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**Inquiry into residential and community care in Australia**

**Help for today  
Hope for tomorrow**

19 November 2008

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# 1. Executive Summary

In recent times there has been a lot of research and much written about Australia's ageing population and the increasing demands that this phenomena will have on future budgetary outcomes. At the same time there have been few constructive reports with positive steps on how to tackle the many issues that are confronting the process of ageing with dignity.

This submission doesn't address all of the issues referred to the Finance and Public Administration Committee – instead it seeks to establish a number of constructive and pragmatic proposals aimed at reforms to provide sustainable improvements in the performance of the aged care system – particularly for people with Parkinson's disease, their families and carers. 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 reduce discrimination and at the same time enable people to remain in employment longer, require less hospitalisation and medical treatment and most importantly continue living at home longer. Of note, to the Senate Inquiry 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>. The proposed savings from these proposals combined with the capacity building in the health and ageing areas needs to be considered.

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. Parkinson's sufferers, their families and carers are confronted with major issues of disability including tremor (trembling in hands, legs, jaw and face), rigidity and stiffness of limbs and trunk, sudden slowness and loss of spontaneous movement and impaired balance and coordination. Some of the symptoms can be controlled with medication, although side effects are common and people often experience fluctuations throughout the day in their ability to move. In many cases Parkinson's results in considerable pain and suffering,

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

impaired speech and various mental health issues, such as depression and anxiety. There are other side effects of the multiple medications regime including compulsive disorders of gambling, hyper sexuality and overeating. Other Parkinson's symptoms include sleep disruptions, difficulty with chewing and swallowing as well as urinary and constipation problems.

Parkinson's is a surprisingly prevalent condition (the second highest prevalence of all neurological conditions – with higher prevalence than a number of disease and injuries considered National Health Priority Areas<sup>2</sup>. It is recognised as one of the worst degenerative illnesses and needs to be considered a national health priority. There is considerable disability and the costs of burden associated with this chronic health illness were \$6.8 billion in 2005<sup>3</sup>. 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 by 2033 to around 240,000. This data supports the Federal Health Minister's own estimation of the key challenges to the health system where neurological disorders will increase by 280% in the next 25 years and will be the second fastest escalation in costs in health expenditure<sup>4</sup>. The youngest person diagnosed in Australia with Parkinson's is 14 years old.

In 2005 Parkinson's Australia commissioned Access Economics to conduct the first systematic and in-depth research into the extent and scale of the costs and disability burden faced by people with Parkinson's, their families and their carers. The report found that there was a lack of awareness in the health, ageing 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, ageing and support services. Misdiagnosis was common preventing patients receiving correct medication, treatment and intervention at an early stage.

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<sup>2</sup> Living with Parkinson's Disease – Challenges and Positive Steps for the Future, Access Economics, June 2007, pi

<sup>3</sup> Living with Parkinson's Disease: Challenges and Positive Steps for the Future, Access Economics, June 2007.

<sup>4</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 2008.

## **2. Summary of Recommendations**

This submission includes recommendations to improve the quality of life for all Australians (including indigenous Australians) with Parkinson's and other neurological conditions by improving quality service outcomes in the Aged Care sector.

### **1. Increased access to effective health interventions and services, namely specialist Neurological nurse educators.**

Timely, accurate diagnosis and cost effective health interventions have the ability to significantly reduce the immediate burden of the disease, help people with Parkinson's and other neurological illnesses maintain their independence and slow growth in future costs of these chronic conditions. The role of the Specialist Neurological nurse educator is the most critical service that is lacking in Australia and is the one area that will save Australian governments around \$40m per year in hospitals costs and \$8 to \$25m per year in aged care costs (rising to \$24 - \$75m by 2033) and this is only in the one area of Parkinson's. In the regional and remote areas the prevalence of Parkinson's is significantly greater (20%). Unfortunately there are no neurologists based in these areas, which makes the role of the specialist neurological nurse educators all the more important.

### **2. Parkinson's training programs for residential care facility staff, including those in hostel and nursing homes**

There is a lack of knowledge and awareness of Parkinson's in aged care and as a result the quality of care and understanding of effective management of this disease is very poor. Education workshops for staff in residential care facilities on basic concepts of effective management of this condition will significantly improve quality of service with benefits to both staff and sufferers.

### **3. Provision of more treatment options**

Parkinson's is an illness where the timely access to pharmaceuticals is crucial to the well-being of the sufferer. As new and more effective medications are developed and utilised, people benefit by delaying the latter stages of the disease. A number of new and more effective methods of delivery of medications for people with Parkinson's have recently been developed. These methods have significant economic benefits for both governments and people with Parkinson's as they enable sufferers to remain independently longer and delay the need for institutionalised care. However, many new treatment options are still only available in Nth America, Europe and the UK.

