

PARKINSON'S AUSTRALIA: PARKINSON'S NURSE SPECIALIST POSITION PAPER

THE ISSUE

Current Australian Federal Government policy fails to address the needs and requirements of people with Parkinson's in spite of **the prevalence** of the disease and it being one of the most **difficult challenges** for the treating physician (World Health Organisation 2006).

Parkinson's disease needs an urgent public policy response (World Health Organisation 2006). Neurological disorders are one of the greatest threats to public health. Because of its chronic progressive nature, insidious onset, complicated and diverse motor and non-motor symptoms Parkinson's is one of the most challenging for the treating physician (World Health Organisation 2006). Parkinson's is a neurodegenerative condition with currently no known cure.

EVIDENCE

Prevalence and incidence

Parkinson's is more common than prostate cancer, bowel and many other cancers considered National Health Priority Areas. Parkinson's had the second highest prevalence in 2005 compared to other neurological conditions, exceeded only by dementia (Deloitte Access Economics 2011).

Furthermore, Parkinson's is growing in numbers, by 17% over the last six years, with 30 people diagnosed with Parkinson's every day. In Australia, approximately 1 in every 350 people live with Parkinson's. Although the incidence of Parkinson's increases with age, 20% of people who are affected are of working age (Deloitte Access Economics 2011).

Burden

Parkinson's disease places a **burden** on society, on the person with Parkinson's and on the caregiver and family.

Economic burden on society

The net value of the burden of Parkinson's in 2011 was \$7.6 billion with total economic cost¹ being \$8.3 billion (Deloitte Access Economics 2011, p. 67). The financial cost of Parkinson's increased by 48% between 2005 and 2011 because of health system costs and productivity costs (Deloitte Access Economics 2011).

In Australia, governments bear the greatest cost of Parkinson's with the Federal government bearing 39% of costs and state governments 16% (Deloitte Access Economics 2011).

Research in the United Kingdom showed that there was approximately a 500% increase in costs if a person moved from home to residential care (Findley et al 2003). Because there is a higher risk of people with Parkinson's living in a nursing home and a higher cost (Vossius et al 2008) interventions to delay nursing home placements are paramount.

Individual cost and disease burden

People with Parkinson's experience extremely high levels of disease burden. This is summed up by Rubenstein et al (2001, p.729):

The progressive disability of Parkinson's disease results in substantial burdens for patients, their families and society in terms of increased health resource use, poorer quality of life, caregiver burden, disrupted family relationships, decreases in social and leisure activities, deteriorating emotional well-being, and direct and indirect costs of illness. Patients with Parkinson's disease

¹ The net value of the burden of disease plus the financial cost of Parkinson's.

incur higher hospital expenses, have increased number of prescriptions, and experience earnings loss.

According to the Access Economics Report (2007) living with Parkinson's is considered more burdensome than blindness or deafness in the initial stages; on par with severe depression in the intermediate stages; and in the final stages on par with terminal cancer or severe dementia. The quality of life for people with Parkinson's deteriorates significantly with increasing disease severity especially in terms of physical and social functioning when compared with the general population (Schrag 2000).

Carer Burden

The burden on carers in economic, emotional and health terms is significant. The cost of informal care provided to people with Parkinson's in 2011 was \$11.2 million (Deloitte Access Economics 2011). The impact of Parkinson's on a person's health related quality of life in terms of physical mobility, pain, social isolation and emotional reactions affects care giver's health as well as their own (Karlsen et al 2000).

In Australia, researchers found that where people with Parkinson's had poor health related quality of life issues, there was significantly increased strain on care givers (Kelly et al 2012). There is a substantially increased burden suffered by carers of people with both cognitive and physical impairment (Tooth et al 2008, p.272), a key characteristic of Parkinson's. Parkinson's has a heightened impact on carers over time which needs to be reflected in the clinical management of Parkinson's (Morley et al 2012).

Policy Framework

The World Health Organisation's policy framework for people with a chronic neurodegenerative condition such as Parkinson's, emphasises the critical need for positive government policy relating to the condition, with links to health care organisations and community (Davidson 2006).

Parkinson's is not a national health priority with the Australian Government. The Government has a chronic care strategy which recognises integration, continuity of care and self-management as key action areas for chronic conditions (National Health Priority Action Council 2006 p.11, 12)

providing integrated and continuous care across time, different stages of the disease, co-morbid conditions, and different services and service providers

It is essential that supports are put in place at all levels of the health system to optimise people's ability to self-manage. This will not only improve health outcomes and quality of life for people with chronic disease and their families and carers, but also reduce the burden of chronic disease care on the health system.'

The key principles are sound but Parkinson's is not a priority² in spite of the fact that they contribute substantially to the burden of disease on Australian society. In fact, Parkinson's is not even mentioned.

Parkinson's nurse specialist: implementing the Australian government's national health management principles

In order for self-management to be effective, people need to be able to make informed decisions about their health and have access to care planning and medication management (NHPAC 2006). The promotion of a patient centred self-management model of care (Giroux & Farris 2008) and timely interventions rather than crisis management (Martin & Mills 2013) is central to the management of Parkinson's.

