



PARKINSON'S AUSTRALIA INC.

Parkinson's Australia
Submission to

**The Productivity Commission Inquiry into Aged Care
Services**

This submission was prepared by

Parkinson's Australia
PO Box 222
Calwell ACT 2905
Tel. (02) 6278 8916

Introduction

Thank you for the opportunity to respond to the Productivity Commission Inquiry into Aged Care Services in Australia.

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*, and consultations with the Parkinson's community.

This Inquiry is extremely relevant to Parkinson's Australia as 82% of people with Parkinson's are over 64 years of age at the time of diagnosis. It has been estimated that people with Parkinson's make up between 5% and 8% of the population in aged residential care¹, compared to the general population rate of 0.7%. This equates to 12,283 people based on the number of residential aged care places in Australia at 30 June 2008².

People with Parkinson's in aged residential care are usually elderly (79.7 years), dependent, cognitively impaired with a high rate of dementia, depression and associated high falls rate³. People with Parkinson's in aged care facilities suffer a high disease burden due to *functional impairment, drug complications (such as hallucinations) and comorbidities associated with PD (such as dementia and incontinence)*.⁴

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%)⁵

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.

General Facts on Parkinson's

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 supports 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.

¹ 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

² AIHW *Residential aged care in Australia 2007-2008: a statistical overview*

³ 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

⁴ Access Economics Pty. Ltd, *Living with Parkinson's Disease, 2007*, p347

⁵ Access Economics Pty. Ltd, *Living with Parkinson's Disease, 2007*, p.47

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.⁶ The prevalence of Parkinson's disease is expected to grow by 4% per annum due to demographic ageing.⁷ Consequently Parkinson's disease will have a significant influence on current and future planning for aged care services in Australia.

Parkinson's Australia recommends that the Commission consider the following recommendations:

1. That there is a need to recognise disease specific groups such as Parkinson's;
2. Increase the awareness and knowledge, of the condition and its impact, in both the aged care industry and in the general community;
3. Ensure that aged care community services reflect the person-centred services wanted by consumers and currently used in countries such as the United Kingdom (such as neurological nurses to assist People with Parkinson's (PWP) to manage their condition at home for as long as possible); and
4. Reduce the cost of effective treatment options.

This submission aims to begin to address these challenges whilst reducing the Australian Government's financial costs of providing aged care services for older people with Parkinson's disease, and reducing the disease burden for these people, their families and carers.

Parkinson's Australia has put forward this four point plan for a new national approach to Parkinson's disease in aged care services which complements the current focus of *Ageing well, ageing productively*. It is becoming abundantly clear that potential solutions must be explored without delay if we are to avoid significant consequences.

⁶ Access Economics Pty. Ltd, *Living with Parkinson's Disease, 2007, p.90-91*

⁷ Access Economics Pty. Ltd, *Living with Parkinson's Disease, 2007, p.ii*

The Challenge of Parkinson's disease for aged care services in Australia

In relation to the Productivity Commission Inquiry into Aged Care Services, Parkinsons Australia recommends that the Commonwealth Government addresses the following priorities for older people with Parkinsons disease, their carers and families. Four key Recommendations are proposed which will both reduce Government expenditure and provide aged care services that begin to address the health and well being needs of older Australians enduring the significant disease burden of Parkinson's.

1. The need to recognise disease specific groups such as Parkinson's

Though the Productivity Commission's Inquiry recognises the special needs of older Australians with diverse cultural backgrounds, the special needs accompanying the disease trajectory of Parkinson's is not recognised in policy documents, in the ACAT assessment which is a key to accessing all types of care within the existing system, nor in aged care services. This has the consequence that general aged care services are normally provided to people with Parkinson's disease. This combined with the lack of awareness of the disease in the health and general community results in the lack of an easily assessable and targeted pathway to aged care services for people with Parkinson's, their families and carers. Continuity of care for a progressive disease such as Parkinson's is compromised as the rehabilitation model is not consistent with a degenerative and increasingly complex disease and self-management is only relevant for the first three stages of Parkinson's disease (see Appendix 1).

The current system has developed a model of specialist care for people living with Dementia in both community and residential settings and dementia specific units in residential aged care facilities. PWP are becoming an emergent group of patients with complex medication regimes and a complex disease trajectory that needs to be supported by allied health professionals and visiting neurologists and GPs in residential aged care facilities.

