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The Secretary  
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### **Parkinson's Australia submission to the Senate Community Affairs References Committee Inquiry into the funding and operation of the Commonwealth State/Territory Disability Agreement**

#### **Introduction**

Parkinson's Australia (PA) welcomes the opportunity to make a submission to the Senate Community Affairs Committee's Inquiry into the funding and operation of the Commonwealth-State/Territory Disability Agreement (CSTDA).

This PA submission takes into account the inquiry's terms of reference:

- (a) an examination of the intent and effect of the three CSTDAs to date;
- (b) the appropriateness or otherwise of current Commonwealth/State/Territory joint funding arrangements, including an analysis of levels of unmet needs and, in particular, the unmet need for accommodation services and support;
- (c) an examination of the ageing/disability interface with respect to health, aged care and other services, including the problems of jurisdictional overlap and inefficiency; and
- (d) an examination of alternative funding, jurisdiction and administrative arrangements, including relevant examples from overseas.

Essentially, for reasons which we will briefly outline below, people with Parkinson's are failed by both the disability and health systems, across sectors and jurisdictions. We look forward to the opportunity to elaborate and to discuss this with Senators at your public hearings.

#### **Background**

Parkinson's is second only to dementia as the most common chronic neurological condition.

Parkinson's disease (Pd) is a chronic disease (it persists over time) and progressive disease (the symptoms get worse over time) with substantial disability.

According to the National Institute of Neurological Disorders and Stroke (April 2005):

*Parkinson's disease is a progressive neurological disorder that results from degeneration of neurons in a region of the brain that controls movement. This degeneration creates a shortage of the brain signalling chemical (neurotransmitter) known as dopamine, causing the movement impairments that characterise the disease.*

PA is the national association representing people with Parkinson's in bringing awareness of Pd and Parkinson's-like conditions to the community, and to our decision-makers.

Generally speaking, we do not know what causes or triggers Pd. There is no current cure for Parkinson's. It is a progressive disorder whose impact reaches far beyond the clinical signs and symptoms exhibited by those afflicted. It not only places severe burden on the individual, but also on their family, friends, work place and society.

### **Prevalence of Parkinson's**

We do not know how many people with Pd there are in Australia, although we believe that the total number of people with Parkinson's is four times the number with MS, forty times the number with Motor Neurone and Huntington's disease, and sixty times the number with Muscular Dystrophy. Numbers will double in thirty years.

In terms of prevalence, incidence, disability weighting, burden of disease and years of life lost due to disability, Parkinson's far outweighs Multiple Sclerosis (MS), Huntington's, Motor Neurone Disease, and Muscular Dystrophy combined.

Pd is a neurological condition which primarily affects older people, but, like Alzheimer's and other forms of dementia, there are a significant number of younger people. Twenty per cent are under 50 when diagnosed. The number of people under 50 with Parkinson's is equivalent to 60% of the entire number of people with MS.

PA welcomes the important work being undertaken on the Australian Institute of Health and Welfare (AIHW)'s behalf by the Centre of Burden of Disease and Cost-Effectiveness in the School of Population Health at the University of Queensland. This work will update the major report first done in 1999 on Burden of Disease, with data on the cost of 180 conditions, including Pd.

The only type of Pd included within the study is ***Idiopathic or Primary Pd*** – where the cause is unknown. We contend that the fact that the cause is unknown is not such a good peg because we suspect that sooner or later, medical research will identify a cause or causes for Parkinson's.

***Secondary Pd*** – where the cause is known – includes:

- Malignant neuroleptic syndrome and other drug-induced parkinsonism: such as that caused by neuroleptic drugs (such as antipsychotics), anti-emetic agents (such as prochlorperazine), gastrointestinal anti-motility drugs (such as metaclopramide), antihypertensive drugs (reserpine), and some calcium-channel blockers.
- Post-encephalitic parkinsonism.
- Other secondary parkinsonism such as that caused by environmental toxins, trauma, metabolic derangement, stroke and brain tumour.

***Other Parkinson's-like conditions*** which have symptoms similar to Pd include:

- Essential Tremor

- Multiple System Atrophy
- Progressive Supranuclear Palsy
- Cortico-Basal Degeneration
- Dementia with Lewy bodies
- Normal-pressure Hydrocephalus
- Binswager's Disease, and
- Vascular Parkinsonism.

PA has concerns regarding the very narrow definition adopted for classification as Pd within this study, and suggest that a broader working definition of Parkinson's would be more consistent with the approach taken with other chronic conditions such as dementia and diabetes. The data for Pd will not be based on Australian surveys, but are extrapolated from European data.

We understand that this extrapolated data will indicate that some 47,000 Australians had Idiopathic Pd in 2003. We estimate that the overall figure for Parkinson's by the broader definition is likely to be double that.

Parkinson's Australia believes that a broad definition of Pd is important. While we appreciate the complexities of disease classification, we suggest that a definition that embraced all of the following Parkinson's-like conditions – whose symptoms and treatments are similar – would help Australia to better come to grips with the issues at a clinical, care, social, and economic level and would support better public policy.

