



## **2017-18 Budget: Parkinson's Australia Submission**

18 January 2017

# Contents

- Introduction.....3
- Recommendations .....4
  - Recognition of Parkinson's as a National Health Priority Area .....4
  - Investment in better care and support.....4
  - Investment and capacity building in Parkinson's research .....5
  - Investment in upskilling the workforce to enable timely diagnosis, better care and support of people living with Parkinson's.....5
- Costing of Initiatives .....6
- About Parkinson's Australia.....7

## Introduction

Parkinson's Disease is a neurodegenerative condition has no cure and has a higher prevalence than many cancers including breast and prostate cancer. Previous estimates conservatively estimated that 70,000<sup>1</sup> people live with Parkinson's; however, more recent research indicates that the actual prevalence is over 108,000.

As the major risk factor for Parkinson's is aging the number of people living with this condition is increasing at a rate of 4%, as the populated ages, compared with a general population growth rate of around 1%.

The cost of Parkinson's to the community was estimated to be \$9.9b in 2014 based on the 70,000 prevalence figure, it would be expected that this figure has increased significantly since 2014. The lifetime cost of Parkinson's estimated at \$161,300 and significantly greater than the average lifetime cost of cancer (\$144,000)<sup>2</sup>.

Parkinson's is a chronic condition that varies in severity, disease course and the range of symptoms. Symptoms include motor symptoms such as tremor, muscle rigidity, slowness and instability as well as a range of non-motor symptoms such as depression, anxiety, hallucinations, mild cognitive impairment through to dementia, gastrointestinal symptoms, sleep disturbance and sensory deficits. The average time from diagnosis to death is just over 12 years; however, some people will live for many years with the condition particularly if they are diagnosed early in life.

People living with Parkinson's struggle to access to the range of services and supports they need to achieve a good quality of life and to remain active and independent in the community. Whilst there is currently no cure there is a range of cost effective measures that will both improve the quality of life of people living with Parkinson's and reduce the cost of this condition to the community.

---

<sup>1</sup> Deloitte Access Economics, Living with Parkinson's Disease: An updated economic analysis 2014, August 2015

<sup>2</sup> Deloitte Access Economics, Living with Parkinson's Disease: An updated economic analysis 2014, August 2015 pp79

## Recommendations

Parkinson's Australia, after extensive consultation with the Parkinson's community, has developed the evidence based *Make Parkinson's a Priority Action Framework*<sup>3</sup>, in this submission we highlight the recommendations contained in that Action Framework.

The immediate priorities are:

- **Recognition of Parkinson's as a National Health Priority Area;**
- **Investment in better care and support for people living with Parkinson's through access to Parkinson's Nurse Specialists and equitable access to medications and therapies;**
- **Investment and capacity building in Parkinson's research; and,**
- **Investment in upskilling the workforce to enable timely diagnosis, better care and support of people living with Parkinson's.**

### Recognition of Parkinson's as a National Health Priority Area

Recognition of Parkinson's as the tenth National Health Priority Area will assist in driving the development of strategies and policies in areas such as research, education, community awareness and support services.

Parkinson's has a greater prevalence in the community than many other diseases already recognised as National Health Priority Areas and in 2017 it is expected that at least 13,000 will be diagnosed with Parkinson's.

### Investment in better care and support

There are two significant areas where investment in cost effective care and support will both increase the quality of life of people living with Parkinson's and reduce the cost of this condition to the community and government.

#### Access to Parkinson's Nurse Specialists

As there are no treatments that can alter the course of Parkinson's the focus of health intervention is on the control and management of symptoms and complications associated with Parkinson's. Access to a Parkinson's Nurse Specialist has been shown to:

- Reduce hospital admissions and reduce length of stay where and admission is necessary
- Reduce or delay entry into Residential Aged Care Facilities

---

<sup>3</sup> Make Parkinson's a Priority: Action Framework - <http://www.parkinsons.org.au/Documents/Parkinson's%20Australia%20-%20Action%20Platform%20Feb%2016%20Graphics%20included%20.pdf>

- Reduce the need for medical consultations and interventions related to Parkinson's and associated complications
- Improve the quality of life of people living with Parkinson's and allow them to remain independent and productive in the community.

### Equitable access to medications and therapies

People living with Parkinson's often have trouble accessing treatments that have been shown to be effective in reducing symptom and the complications of Parkinson's.

Parkinson's is an extremely complex condition to manage with it is appropriate that clinician have access to the full range of treatment options so symptom control and quality of life can be optimised for their patients. These Treatments include Deep Brain Stimulation which for some people with Parkinson's provides significant symptomatic relief and a range of drugs which have not been approved for the Pharmaceutical Benefits Scheme.

### **Investment and capacity building in Parkinson's research**

There are no treatments available which will slow, stop, reverse or cure Parkinson's. The current treatments available only reduce the impact of symptoms and over time become increasingly ineffective. The cause(s) of Parkinson's and related conditions remains unknown and there are no diagnostic tests that can be used to diagnose and monitor the progress of the condition.

Focused research, including clinical trials, aimed at increasing our understanding of Parkinson's and its causes, identifying better treatments to reduce the impact of Parkinson's and treatment which will alter the course of the condition can provide significant benefits to people living with Parkinson's and the community.

### **Investment in upskilling the workforce to enable timely diagnosis, better care and support of people living with Parkinson's**

Knowledge about the diagnosis and treatment of Parkinson's in the health and aged care workforce is generally very low. Whilst some people are able to access specialised Parkinson's clinics the majority of people living with this disease rely on the general health and aged care workforce to provide their care.

Parkinson's Australia and its members only have very limited capacity to provide training for the health and aged care workforce and as such only reach a small proportion of clinician and care providers. Additional funding to support enhanced education services would assist in ensuring that people living with Parkinson's can access quality clinical and aged care services and would assist in reducing the cost of this condition to the community and government.

## Costing of Initiatives

	Forward Estimates Cost <sup>i</sup>
Recognition of Parkinson's as a National Health Priority Area	No cost
Investment in better care and support <ul style="list-style-type: none"><li>• Parkinson's Nurse Specialists</li><li>• equitable access to medications and therapies</li></ul>	\$20.3m phased over 4 years N/A
Investment and capacity building in Parkinson's research	\$33.7m phased over 4 years
Investment in upskilling the workforce	\$10.9m

Further detailed information on the action proprieties and costings can be found in the *Make Parkinson's a Priority: Action Framework* which is available at <http://www.parkinsons.org.au/Documents/Parkinson's%20Australia%20-%20Action%20Platform%20Feb%2016%20Graphics%20included%20.pdf>

## About Parkinson's Australia

Parkinson's Australia is the national peak body and charity representing Australians living with Parkinson's, their families and carer, clinician and researcher.

Parkinson's Australia represents, at the national level, the interests of its federation of state and territory members on all matters relating to Parkinson's and carer issues.

The role of Parkinson's Australia is to advocate on the basis of evidence-based policy, promote awareness of Parkinson's and administer national contracts with the Commonwealth Government.

Parkinson's Australia has a strong consumer focus and works with all Parkinson's state organisations (who provide support services, education and information) to advocate on behalf of the Parkinson's community at a federal level.

We are represented on the National Neurological Alliance group advocating for better services to people affected by progressive degenerative neurological diseases in Australia.

We are committed to achieving a Parkinson's-friendly society where people living with Parkinson's, their carers and family members are supported, respected, empowered, and engaged in community life.

---

<sup>i</sup> Based on 2015 costings contained in the *Make Parkinson's a Priority: Action Framework* updated to 2017