The aim of this recommendation is to reduce the levels of disease discrimination in Aged Care Services.

2. Increase the awareness and knowledge, of the condition and its impact, in both the aged care industry and in the general community;

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.⁸

Service levels need to reflect the trajectory of the disease, that is, self management and community services such as community neurological nurses for stages 1-3 of the disease and intensive support for stages 4-5, such as provided in aged care facilities

This recommendation 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.⁹ Most staff in aged care

⁸ Access Economics Pty. Ltd, *Living with Parkinson's Disease, 2007, p.i*

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 PWP¹⁰. Consequently it is proposed that 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. Ensure that aged care community services reflect the person-centred services wanted by consumers and currently used in countries such as the United Kingdom e.g. neurological nurses to assist. PWP to manage their condition at home for as long as possible;

This recommendation aims to keep older people with Parkinson's disease living in the community for longer and to reduce the carer burden of the disease, and so reduce admissions to residential aged care facilities for as long as possible.

Specifically, it is proposed that the Federal Government provide funding to employ 200 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.

It is envisaged that an initial 50 specialist nurses would be established at a cost \$7.5m per year, \$30m over 4 years.

The aim of this recommendation is to delay in the progression of the disease and to reduce aged care admissions, through initial appropriate self management strategies that would be provided by neurological nurse educators.

4 Reduce the cost of effective treatment options

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

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.

⁹ M.Makoutonia & R Ianseck ,*Optimising Care of residents with Parkinson in supervised facilities p.2*

¹⁰ M.Makoutonia & R. Ianseck, *Optimising Care of residents with Parkinson's in supervised facilities, p3*

Background Information

The cornerstone of this response to the **Productivity Commission Inquiry into Aged Care Services** is a commitment to better health for 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 aged care services.

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 a new national approach for aged care services for PWP 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 PWP to continue to remain in the community and therefore reduces residential aged care facility usage.

"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.

Appendix 1

1. The need to recognise disease specific groups such as Parkinson's

Though the Productivity Commission's Inquiry recognises the special needs of older Australians with diverse cultural backgrounds, the special needs accompanying the disease trajectory of Parkinson's is not recognised in policy documents, in ACAT assessments, nor in aged care services. This has the consequence that general aged care services are normally provided to people with Parkinson's disease. This combined with the lack of awareness of the disease in the health and general community results in the lack of an easily assessable and targeted pathway to aged care services for people with Parkinson's, their families and carers.

The disease trajectory of Parkinson's illustrated by Scheife (2000: 956) is condensed as follows:

5 Stages of Parkinson's disease:

1. Bilateral or midline involvement: posture and gait affected.
2. Minimal or no functional impairment: symptoms include tremor of one limb, changes in posture, locomotion and facial expression
3. First signs of postural instability: significant slowing of body movements, some restriction of activities, but can lead an independent life: disability is mild to moderate
4. Severe symptoms: walking is limited, rigidity and bradykinesia. Severely disabling disease, individual is markedly incapacitated and unable to live alone
5. Individual is restricted to bed or a wheel chair unless aided.

These stages indicate the need for specific and targeted services to address the trajectory of the disease.

Appendix 2

2. Increase the awareness and knowledge, of the condition and its impact, in both the aged care industry and in the general community;

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

It was estimated that people with Parkinson's make up between 5% and 8% of the population in aged residential care¹¹. This equates to 12,283 people based on the number of residential aged care places in Australia at 30 June 2008¹²

They are usually elderly (79.7 years), dependent, cognitively impaired with a high rate of dementia, depression and associated high falls rate¹³. People with Parkinson's in aged care facilities suffer a high disease burden due to *functional impairment, drug complications (such as hallucinations) and comorbidities associated with PD (such as dementia and incontinence)*.¹⁴

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%)¹⁵

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 Margarita Makoutonina and 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:

¹¹ 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

¹² AIHW *Residential aged care in Australia 2007-2008: a statistical overview*

¹³ 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

¹⁴ Access Economics Pty. Ltd, *Living with Parkinson's Disease, 2007, p347*

¹⁵ Access Economics Pty. Ltd, *Living with Parkinson's Disease, 2007, p.47*

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

It is recommended 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. The aim would 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 could be trialled and assessed and then provided to all residential aged care facilities in Australia. The consultation process would need to involve all state and territory Parkinson's Associations, and representatives from DEEWR, Aged Care Sector and Consumers.