## 3.1 Priority Needs

### The issues

As previously mentioned the Access Economics report into Parkinson's found a lack of awareness in the health, ageing and general community of the challenges and needs of those suffering from this complex and disabling condition. This has contributed to serious constraints in the delivery of health, ageing and support services. These issues are confirmed by calls to all our state organisations' InfoLines, requests from residential care facilities as well as issues raised in counselling sessions for people living with Parkinson's, their families and carers and in visits by our support group network members to local residential care facilities – where the common thread is always that staff in these facilities lack adequate knowledge and understanding of the basic principals in the nursing care of people living with Parkinson's.

### Positive Steps

#### **3.1 Increased access to effective health interventions and services, namely Specialist Neurological nurse educators.**

Parkinson's is a surprisingly prevalent condition (the second highest prevalence of all neurological conditions) – with higher prevalence and costs of burden than a number of disease and injuries considered National Health Priority Areas<sup>5</sup>. This situation will have dire consequences unless urgent action is taken. At a speech to the Council for Economic Development on 30 April 2008, the Federal Minister for Health and Ageing, the Hon Nicola Roxon said on a three-decade projection to 2033, the second fastest escalation in costs in health expenditure will be for neurological disorders, at 280%. Similarly, these increases can be expected in the Aged Care sector.

Currently (2005) the majority of people with Parkinson's are in the first three stages of the disease. It is, however, the last two stages of Parkinson's that bears over 54% of the financial costs<sup>6</sup>. As a result, the financial burden and costs associated with this order are about to escalate sharply. There are currently around 80,000 Australians with this debilitating and chronic illness and by 2033 this number is expected to triple to around 240,000. This will have major financial and budgetary implications for our health system in particular hospitals and aged care programs.

This rapid escalation in costs can be slowed. Timely, accurate diagnosis and cost effective health interventions have the ability to reduce the immediate burden of the disease, help people with Parkinson's maintain their independence and significantly slow growth in future costs of Parkinson's. In addition they will enhance the quality of life for people with Parkinson's and their carers & families over the

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<sup>5</sup> Living with Parkinson's Disease – Challenges and Positive Steps for the Future, Access Economics, June 2007, pi

<sup>6</sup> Living with Parkinson's Disease – Challenges and Positive Steps for the Future, Access Economics, June 2007, p22&46

longer term.

The Access Economics report into the prevalence of Parkinson's in Australia (2007) found that a number of strategies could easily affect these changes, namely:

an increase in training of doctors and nurses in relation to Parkinson's diagnosis, treatment, knowledge of medications and hospital protocols – this could be achieved through increased access to Specialist Parkinson's nurses which would also significantly help in increasing access to health services in regional and remote areas where the prevalence of Parkinson's is 20% higher.

Long lead times between the on set of Parkinson's, the start of the symptoms and the diagnosis causes ineffective treatments. In many cases the wrong disease and diagnosis has been made because of poor knowledge of Parkinson's within the GP population. Misdiagnosis is common which means that the prescription of drugs is less able to reduce the effects of the symptoms or manage the progression of the disease and contributes to unnecessary diagnostic testing<sup>7</sup>. The rate of undiagnosed cases in Australia may be as high as 3.2 undiagnosed cases for every ten diagnosed cases – this has led to Parkinson's being labelled the 'hidden disease'. Studies have shown that the reduction of dopamine is already well advanced in the brains of people with Parkinson's with only mild symptoms. Therefore, the underlying disease process has been progressing over a number of years (at least 4) before clinical deficits present. Even when symptoms become noticeable, it sometimes up to two years before a definitive diagnosis is made resulting in a significant decrease in the window of opportunity for preventive or protective treatments<sup>8</sup>.

Improving rates of early diagnosis and enabling earlier treatment to begin will result in people with Parkinson's, governments and health insurers avoiding higher levels of financial costs. Treatments are much less expensive than institutionalised care. Also people with Parkinson's would be more likely to remain in the workforce longer (currently people with Parkinson's leave the workforce 5.4 years earlier than the average<sup>9</sup>) – all of which means that governments would increase their tax revenue and save more on welfare payments. And most importantly, people with Parkinson's would avoid experiencing unnecessarily high levels of disease burden (currently the lifetime financial cost of a person living with Parkinson's for 12 years - around \$100,000 in 2005 is on par with the average lifetime financial cost of cancer).

Governments can tackle these issues and at the same time tackle the escalation of health & ageing costs by increasing access to health services through the use of new information technologies. For example,

in 2008, Parkinson's Australia raised over \$210,000 (includes Federal Government assistance of \$90,000) to develop an on-line educational and support resource, which will be provided free of charge to all medical practitioners throughout Australia, with information, resources and best practice guidelines on Parkinson's. The proposed program, which will be operational by early 2009, is innovative in its use of IT and its focus on both medical knowledge as well as information on the psychosocial factors associated with Parkinson's, including links to the community for people living with this condition and their partners, carers and families.

