

Parkinson's Australia: Pre-Budget Submission 2019-20



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Introduction

Parkinson's Disease is a neurodegenerative condition that has no cure and has a higher prevalence than many cancers including breast and prostate cancer. The most recent research indicates that more than 110,000 people live with Parkinson's and that more than 1 million carers, family and friends are directly impacted.

The cost of Parkinson's to the community was estimated to be \$9.9b in 2014¹ based on a lower 70,000 prevalence figure. With the revised prevalence and the growth in the Consumer Price Index it could be expected that this figure would be well over \$15b in 2019. The direct financial cost of Parkinson's to the Government is estimated at over \$1b annually.

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 postural 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. They also are overrepresented in nursing home admissions and many have frequent hospital visits because they do not receive appropriate care and support 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.

Federal Government Initiatives

On 30 January 2019 Greg Hunt MP, Minister for Health, announced funding of \$30m for the Australia Parkinson's Mission through the Medical Research Futures Fund and \$6.8m for Parkinson's nurses to improve the life of people living with the disease and ultimately to find a cure for Parkinson's.

This announcement by the Government was very welcome but more needs to be done to support people living with Parkinson's to keep them well and out of hospital and residential aged care and to give them hope for the future.

Recommendations

In 2015, after extensive consultation with the Parkinson's community, Parkinson's Australia released the [Make Parkinson's a Priority: Action Framework](#)² which highlighted four cost effective interventions that would improve the lives of people living with Parkinson's and reduce the cost of the condition to the community and the Government. The four recommendations were:

- 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;

¹ Living with Parkinson's Disease: An updated economic analysis 2014. (2015). Canberra: Parkinson's Australia, pp.85-86. Available at: <https://goo.gl/UQRkBM> .

² Make Parkinson's a Priority: Action Framework <https://goo.gl/3Lfx9M>

- 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.

For the 2019/20 Budget, Parkinson's Australia calls on the Government to join Parkinson's Australia in our mission to create a world without Parkinson's and provide our community help for today and hope for tomorrow. Parkinson's Australia calls on the Government to:

- **Increase the funding for Parkinson's Nurse Specialists across Australia** to enable 51 nurses to be employed to support people living with Parkinson's to remain living independent, productive and rewarding lives in the community.
- **Invest in training the Aged Care workforce in Parkinson's care** to enable those living in residential aged care facilities to maximise their good quality of life.

Investment in Parkinson's Nurse Specialists

The \$6.8m announced for Parkinson's nurses is expected to fund up to 15 locations around Australia to employ a Parkinson's Nurse Specialist. International evidence indicates that the appropriate nurse to patient ratio would require that at least 250³ nurses are required to provide the quality care to the Australian Parkinson's community.

Access to a Parkinson's Nurse Specialist has been shown to⁴:

- Reduce hospital admissions and reduce length of stay where an admission is necessary;
- Reduce or delay entry into Residential Aged Care Facilities;
- Reduce the need for medical consultations and interventions related to Parkinson's and associated complications; and,
- Improve the quality of life of people living with Parkinson's and allow them to remain independent and productive in the community.

International and Australian studies indicate that savings generated by Parkinson's Nurse Specialists in hospital, aged care and medical benefits programs will more than fully offset the costs associated with the employment of these nurses⁵

Parkinson's Australia recommends that an additional \$13.6m (net of the \$6.8m previously announced) be provided to increase the number of nurses to 51. Whilst this is well short of the 250 required, it will enable those living with Parkinson's who have complex requirements to access the services of a nurse.

Invest in training the aged care workforce in Parkinson's care pilot

It is estimated that 5-8% of people living in residential aged care have Parkinson's or Parkinsonian conditions such as Progressive Supranuclear Palsy (PSP) and Multiple System Atrophy (MSA) this is compared to the general aged community where 1-2% of people have these conditions.

³ Based on the recommended Parkinson's nurse ratio's in the United Kingdom

⁴ Living with Parkinson's Disease: An updated economic analysis 2014. (2015). Canberra: Parkinson's Australia, pp.107-112. Available at: <https://goo.gl/UQRkBM> .

⁵ Living with Parkinson's Disease: An updated economic analysis 2014. (2015). Canberra: Parkinson's Australia, Table 14.1: Potential cost savings pp.109-110. Available at: <https://goo.gl/UQRkBM> .

The aged care workforce receives little or no training in the care of people living with Parkinson's and Parkinson's Australia has observed that, as a consequence, the quality of care provided in residential aged care facilities is generally poor.

Parkinson's Australia, with support from the Federal Department of Health grant, developed an aged care training package for residential aged care staff. The package provides a basic understanding of Parkinson's, care requirements and how an aged care worker can best support and care for someone living with Parkinson's in an aged care facility. Whilst funding was sought to actually deliver the training in the original application to the Department of Health, this was not provided in the grant.

Parkinson's Australia recommends that the Government fund a small pilot program that would enable the delivery of the aged care training through three different training approaches including: face to face delivery; train the trainer; and, online training modules. The effectiveness of the training approaches would be evaluated including cost and sustainability.

It is expected the project will improve the quality of life for people with advanced Parkinson's disease who are in residential care, using best practice training, support and consultation for staff.

Costing of Initiatives

| | 4 Year Cost ⁶ |
|--|------------------------------|
| Investment in Parkinson's Nurse Specialists | \$13.6m phased over 4 years* |
| Invest in training the aged care workforce in Parkinson's care pilot | \$2.4m |

*net of the \$6.8m already announced.

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.

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 who advocate 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.

⁶ Based on 2015 costings contained in the Make Parkinson's a Priority: Action Framework updated to 2017