Appendix 3

3. Ensure that aged care community services reflect the person-centred services wanted by consumers and currently used in countries such as the United Kingdom e.g. neurological nurses to assist People with Parkinson's (PWP) to manage their condition at home for as long as possible;

Parkinson's has a complicated disease trajectory. However, in the early stages of the disease self management strategies can result in 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.

Currently, the provision of health care services for patients and families affected by PD like other neurological conditions are concentrated around pockets of specialist care within metropolitan centres with a marked deficiency in rural and remote regions. This problem is further compounded by the fact that many of these communities represent common retirement enclaves, thus increasing the proportion of people living with PD. Therefore, strategic targeting of these communities with innovative initiatives offers a clear opportunity to measure the impact of interventions efficiently. This proposal is an excellent example of what the National Health & Hospitals Reform Commission (NHHRC) had in mind when it 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).

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 where there has been the widespread introduction of PD specialist nurses. This bold initiative has been growing over the past 20 years. The fact that the UK now has a network of over 260 specialist Parkinson's nurses is testament to the success of this arrangement. This approach also recognises one of the central issues that inhibits the attraction and retention of highly skilled nurses, namely position security and career pathway.

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.

Working together, Parkinson's Australia and the Commonwealth Government have recently launched the Parkinson's Rural and Remote Online GPs Education Program. This resource allows primary health care workers online access to vital information to improve the care given to patients with PD. This major project covering all aspects of disease was completed in less than 12 months and represents a shining example of successful partnership with enormous benefits to the Australian nation. Detailed below is a proposed new policy initiative, based on the innovative pilot project in the Shoalhaven, NSW where 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. Parkinson's Australia believes that this initiative sets the model that forms the basis of future strategies to tackle some of the major health and socioeconomic crises facing our nation.

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

1. Monitoring clinical indicators (e.g. the development of falls and dementia);
2. Overseeing and assessing adjustments in medication in consultation with the neurologist and GPs;
3. Coordinating access to other essential services (e.g. speech pathology, physiotherapy), particularly for those in regional and remote areas;
4. Providing an effective integrated primary care service including health and social support via community and home-based care;
5. Providing practical support and education for the unpaid carers of people with Parkinson's;
6. 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
7. 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.

As highlighted above, the role of these specialist nurses has been widely implemented in the UK. Indeed the National Institute for Health and Clinical Effectiveness (NICE), who are the UK's independent organisation responsible for providing national guidance on promoting good health and preventing and treating ill health, have included Parkinson's specialist nurses in their pathway for the management of the disease, recognising the vital function they perform.

One randomised control trial assessing health outcome and costs over a 2 year period in approximately 2000 patients confirmed community based Parkinson's nurses did improve patients' sense of wellbeing with no increase in patients' healthcare costs, despite including the specialist nurse salary (Jarman, Hurwitz et al. 2002). In addition to this 'cost neutral' finding a number of local health authorities have identified direct cost savings from improvements in both inpatient and outpatient services (for summary see, *Commissioning Parkinson's services: The clinical and financial value of Parkinson's Disease Nurse Specialists*, PDS 2007). Also, the interim NHHRC report accepts and acknowledges a sound working system of primary health care means avoidable hospitalisation (p84). Finally, although, no study has yet evaluated delay in nursing home placement, which is one of the most likely major cost savings that would be anticipated from community based specialist nurse educators. It is anticipated that the pilot project in the Shoalhaven, NSW will provide clear evidence of substantial savings to government in the areas of hospital costs and aged care.

One of the major benefits from the establishment of specialist Neurological nurse educators will be to reduce 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; reduce the incidence of complications – all of which reduces not only hospital admissions, outpatient attendances but also nursing home admissions and disease burden¹⁶. 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.

New Policy Initiative

¹⁶ Access Economics Report, "Living with Parkinson's disease: Challenges and Positive Steps for the Future", (2007) p 113.

The UK model of national Parkinson's specialist nurses is compelling, and 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 areas¹⁷.

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 case load of about 300 patients. The Australian model goes further and includes a number of other neurological conditions such as Motor Neurone Disease.

Savings

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%¹⁸. 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 prevention¹⁹ - the evidence from specialist nurse educators in WA and in the UK²⁰ 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 alone²¹. 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 \$74.4m²² - much of these costs can be provided cheaper and out of the hospital system.

