



Pre-Budget Submission

Budget 2020-21

About Parkinson's Australia

Parkinson's Australia is the national voice for People with Parkinson's Disease (Parkinson's) representing over 100,000 Australians living with Parkinson's, their families and carers, health, and community care providers. We aim to improve the lived experience for people with Parkinson's by working with care providers to offer options for care, improved wellbeing through access to better primary care health services and supporting research into clinical guidelines for evidence-based care for people with Parkinson's.

We are committed to achieving a society that includes people with Parkinson's, where people living with Parkinson's, their carers and family have access to care and support to meet their individual needs to enable them to live better for longer and have hope for a future.

Together with state Parkinson's associations we work to advance, promote, and influence Parkinson's care with a vision to achieving a world without Parkinson's.

Introduction

Parkinson's Australia calls on the Government to improve access to needs-based care for all people with Parkinson's disease no matter their age or postcode.

Recent research found neurological diseases are the leading source of disability and Parkinson's is the fastest growing of these disorders¹. Parkinson's Disease², along with other Neurological disorders, is not a natural part of aging, but is a progressive disability, with complex motor and non-motor interactions.

We are currently searching for the cure for Parkinson's. Until it is found, improving the wellbeing, independence, and opportunities for people with Parkinson's remains the priority. This translates as ensuring a timely diagnosis, providing equitable access to health care and Government support, and ensuring the community is accepting of people with Parkinson's (and other disabilities).

Currently, Parkinson's Disease falls in a policy void: between disability, ageing, and health. As a disease, it is not large enough to command intervention, and not rare or unique enough to draw a media following.

The current policy settings of Government programs in the aged care, income support and health systems do not support people with Parkinson's. For example, people with Parkinson's cannot work significant hours, and are inexplicably placed upon Newstart, at which point they can no longer afford consumables that deliver medication as these are not subsidised under the PBS.

More than 100,000 people currently live with Parkinson's in Australia. It is suspected that there are many undiagnosed. It is estimated that 20 per cent of people living with Parkinson's are working age, and often have young families. Parkinson's affects people from all walks of life and is increasingly being diagnosed in those under 65 years of age.

¹ Dorsey, E. R., Sherer, T., Okun, M. S., & Bloem, B. R. (2018). The Emerging Evidence of the Parkinson Pandemic. *Journal of Parkinson's disease*, 8(s1), S3–S8. doi:10.3233/JPD-181474

² The WHO defines Parkinson's disease as "a chronic progressive neurodegenerative disorder of insidious onset, characterised by the presence of predominantly motor symptomatology (bradykinesia, rest tremor, rigidity, and postural disturbances). It is also associated with a diversity of non-motor symptoms, which, together with late-onset motor symptoms (such as postural instability and falls, freezing of gait, speech and swallowing difficulties), are presently one of the most difficult challenges the treating physician is faced with when dealing with patients with a long duration of the disease"

Deloitte Access Economics, indicated the economic cost of Parkinson's was \$775 million back in 2014, including approximately \$480 million in health care costs and \$110 million in lost productivity³. This cost reflects the chronic progression of this disease, with many people living with Parkinson's for up to 20 years.

Recommendations

Parkinson's Australia calls for the Government to support the following initiatives:

- Invest in research that would support the development of Clinical Guidelines for General Practice. This research would provide the evidence-based framework for clinical decision making.
 - Cost: \$10 million over the forward estimate period
- Provide opportunities for care in the Aged Care System:
 - greater access to home care packages (HCP)
 - upskilling HCP care providers
 - Cost: \$750,000 across 2020/21 and 2021/22.
 - greater access to primary care
- Improve MBS and PBS subsidies to offset the cost of daily medications and consumables.
 - Establish a support scheme for consumables
 - Increase MBS rebates for Deep Brain Stimulation surgery
 - Improve access to Ropinirole and a generic form of Madopar.

³ Deloitte Access Economics report Living with Parkinson's Disease Challenges and positive steps for the future, <https://www2.deloitte.com/au/en/pages/economics/articles/living-with-parkinsons-disease.html>

Invest in research for Clinical Guidelines for General Practice

Parkinson's Australia is calling for a Parkinson's clinical pathway to be developed that meets the evolving trajectory of disease and the complex interplay of therapies.

People see their General Practitioner when issues arise with their health. General Practice is therefore the first point in the diagnosis pathway, however there are currently no guidelines, screening tools, and no definitive test available for Parkinson's Disease, leaving GPs to find clinical pathways in an unstructured environment.

The most important risk factor for Parkinson's is age, but it is also linked to genetics and environmental factors such as pulse production, industrial chemicals and pollutants, such as pesticides, solvents, and metals⁴. Despite years of research, there is limited progress in being able to provide definitive risk factors, cause or treatment. There are a wide variety of signs and symptoms that affect both motor and non-motor areas of the brain. It is a progressive condition but with significant variation between initial symptoms, age of onset, rate and pattern of progression and survival time.

⁴ Pang, SY, Ho PW, Liu DF et al 2019, [The interplay of aging, genetics and environmental factors in the pathogenesis of Parkinson's disease](https://doi.org/10.1186/s40035-019-0165-9). DOI:10.1186/s40035-019-0165-9.

