to maintain the core services.

The initial set up costs for such a centre would require funding of \$190,000 for year 1 and year 2. An external evaluation would be included in the budget for year 1 and would advise on future directions for the Project Centre. It is envisaged that a part time coordinator and volunteers could maintain the Centre after the initial two year phase. (see Attachment 3 for more information).

Recommendation: that the Australian Government provides assistance of \$400,000 over two years for the establishment of a National Young Onset Project Centre.

¹⁹ *Living with Young Onset Parkinson's Disease p.6*

4. Equitable Access to Treatments for Parkinson's disease

There is an urgent need for Commonwealth funding for an infusion pump and the related consumables to provide all appropriate patients with access to highly effective apomorphine infusion therapy. The APO-go II Pump offers moderate to late stage Parkinson's patients greater symptom control over alternative therapies, maximizing the patients "Quality of Life" and reducing the burden on the health budget both directly and indirectly.

Apomorphine was deemed cost effective by the Federal Government and has been reimbursed by the Pharmaceutical Benefits Schedule (PBS) since 1995. The full economic benefits of this product to the Government are not being fully realized however as the medicine is often given via the "intermittent injection" method instead of via "continuous infusion" despite patients being indicated for the latter.

Intermittent injections of apomorphine are a highly effective and useful way to manage moderate Parkinson's disease symptoms. For patients who experience infrequent drops in their dopamine levels, these injections can successfully fill the void and alleviate symptoms. As the disease progresses however and these dopamine deficits become more frequent, "intermittent injections" don't provide patients with the consistent brain levels of apomorphine that are required to control symptoms. Only continuous infusion offers this. Continuous infusion is therefore the form of treatment that offers the best therapeutic as well as cost effective outcomes.

The use of "intermittent injection" in a patient group indicated for "Continuous Infusion" often results from a funding gap for the infusion pump and necessary consumables (needles etc.). Parkinson's Australia believes this deficiency needs to be addressed so that all appropriate patients with this chronic, progressive and highly disabling disorder may enjoy improved health outcomes that can result from continuous infusion.

Parkinson's Australia recommends that the Commonwealth implements one of the three funding options put forward (see Attachment 3). If other potential mechanisms or channels for Commonwealth support exist that we are not aware of, Parkinson's Australia would obviously be keen to discuss them.

For example, the National Movement Disorder Services Scheme could be similar to the National Diabetes Services Scheme.²⁰ The ancillary treatment costs of diabetic patients have been supported for many years by a federal scheme that has provided similar consumables similar to those used by Parkinson's patients.

It is estimated that the amount of funding required to support access to the apomorphine pump and consumables would range from \$758,800 per year with the current number of patients, to \$1,581,000 (see Attachment 3).

This Quality Use of Medicine (QUM) initiative has very significant patient benefits for quite marginal extra cost. This therapy and method of infusion has been deemed cost effective by the Pharmaceutical Benefits Advisory Committee (PBAC). It dramatically improves the health and quality of life for many people with severe Parkinson's disease.

Recommendation: That the Federal Government provide funding for the apomorphine pump and consumables for people with Parkinson's disease. Cost \$6.4m over 4 years.

²⁰ National Diabetes Services Scheme: <http://www.diabetesaustralia.com.au/ndss/>

Summary of Total Funding Costs Over 4 years

1.	Increase access to specialist neurological nurse educators	\$17.55m
2.	Development and provision of PD training package in the Aged Care sector	\$1.8m
3.	Establish a National Young Onset Resource Centre	\$0.40m
4.	Develop a patient reimbursement system for continuous infusion devices	\$6.4m
Total costs		\$26.15m

It is anticipated that the savings from these initiatives would make this new policy initiative at least cost neutral and at best would represent a savings of tens of million dollars a year.

Given that the number of people with PD and the costs associated with this illness are expected to double within the next two decades, it is timely for the Commonwealth Government to commit to investing in programs that will reduce these financial pressures on future governments as well as improving the quality of life for people suffering from this chronic illness and their families and carers.