Total net savings to governments from 50 Specialist Neurological Nurse Educators could be \$7.5m.

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 2020²³

¹⁷ 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.

¹⁸ '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

¹⁹ 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

²⁰ Commissioning Parkinson's services: the clinical and financial value of Parkinson's Disease Nurse Specialists (attached)

²¹ "What is the Economic Utility of Introducing a PNS Service?", S Roberts, Conway and Denbighshire NHS Trust (see attached)

²² P47, Access Economics "Living with Parkinson's Disease", June 2007

²³ P37, Access Economics "Living with Parkinson's Disease", June 2007

Appendix 4

4. Effective treatment options 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 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.

This preference for "intermittent injection" use in a patient group indicated for "Continuous Infusion" is often a result of the gap in the funding of 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, and the benefits of a cost effective treatment are realised.

Parkinson's Australia recommends that the Commonwealth implements one of the three funding options put forward. 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.²⁴ 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 would be expected that the amount of funding for the apomorphine pump and consumables required, would range from \$758,800 per year with the current number of patients, to \$1,581,000 (*see table 1. below*) if all appropriate patients were treated.

Closing this funding gap will provide access to all patients whose care could be optimised via access to a state of the art infusion device and necessary ongoing consumables (equipment) required for the continuous infusion of apomorphine.

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.

²⁴ National Diabetes Services Scheme: <http://www.diabetesaustralia.com.au/ndss/>

What is Apomorphine infusion?

Parkinson's disease is the second most common neurodegenerative disease affecting an estimated 80,000 people in Australia²⁵, including roughly 2% of the population over the age of 65²⁶.

Early in the disease, oral medications (such as Levodopa/L-dopa therapy) are the mainstay therapy for relief of symptoms. As Parkinson's disease progresses however, the effectiveness of oral medications at controlling symptoms diminishes and side effects in the form of motor complications develop, limiting their long term effectiveness.

After long-term L-dopa treatment, patients can suddenly fluctuate from an "ON" phase (a period of effective symptom control, mobility generally being restored) to an "OFF" phase (a period of poor or no symptom control, mobility significantly reduced, even freezing episodes common) many times a day.

To make this even worse, side effects such as dystonia (twisting cramping posture) and other involuntary movements known as dyskinesias may begin to occur. These occur in about 50% of people with Parkinson's after five years of L-Dopa therapy. These symptoms may not always be managed with other oral medications, and for those who become seriously disabled they can result in a virtual collapse of quality of life. It is for these patients that "Continuous Dopaminergic Stimulation" in the form of apomorphine infusion therapy can provide significant benefit.

Apomorphine (Apomine®, Hospira Pty Ltd) is a potent dopamine agonist, and currently represents the only form of "Continuous Dopaminergic Stimulation" therapy available in Australia. It is indicated to reduce the number and severity of 'OFF' phases where the usual daily oral medications fail to have effect. "OFF" periods can leave some patients unwilling to leave their home due to a fear of being left stranded in a frozen "OFF" state without assistance. In other cases, the "OFF" symptoms may present as painful dystonias, urinary incontinence, or uncontrollable tremor.

Apomorphine is usually provided via public hospital neurologists specialising in Parkinson's disease. It is administered via intermittent subcutaneous injection or continuous infusions depending on the needs of the patient. For patients whose overall control remains unsatisfactory using intermittent injections or who require many and frequent injections (often up to 10 a day), it is recommended that apomorphine be administered via continuous infusion using a portable infusion pump (APO-go II™ pump). The pump costs in excess of \$4900 and have a life span of approximately three years.

Apomorphine treatment via continuous infusion is critical to patient care

Patients requiring continuous apomorphine therapy have virtually no effective medical alternative available to them. As oral medication therapy is now associated with limited clinical effect and significant side effects, apomorphine really is their last therapeutic option before trying invasive and expensive procedures such as Deep Brain Stimulation (a procedure where a conscious patient has holes drilled into their skull so electrodes can be inserted to stimulate the parts of the brain responsible for controlling movement).

The clinical benefits of continuous apomorphine infusion are comparable to Deep Brain Stimulation (DBS), but with much lower morbidity.²⁷ DBS is also significantly more expensive, and yet is reimbursed via Medicare Australia.