### *Why Specialist Neurological (Parkinson's) nurse educators?*

The role of the Neurological specialist nurse educator is important in the coordination of care for the person with Parkinson's, conducting holistic assessments of the individual needs as well as making referrals to other health and allied health professionals. The specialist nurse, as part of a multi-disciplinary community based team, would also provide education and advice for health and allied health professionals, individuals and carers living with the illness. The need for a multidisciplinary approach is gaining wide support and is also recommended in the area of combating grief and depression in terminal illness as a way of restoring dignity and hope, strengthening coping skills and encouraging social connection<sup>10</sup>. The organisation of neurological specialist nurse educators is ideally community-based, set up around a specialist (for example, GP, consultant in elderly care, consultant neurologist) with an interest in Parkinson's. In the rural and remote areas, the specialist nurse educator would have a broader role in providing services to include all of the neurological illnesses. Rather than limiting these specialist nurses to one field there would be significant more benefits in having these Nurse educators manage all neurological disorders, similar to neurologists.

The main role of the Neurological Specialist Nurse Educator Service is to:

- Reduce the impact of unnecessary hospital admissions and visits including:
  - casualty outpatient appointments
  - emergency hospital admissions (falls prevention etc)
  - nursing home admissions
  - specialist neurological visits to hospitals and nursing homes;
  - GP visits to nursing homes and homes
- Provide effective integrated primary care services including health and social service support via community and home-based care.
- Reduce the impact of hospitalisation by educating all medical staff and surgeons on the problems associated with Parkinson's medication and hospital treatments.
- Provide long term sustainable support to people with a chronic condition.
- Provide a high quality, best practice clinical community based service.
- Work collaboratively with, but not limited to, GPs, neurologists, Parkinson's clinics, pharmacists, aged care nursing staff,

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<sup>10</sup> "Growing old and getting sick: Maintaining a positive spirit at the end of life", David M Clarke, Australian Journal of Rural Health, 2007, 15 p 148-154.



physiotherapists and occupational therapists to case manage long term needs of sufferers, their family and carers.

- Provide practical support and education for the (unpaid) carers of people with Parkinson's as well as help support self care and preserve patient's sense of well-being.
- Provide educational resources for allied health professionals in hospitals, nursing homes, hostels and community groups providing care.
- Provide expertise, advice and education in Parkinson's Management to rural based Parkinson's and Neurological clinics.
- Provide expertise, advice and education for rural allied health professionals.

One of the major benefits from the establishment of specialist Parkinson's and neurological nurse educators will be to reduce the growth in the health & ageing expenditure over the coming decades. This would be achieved by avoiding unnecessary hospital admissions and delayed entry into aged care facilities through the provision of better integrated care services and community and home-based care, particularly for the older Australians and for people with chronic and complex conditions. 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 burden<sup>11</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 guidelines on Parkinson's specialist nurse educators are based on case loads of about 300 patients. This translates to a requirement of around 182 specialist Neurological nurse educators in Australia, each with a case load of about 300 patients. The number of people with Parkinson's in Australia continues to grow with the latest research estimating 8,900 new cases in 2005 (25 new cases every day of the year).

### **Lessons from the United Kingdom – Hospital Savings**

UK National Institute for Health and Clinical Excellence (NICE) Guidelines estimated that access to specialist nursing care and therapy services reduce hospital inpatient admissions by 50% and hospital outpatient attendance by 40%<sup>12</sup>.

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<sup>11</sup> Access Economics Report, "Living with Parkinson's disease: Challenges and Positive Steps for the Future", (2007) p 113.

<sup>12</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

In the Australian setting this would equate to a net saving of around \$150,000 per annum per specialist nurse educator in consultant clinical outpatients alone<sup>13</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 Parkinson's 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 Parkinson's in 2005 were \$74.4m<sup>14</sup> - much of these costs can be provided cheaper and out of the hospital system. 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>15</sup> - the evidence from specialist nurse educators in WA and in the UK<sup>16</sup> clearly show that a large number of these hospital admissions are Parkinson's related and are preventable.

An example of how Parkinson's Australia can work with governments to improve the quality of life as well as slow the escalation of health and ageing costs for not just Parkinson's disease but all the neurological disorders can be seen where

In 2008 Parkinson's Australia has been negotiating with the University of Notre Dame and recently they have agreed to establish a new post-graduate neurological nursing program (open-university) commencing in 2009 (see [http://www.nd.edu.au/news/sydney/parkinsons\\_course.shtml](http://www.nd.edu.au/news/sydney/parkinsons_course.shtml)). This program will have far greater benefits than outlined above as it will significantly increase the knowledge, treatment and care for one of the major chronic illness categories, namely neurological conditions. It is another example of the initiative being shown by Parkinson's Australia and will have a major impact in reducing the escalation of costs anticipated in the area of neurological disorders.