The benefits of a nationally derived clinical guidelines and care pathways include:

- Timely (early) expert diagnosis – improving options to manage the symptoms of the disease.
- Support patient choice in accessing evidence-based interventions in a timely manner thereby improving quality and length of life⁵
- Reduce or delay hospital admissions and reduce length of stay where an admission is necessary
- Provide expert support to community health care providers
- Reduce or delay entry to Residential Aged Care Facilities
- Improve access to evidence-based therapies
- Support early referral to palliative care services and advance care planning
- Increase patient participation and access to clinical trials and research

Primary prevention strategies remain the most cost-effective interventions and best placed for improving wellbeing and quality of life and at the same time reducing the cost to the community.

Overall, these interventions offer the ability to remain in the home environment with improved safety and comfort.

Recommendation:

Invest \$10 million over the forward estimate period for research to enable the development of clinical Guidelines for General Practice, including improved and nationally consistent screening programs, and improved patient pathways, currently lacking in the Parkinson's space⁶.

⁵ Ng and others 2009, Multidisciplinary care for adults with amyotrophic lateral sclerosis or motor neuron disease

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Provide opportunities for care in the Aged Care System

Retrofitting a complex, multifactorial neurological disease into the current model has left people with Parkinson's over-represented in Residential Aged Care Facilities. As Parkinson's is not an aging condition, these facilities are not equipped to meet the care needs of people with Parkinson's.

The AIHW estimates that 10,000 people with Parkinson's are in permanent residential aged care, with 265 of those aged under 65 years.

It is estimated that between 70,000 – 150,000 people living with Parkinson's are engaged with the non-residential part of the aged care system⁷. It is likely that people with Parkinson's are overrepresented in the HCP program, similar to the overrepresentation in residential aged care facilities, due to the degenerative nature of the disease. People with Parkinson's usually require a level 3 or 4 category of package due to the complexity of the disease.

Improve access to HCP:

People affected by a progressive neurological condition over the age of 65 are added to long waiting lists for aged care services or have been assigned lower level aged care packages that do not meet their needs. This lack of support for remaining in the home in the aged care system is causing people to be pushed into financial hardship or residential aged care earlier than they wish.

Upskilling HCP care providers:

Develop and implement a Parkinson's Awareness for Home Care Providers training package - aimed at upskilling care providers. There is little or no understanding of the specific care and symptom management that is required to manage this progressive disease with complex symptoms. This proposal would enable HCP carers to provide effective care to people with Parkinson's, improve adherence to treatment protocols and therefore reduce acute episodes requiring tertiary level treatment. Working with people living with Parkinson's, specialists, carers and primary health care providers, Parkinson's Australia will develop and implement the training package

Implementation cost: \$750,000.

⁷ There are over 100,000 people living with Parkinson's. 80% are diagnosed over the age 65 meaning in excess of 80,000 people are in the aged care system. Approximately 10,000 are in a Residential Aged Care facility (although we suspect the number is higher).

Improve access to Primary Care in a Residential Aged Care Facility: People with Parkinson's health care needs do not change once they enter a Residential Aged Care Facility. They should be able to access their own GP or their choice of GP. They should also have access to a Parkinson's Nurse Specialist and allied health services.

This access will allow them to maintain the best quality of life possible.

Recommendations:

- *Increase the number of HCPs available*
- *Develop and implement a Parkinson's Awareness for Home Care Providers training package – \$750,000.*
- *Improve access to Primary Health Care providers for people with Parkinson's in Residential Aged Care Facilities.*

Improve MBS and PBS subsidies to offset the cost of daily medications and consumables

For many people with Parkinson's, the cost of effective treatment is prohibitive. Proven surgery is out of reach for most. Many medications are expensive, there is an inconsistent approach to subsidising medications, and the delivery mechanisms (consumables) are not supported by the Australian Government.

In the Deloitte Report¹, lifetime cost of care for Parkinson's is estimated to be \$161,000. Additional therapies and treatments are often an out of pocket cost for patients. Necessary services such as Occupational Therapy, Physiotherapy and Speech therapy add to the large costs of medications.

Deep Brain Stimulation therapy has been proven to reduce medication need and improve the motor functioning of a person with Parkinson's. It is complex surgery and costs range depending upon the surgeon, hospital and patient needs. What is guaranteed is that the patient will face a significant out of pocket cost – with outlays ranging from \$5,000 to \$50,000 per treatment. Medicare covers only a small fraction of the cost of the surgery. Patients (some as young as 35) resort to fundraising activities in order to have this necessary surgery.

Pump drivers, for example, allow constant delivery of medication - usually dopamine infusions in the case of Parkinson's – but require more upkeep and consumables. Timing of medication is crucial to the management of symptoms, and the pump delivery replaces the need for many tablets. Patient's "make do" with tablets, until hospital admission is required. Once the patient is stabilised, often using pump delivered medication, the patient is discharged home, there they resume their less efficient oral medication routine. The cost of administering medication through a pump is estimated to be \$200 – 300 per month. These costs are covered by other disease specialty groups, such as the National Diabetes Services Scheme, and Parkinson's Australia calls for these costs to be covered by a similar scheme.

Parkinson's Australia calls for consistent treatment of medications for the treatment of Parkinson's to be covered by PBS. There is disparity between some medications that are subsidised for patients with certain diseases, but not for people with Parkinson's. These medications have been shown to be effective, however are now beyond the reach of people with Parkinson's. People with Parkinson's should be able to access Ropinirole (Requip®) and a generic form of Madopar.

Recommendations:

- Provide significantly increased support for Deep Brain Stimulation through improving MBS rebates.
- Support the provision of consumables through a subsidy system for Parkinson's.

- Improve PBS listing of medications for people with Parkinson's in line with current best practice around the world.