Many patients treated with apomorphine by continuous infusion experience great reductions in dyskinesia severity and a mean reduction in frequency and duration of occurrences, while still maintaining motor function. In one study it has been shown that continuous apomorphine infusion can reduce the total 'OFF' hours per waking day from 9.5 to 3.8 hours after 12 months treatment with the

²⁵ Parkinson's Australia Website at <http://www.parkinsons.org.au/aboutparkinson.php>

²⁶ Clarke, C. E. Parkinson's Disease In Practice. The Royal Society of Medicine Press Ltd. London. 2001.

²⁷ Manson A et al; Apomorphine Monotherapy in the Treatment of refractory Motor Complications of Parkinson's Disease: long-Term Follow Up Study of 64 Patients. Movement Disorders 2002 Vol17 No 6 pp1235 - 1241

drug.²⁸ This has a considerable impact on daily function for the patient and improves quality of life for both patients' and their carers.²⁹

The majority of patients are also able to gradually reduce and sometimes even cease their oral Parkinson's medications, this achievement of "mono-therapy" being associated with even greater clinical benefits to the patient.⁶

Different funding schemes and the patient gap

After a thorough assessment, Parkinson's Australia has found there to be no funding mechanism to access the apomorphine therapy through the infusion pump and consumables. Although apomorphine is PBS listed via the Highly Specialised Drug Program (Section 100), the pumps and consumables are not reimbursed.

Some public hospitals have financial difficulty with providing the pumps and they do not provide the ongoing consumables required. Hospira has assisted in providing funding for the pump on a trial basis. Parkinson Australia however understands that this trial funding will finish by the end of 2010. The trial funding has not included consumables which are a considerable financial burden to many patients.

Patients whose public hospital cannot afford to purchase the pumps and provide ongoing supply of consumables are often not offered this treatment as the therapy may be beyond their financial means. Up to 80% of the patients (400+) who could greatly benefit from this therapy are currently denied access to it. While the drug is appropriately funded by the federal government, the state government run hospitals do not provide the ancillary items, resulting in limited treatment access and compromised patient care.

This asymmetry in state and federal funding results in only a selection of patients getting appropriate care. Parkinson's Australia believes this is inequitable and discriminatory.

Costs of apomorphine infusion

The APO-go II pump costs \$4950 and lasts 3 years. The necessary consumables which need to be changed daily include the infusion lines, syringes, needles and dressings. These result in a minimum cost of approximately \$3162 per patient per year (see table 1).

Table 1: Costs per patient per year for treatment with continuous apomorphine infusion (excluding drug costs).

Item	Unit Cost (\$)	Daily Usage	Daily Costs	Yearly Costs
Apomorphine Pump (APO-go)	\$4950 per 3 years			\$1,650
Drawing up needles	\$0.04	1	\$0.04	\$15
Extension tubing	\$2.00	1	\$2.00	\$730
S/c butterfly needles	\$0.60	1	\$0.60	\$220
Normal Saline	\$0.57	1	\$0.57	\$208
Tagaderm dressing	\$0.90	1	\$0.90	\$329
Alcohol Swabs	\$0.029	1	\$0.029	\$10
Total per year:				\$3,162

* These are the minimum consumable costs. Some patients for tolerability reasons may require more expensive options.

²⁸ Hughes A.J et al; Subcutaneous Apomorphine in Parkinson's Disease: Response to Chronic Administration for up to Five Years. *Movement Disorders* 1993. Vol. 8, No.2, 1993. pp 165 - 170

²⁹ Katzenschlager et al. 'Continuous Subcutaneous Apomorphine Therapy Improves Dyskinesias in Parkinson's Disease: A Prospective Study Using Single Dose Challenges.' *Movement Disorders*. Vol 20, No.2, 2005. pp151-157

The minimum total cost to the Government for funding the pump and consumables for continuous apomorphine infusion with the current number of patients would be \$758,880.

Dr Andrew Evans, a neurologist from Royal Melbourne Hospital has estimated the number of patients that would benefit from this therapy in Australia to be around 500. This number is a similar proportion of Parkinson's disease patients to that on apomorphine therapy in the UK, the current world leaders in apomorphine therapy.

Therefore, the minimum total cost to the Government for funding the pump and consumables for all appropriate patients in Australia would be around \$1,581,000.