For the purposes of the AIHW's Burdens of Disease study, Parkinson's disease has been defined as only Idiopathic or Primary Pd where the cause is unknown. The estimates of prevalence and burden do not extend to secondary Parkinson's (which may have been induced by drugs, environmental toxins, trauma, metabolic derangement, stroke and brain tumour) or Parkinson's-like conditions such as Essential Tremor. Further study would be needed to get a more complete picture of the burden of Parkinson's when more broadly defined to include very similar and related conditions.

PA supports a broad definition to include all these conditions because they have similar symptoms, similar effects, and similar treatments. We believe this is consistent with the approach taken with other chronic conditions.

### **Putting Parkinson's on the agenda**

For a range of reasons – including this definitional problem – Pd is largely an unknown – or at least not publicly visible – condition. There is a lack of awareness and service coordination, whereby people do not access services that would reduce the impact of Parkinson's.

It is to help redress this situation that the National Assembly of Parkinson's Australia (PA) has taken two landmark decisions.

Firstly, PA has commissioned Access Economics to undertake a study for us to help establish the dimensions of Pd within Australian society, and for the individuals, families and communities affected. This will help us to develop effective strategies to tackle the many issues.

Secondly, PA has established a national office in Canberra to lead our efforts in bringing awareness of Pd to the community, and to our decision-makers.

## Poor disability services support for people with Parkinson's

Another side effect of the lack of visibility of Parkinson's is the poor access to community-based disability services for people with Parkinson's, and their support agencies.

Only some State and Territory Parkinson's associations receive any community services funding, and that is very minimal. Governmental funding in 2005-06 was in the order of:

- Parkinson's Victoria: \$180,000 recurrent funding for 2 x Client services officers from State Department of Human Services for provision of information services including 1800 number and website.
- Parkinson's Queensland: \$125,000 recurrent funding from Home and Community Care (HACC) for Parkinson's information, awareness and services programs.
- Parkinson's SA: \$105,000 shared premises subsidy from the State Government Disability Sector for rent, electricity, photocopying and rates shared with 8 other charities.
- Parkinson's WA: \$220,000 recurrent funding from State Department of Health to operate a community based Parkinson's Nurse Specialist program (to reapply every three years with no guarantee of funding).

The remaining State and Territory Parkinson's associations receive nothing from State or Federal governments. Neither does the newly established national PA office.

In Tasmania, Multiple Sclerosis Society Tasmania is currently hosting Parkinson's Tasmania. MS Tasmania provides limited information and support for people living with Parkinson's.

In NSW, all resources come from members' dues and benefactors' generosity.

Parkinson's ACT, operates on a voluntary basis and shares resources with other community-based charities.

In the NT, there is no association to look after the interests of people with Parkinson's.

There will clearly be many advantages to all concerned if we can put together a successful strategy to redress these care and awareness deficiencies for Pd in Australia.

A better level of disability support for people with Parkinson's would mean fewer admissions to acute care hospital because of conditions such as broken limbs from falls. This will have positive benefits for the overall health system, as well as for people with Parkinson's.

It is also worth noting that the length of hospital admissions for people with Parkinson's is often accentuated due to medication problems within the hospital system – the medication needs of people with Parkinson's are not adequately recognised, resulting in routine hospital ward medical rounds not meeting the needs of people with Parkinson's. This year's National Parkinson's Awareness Week will highlight this issue with our *Get it on Time* campaign.

The challenge for government is to adopt public policies which will enable society to adapt to changing socio-demographic circumstances.

Governments must look beyond the next election and commit adequate funding and deliver responsible progressive health policies to ensure access and affordability to high quality health and disability care services for all Australians, no matter where they live and no matter their socio-

economic background.

Many people with Parkinson's do not need, and never receive residential care services. People would generally prefer to remain in their own homes, supported as necessary by community care services with advice and support from clinical nurses specialising in Pd. With appropriate support services in the home, we can delay the need for residential care, at great benefit to both the individuals concerned, and to society.

There is increasing recognition that community care programs can no longer be considered in isolation from other service sectors, including residential aged care, disability services and primary and acute health services.

PA calls on all political parties need to acknowledge that there are serious barriers to the delivery of appropriate care for people with Parkinson's.

Better continuity of care must be achieved by conscious policies and strategies aimed at enhancing integration and communication. Support programs need to be on-going, not one-off.

From the perspective of governments at both federal and State/Territory level, the establishment of the national PA office will make the job of liaising with this constituency far easier.

### **Conclusion: Challenges for the future**

Parkinson's Australia is committed to working with other stakeholders including government to ensure that people with Parkinson's receive the care that they are entitled to expect in an accessible and timely manner within a quality framework preserving dignity and promoting wellness.

We look forward to discussing ways of achieving this with Senators at a public hearing.

Bruce Shaw  
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