Access to GPs, specialists and allied health professionals is limited in regional and remote areas. For example, there are no neurologists north of Perth in West Australia, the NT has no trained staff of any description with knowledge of Parkinson's and in the area from Tweed Heads to Coffs Harbour there are over 1500 people with Parkinson's and only one neurologist with assistance from a visiting Sydney specialist, one day a month, to service their needs. Consequently, people with Parkinson's are more at risk of delayed diagnosis and a more rapid onset of debilitating effects of the disease. It is estimated that the prevalence of

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<sup>13</sup> "What is the Economic Utility of Introducing a PNS Service?", S Roberts, Conway and Denbighshire NHS Trust

<sup>14</sup> P47, Access Economics "Living with Parkinson's Disease", June 2007

<sup>15</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>16</sup> Commissioning Parkinson's services: the clinical and financial value of Parkinson's Disease Nurse Specialists (attached)

Parkinson's in regional and remote Australia is 1.6 times the rate in metropolitan areas<sup>17</sup>.

As previously mentioned the new on-line education program for medical practitioners will be available in 2009. However, more services and support needs to be provided in the rural and regional areas including the aboriginal communities. The availability of specialist neurological nurse educators in these areas will certainly help as will Community Outreach Teams.

**Recommendation: That the Finance and Public Administration Committee recommends to the Federal Government that the employment of specialist neurological nurse educators needs to be considered.**

### ***3.2. Parkinson's training programs for residential care facility staff, including those in hostel and nursing homes.***

One of the major issues in aged care is that staff, in residential care facilities, hostels and nursing homes, all lack adequate knowledge and understanding of the basic principals in the nursing care of people living with Parkinson's. To change this situation it is proposed that nursing homes and hostels receive education workshops on basic concepts of effective management of Parkinson's disease. The workshops would cover the following basic training:

- What is Parkinson's disease
- Symptoms of Parkinson's
- Parkinson's medication
- Principals of giving Parkinson's medication – correct dose, correct time, every time
- Benefits from correct medication regime (nursing staff and also the patient)
- Communication techniques with people living with Parkinson's
- Nutrition, swallowing and speech
- Activity-exercise for motor dysfunction
- Sleep-rest pattern
- Cognitive impairment
- Depression, anxiety, obsessive compulsive disorders
- Falls prevention

These workshops would be provided by skilled personnel from the Parkinson's organisations in Australia. Total costs for providing 300 workshops around Australia (including rural and remote Australia) plus education kits would be \$900,000.

**Recommendation: that the Finance and Public Administration Committee supports our request for assistance of \$750,000 to educate staff at 300 residential care facilities, hostels and nursing homes on the basic concepts of effective Parkinson's management.**

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<sup>17</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.

### 3.3. Provision of more treatment options

Parkinson's is an illness where the timely access to pharmaceuticals is crucial to the well-being of the sufferer. As newer and more effective drugs are developed it is recommended that the Government speeds up the approval process. The sooner people with Parkinson's have access to the newer pharmaceuticals the less likely that the same people will be hospitalised for crisis situations, they will be more capable of remaining in the workplace, living independently longer and as a result less need for institutionalised care, there will be a reduction in other Parkinson's medications, and a longer delay in the need for highly expensive surgical interventions.

Due to the nature of Parkinson's disease, most people experience "ON" and "OFF" phases including periods of poor or no symptom control, mobility significantly reduced and even freezing episodes. These can happen many times a day. Other side effects include dystonia (twisting cramping posture) and other involuntary movements. These symptoms may not always be managed with oral medications and therefore for those who become seriously disabled it can result in a virtual collapse of quality of life. It is for these patients that "Continuous Dopaminergic Stimulation" can provide significant benefit and can come in the form of apomorphine infusion therapy via a portable pump. Other methods of continuous infusion delivery of medications include patches.

Whilst new medications may be PBS listed the process for including the devices is virtually impossible. The Federal Health Department has not recognised the importance of these new technological devices and is not structured to consider the importance of them in delivering improved quality of life.

In addition, the process of PBS approval should be improved. Parkinson's disease is a chronic, progressive, incurable, complex and disabling condition and is not well understood by health professionals, the wider Australian community and members of the Pharmaceutical Benefits Advisory Committee. As a result, the level of disability, discomfort, pain and suffering could be better understood if the PBAC took into account such information by the way of community impact statements.

**Recommendation: that the Finance and Public Administration Committee supports our request for the Federal Government to speed up the approval process for registering new pharmaceuticals and examines ways of funding new devices used to deliver Parkinson's medication.**