Table 2: Total minimum annual costs for the Government of reimbursing the apomorphine pump and consumables

	No of patients using currently	If all appropriate patients had access to this therapy
No of Patients	240	500
Costs per patient per year	\$3162	\$3162
Total annual cost to Government	\$758,800	\$1,581,000

Whilst the Intergenerational Report in the 2002-03 budget highlighted the fiscal demands of healthcare costs by an ageing population it also states that is important to "promote fairness in distributing public resources between generations of Australians".

The financial input required to ensure quality use of this important medicine is very modest but it will go a long way to rectify the inequity of access suffered by some Parkinson's disease patients.

ECONOMIC BENEFITS OF FUNDING THE APO-go PUMP

Several cost of illness studies have shown that the greatest Parkinson's disease costs are not the medical, but costs arising from the need for help and care in patients' homes, nursing home expenses and indirect costs stemming from loss or productivity due to early retirement or disability.

Providing these patients access to continuous apomorphine therapy would be a cost effective initiative when the economic benefits of treatment are compared to the costs of not providing the pump and consumables.

The potential savings include:

1. *Reduced need for home nursing or complete nursing home care*

Successful continuous apomorphine infusion results in savings to the Government because the increase in the percentage of the day spent in an "ON" phase (symptoms successfully controlled) means the patient is significantly more independent, often even self caring. This can lead to a significant reduction in the need for nursing care, and hence a reduced need for hostel and nursing home beds.³⁰

Home care costs accounted for the second largest share of the total annual costs for Parkinson's patient in the Swedish survey (34% of the total annual costs).³¹

³⁰ MacMahon, 'The use of Apomorphine in the older patient'. *Advances in Neuroscience Rehabilitation.* V3.2003

³¹ Hagell P et al, 'Resource use and cost in a Swedish Cohort of Patients with Parkinson's disease.' *Movement disorders*; 17. 2002

2. *Reduced hospital admissions*

There are further savings to the healthcare system with successful continuous apomorphine infusion, as improved symptom control or less "OFF" phases has been shown to result in less crisis visits to doctors and admissions to hospitals.³²

A French study found that among patients with motor fluctuations, the amount of daily "OFF" time had the most significant impact on costs. It was estimated that for every 10% reduction in "OFF" time, medical costs would decline by 5%.³³ In addition the improved quality of "ON" phases also reduces the dependency of patients on hospitalisations and other institutional care.

The results of a specialist survey conducted for the original PBS submission for reimbursement of apomorphine indicated that after a year of continuous apomorphine treatment the number of specialists visits would decrease from 10 visits to 4 to 6 per annum.³⁴

3. *The cost savings from postponing the requirement for alternative therapy such as Deep Brain Stimulation (DBS).*

Deep Brain Stimulation is a much more expensive and invasive therapy than apomorphine infusion. DBS involves the placement of electrical leads into one or both sides of the brain. The procedure is usually performed in two separate steps, implantation of the leads followed by implantation of the neuro-stimulator to which the leads are connected.

Deep Brain Stimulation is associated with similar symptom control outcomes to Apomorphine infusion therapy, in clinical studies however patients have experienced worsening cognitive or neuropsychiatric symptoms following DBS treatment³⁵.

In the submission to Medical Services Advisory Committee (MSAC) in May 2006 the cost of the procedure was estimated to be \$67,475 - \$73,204 over 5 years, plus any other costs related to complications. Despite these costs, MSAC recommended that public funding be provided and the Minister for Health and Ageing accepted this recommendation on 24th August 2006 after several years of pilot funding.

Many patients that go on to have Deep Brain Stimulation could and would benefit from apomorphine infusion therapy. In fact it is a policy at the National Hospital for Neurology and Neurosurgery in Queen Square London that all patients trial apomorphine infusion therapy prior to going on to Deep Brain Stimulation treatment³⁶. In many cases this trial of apomorphine infusion therapy is successful and patients need not go through the trauma of DBS.

4. *Productivity: An increased productivity arising from patients being able to undertake their normal work duties and delay their retirement.*

In one Swedish survey where annual costs were calculated on prevalence, the mean total annual cost of Parkinson's disease per patient was approximately SEK 124 000 (\$22,382 AUD). In the same study, the loss of productivity for uncontrolled Parkinson's patients was found to be the most significant costs, as much as 42% of total health costs SEK 52 000 (\$9384.65 AUD), per patient, per year⁸.