² The national priority areas under the policy framework in 2006 were asthma, cancer, diabetes, heart, stroke and vascular disease, rheumatoid arthritis, osteoarthritis and osteoporosis (NHPAC 2006). There are nine National Priority Areas currently: cancer, cardiovascular health, injury prevention and control, mental health, diabetes, asthma, arthritis and musculoskeletal, obesity and dementia (AIHW n.d.)

People with Parkinson's should have access to a knowledgeable multidisciplinary team (Kale 2004) of which a key member is a Parkinson's nurse specialist. The Parkinson's nurse specialist has the expertise and knowledge to educate and help people with Parkinson's and their families with the management of often complex medication regimes thus improving their quality of life (O'Malley et al 2005) thereby facilitating self-management.

The non-motor symptoms of Parkinson's such as autonomic dysfunction, sleep disorders, pain and neuropsychiatric disorders are strongly correlated to quality of life as well as to institutional placement (Wishart & Macphee 2011). Parkinson's nurse specialists play an important role in providing clinical input, education and support for the person, care giver and community agencies (MacMahon 1999).

Hospitalisation presents many challenges for people with Parkinson's particularly in relation to medication management, falls, mental status changes, infections, and emergence of psychiatric symptoms (Oguh & Videnovic 2011). A Parkinson's nurse specialist plays an important role in the education of the person, family members and staff which may lead to reduced time in hospital.

Caregiver burden influences the ability of the person with Parkinson's to manage (Edwards & Reuttiger 2002). The Parkinson's nurse specialist plays an essential role in alleviating this burden through counselling, education and support. Australian research showed that access to a community based Parkinson's nurse specialist improves the quality of life for the informal carers (Pereira et al 2013).

Informal carers play a significant role in reducing the transition to high level care facilities. A community based Parkinson's nurse specialist plays an essential role in visiting the home to provide advice, education and counselling (National Collaborating Centre for Chronic Conditions 2006) thus reducing caregiver burden and delaying institutional placement. This in turn reduces cost to society (Findley et al 2003). Research shows that there is a higher risk of people with Parkinson's living in a nursing home and once there, their costs are higher (Vossius et al 2008).

The National Institute of Health and Clinical Excellence (NICE) Guidelines 2006 provide the basis for the best practice framework for the service delivery model of care for Parkinson's disease (National Collaborating Centre for Chronic Conditions 2006). The Guidelines are based on extensive evidence-based research. They have been compiled and reviewed by a team of clinical advisors, health economist, scientists, multi-disciplinary professional team, involved health consumers and other stakeholders.

The guidelines emphasise the importance of non-pharmacological aspects of care in managing the progressive nature of Parkinson's including a multidisciplinary team with a specialist nurse. It is the Parkinson's nurse specialist who is a reliable source of information and education, assisting with medication monitoring and integration of services thus encouraging self-management in the community. The Western Australian Government has adopted the NICE guidelines as the best practice framework to inform that state's integrated model of care for people with Parkinson's. It recognises the interdisciplinary care team and the role the Parkinson's nurse specialist plays in enabling people with the condition to live independently in the community, prevent hospitalisations and delay nursing home admissions (Aged Care Network, Department of Health, Western Australia. 2008).

Parkinson's nurse specialists work in the community integrating services and bridging the links between home, hospital and aged care facilities. In Australia telemedicine may bring the services of a Parkinson's nurse specialist to rural and remote areas. This has proved effective in a study in the USA (Dorsey et al 2010).

Cost savings

Where Parkinson's nurse specialists have been in place, the increase in health costs has been lower than those in a control group (Hurwitz et al 2005). Participants of the study who had access to a nurse had an improved sense of well-being.

The Deloitte Access Economics report (2007) states that based on UK research:

- A single Parkinson's nurse can save, on average, £43,812 (A\$57,831) in consultant appointments each year;
- Community-based Parkinson's nurses can save more than £80,000 (A\$105,600) per year in avoided hospital admissions; and
- Parkinson's nurses can save on average £147,021 (A\$194,068) per year in bed days.

Access to Parkinson's nurse specialists combined with regular therapy services has the potential to reduce the need for unnecessary hospitalisation, outpatient appointments, GP attendances and may delay nursing home admissions. This will reduce the growth in the health and ageing expenditure over the coming decades.

POSITION STATEMENTS

- Parkinson's Australia urges the Australian government to declare Parkinson's a national health priority. The condition places a substantial burden on the economy and society and its prevalence is increasing.
- Parkinson's Australia seeks an urgent review of the national chronic disease strategy to recognise the needs of people with Parkinson's.
- Parkinson's Australia calls on the Australian Government to develop a National Service Improvement Framework to improve health service arrangements for people with Parkinson's through all stages of the disease.
- Parkinson's Australia calls on state and federal governments to adopt the evidenced based NICE guidelines as a service delivery model of care for people with Parkinson's.
- Parkinson's Australia calls on the government to invest in Parkinson's nurse specialists as the key person in a multi-disciplinary team to facilitate integrated care and provide education and support to enable self-management and informed decision making by people with Parkinson's.
- Parkinson's Australia supports the Australian Government's telehealth initiative and would welcome the opportunity to explore this technology to enable some people in rural and remote areas to access a Parkinson's specialist nurse.

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