There would also be considerable time saved by carers in regard to missed work and other time in order

³² Chaudhuri and Clough. 'Subcutaneous apomorphine in Parkinson's disease.' British Medical Journal. V316. 1998

³³ LePen C, et al , 'Cost of Illness and Disease Severity in a Cohort of French Patients with Parkinson's Disease' Pharmacoconomics V16. No.1. July 1999

³⁴ Apomorphine Injection PBS submission by David Bull Laboratories (Mayne Pharma) February 2005

³⁵ De Gaspari D, et al. J Neurology Neurosurgery and Psychiatry. 2006 Apr; 77(4):450-3

³⁶ Personal Communication with Dr Andrew Evans, Consultant Neurologist, Royal Melbourne Hospital, June 2007.

to assist the patients at home. In one US trial it was found that patients' carers provided a mean of 22 hours care each week³⁷.

5. *Reduced number of prescriptions of oral levodopa*

Many patients being administered continuous apomorphine infusion therapy can reduce or cease their oral levo-dopa therapy. A 1-year follow up study showed that approximately half the patients reached monotherapy, with this figure rising to 70.3% after three years.⁶

As well as these cost savings, other less tangible benefits could also be expected, these including:

6. *Quality of life of patients and their carers.*

Patients being treated by continuous apomorphine therapy have reported marked improvement in general well-being and quality of life. Patients have made comments such as 'I don't feel like I have Parkinson's disease anymore'. Patients have reported that they were able to do far more, including activities such as going to the theatre and taking the dog for a walk, activities which they had not felt capable of doing for many years previously.³⁸

This quality of life benefit is not limited to the patient though. More independent and active Parkinson's patients naturally have a positive effect on the quality of life of those around them, namely their families and carers, a group that significantly outnumbers the patients alone.

7. *Multi-functionality of the pump*

Dr Andrew Evans, neurologist at Royal Melbourne Hospital, confirms that the APO-go II pump can also be used "ambulatory" care in the treatment of patients with other illness. For instance, the pump can be used for the administration of subcutaneous or intravenous analgesia in palliative care situations.

CONCLUSION

Parkinson's Australia believes that Government funding of the apomorphine pump and consumables, will provide ongoing patient access for all patients who would greatly benefit from the continuous apomorphine infusion therapy. The Apo-go II pump and consumables falls in line with the Federal government's concern to ameliorate the impact of chronic illness management. Currently, many of patients require frequent doses (more than 10 per day) of intermittent apomorphine injections, because there is no funding for infusion pumps and associated consumables.

In addition, there are a number of patients who may be started on continuous therapy in hospital and have their symptoms controlled but once discharged from hospital have to go back to intermittent therapy due to the lack of funding. Parkinson's Australia has seen where this unfortunate practice is jeopardising patient continuity of care and quality use of the apomorphine medicine.

Parkinson's Australia requests this application for funding for the apomorphine pump and consumables be considered favourably.

The small additional funding required has the potential to greatly improve the quality of life for many patients with Parkinson's disease. Apomorphine is an effective and safe treatment which has been determined cost effective by the PBAC. By reimbursing the necessary pump and consumables required for continuous infusion, the true economic benefits of the treatment can be realised.

³⁷ Findley et al. 'Direct Economic Impact of Parkinson's Disease: A research Survey in the United Kingdom. Movement Disorders.18, 10 2003

³⁸ Manson A, et al. 'Intravenous apomorphine therapy in Parkinson's disease. Clinical and Pharmacokinetic Observations.' Brain. Vol 124. pp331-340

Parkinson's Australia proposes the following funding options:

- A. A stand alone Parkinson's treatment funding program which could be used to cover the costs associated with the use of the APO-go II Pump and related consumables.
- B. National Movement Disorder Services Scheme - patient funding for items relating to the out-of-hospital treatment of neurological chronic illnesses such as Parkinson's Disease, MS, epilepsy, dementia and other movement disorders.

or

- C. Establish 2 new separate Medicare item numbers, one for the APO-go II infusion pump and one for the related consumables.

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

Summary of Total Funding Costs

1.1	Development and provision of PD training package in the Aged Care sector	\$3.00m
1.2	increase access to specialist neurological nurses	\$30.0m
1.3	develop a patient reimbursement system for continuous infusion devices	\$1.6m

Total costs **\$31.6m per year**
+ \$3m one-off payment

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.