

Government Budget Submission

National Parkinson's Alliance and Action Plan



National Parkinson's Alliance and Action Plan



National Parkinson's Alliance

The National Parkinson's Alliance is a new national collaboration of key stakeholders and leaders in the Parkinson's community in Australia who have come together to shape policies, strategies, and initiatives that will change the lives of individuals affected by Parkinson's across Australia.

The alliance embraces visionary and impactful leadership, that will drive much needed change. Through our collaboration with and for those living with Parkinson's across organisations, sectors and professional disciplines, we have harnessed the collective power of our diverse national community. By pooling our knowledge, resources, and expertise, we will achieve greater impact, address complex challenges, and create transformative solutions to enhance the lives of people with Parkinson's in Australia.

To ensure the sustainability of this work, the alliance members signed an MOU in December 2023, committing to the establishment of a National Parkinson's Alliance to represent the interests of people with Parkinson's, likeminded organisations, institutions and clinical professionals dedicated to supporting the development, implementation, and assessment of a National Parkinson's Action Plan.

The alliance is committed to supporting vital health initiatives by actively disseminating information on frameworks like the chronic illness framework and guidelines for Parkinson's care, fall prevention, and brain health research. Through collaborative efforts, it aims to contribute to informed strategies and promote comprehensive well-being in these critical areas of healthcare.

What is Parkinson's

Parkinson's is a chronic, progressive, degenerative neurological condition with no cure or treatments that stop disease progression.

People diagnosed with Parkinson's have a complex range of movement related symptoms including tremor, muscle rigidity, poverty of movement and loss of normal posture with an increased tendency for falls and fractures. However, Parkinson's also has major non-movement symptoms such as depression, anxiety, behavioural disturbances, cognitive impairment, sleep disorders, communication and swallowing difficulties, hallucinations, dementia, sensory deficits such as loss of smell and impaired speech.

Parkinson's is the fastest-growing neurological condition in the world.ⁱ Extrapolating the prevalence of Parkinson's in Victoria, at 0.85%ⁱⁱ, using 2021 ABS data suggests an estimated Australian Parkinson's population of 219,000 people. Since 2015, both the prevalence of Parkinson's and the overall financial burden has increased, posing a significant challenge to the Australian healthcare system.ⁱⁱⁱ Funding for research, multi-disciplinary care and support for those affected by this debilitating disease is crucial to improve quality of life and to reduce the financial cost to society.

Parkinson's comprises not only this chronic illness but also other rarer variants known collectively as Atypical Parkinson's Plus conditions. These include Dementia with Lewy bodies (DLB), Progressive Supra-nuclear Palsy (PSP), Multiple System Atrophy (MSA) and Corticobasal Degeneration (CBD). Parkinson's – including the rarer associated conditions – is a neurodegenerative health condition with no known cure. In this proposal we have included both Parkinson's and the Atypical Parkinson's diseases in the discussion.

People living with Parkinson's become increasingly dependent on carers to remain in the home, have high rates of hospital admissions, and as the disease progresses the person is often moved to a residential facility for advanced care. The burden of disease weighs heavily on caregivers, the health and human services workforce, society, and government.

As incidence of Parkinson's is increasing faster than other diseases of ageing, including Alzheimer's, additional factors beyond an ageing population must contribute. These factors are unclear and undoubtedly complex, but likely include exposure to environmental toxins.^{iv}

Worldwide attention and lobbying to raise awareness of these links to Parkinson's has increased since 2019, with Australian researchers leading early analyses of the correlation between farming (pesticides) and increased incidence of Parkinson's.^v The EU, USA and other countries have recognised this risk and taken proactive steps to control chemicals such as trichloroethylene (TCE) and Paraquat; at least 58 countries including the UK, Canada, China and the Netherlands have banned the use of Paraquat.^{vi} Despite this, reducing the risk of Parkinson's through banning or regulating these chemicals has not been actioned in Australia.

Health Impact of Parkinson's

Parkinson's is one of the most challenging diseases to manage due to its chronic progressive nature, insidious onset, complicated and diverse motor and non-motor symptoms.

Without access to multidisciplinary care and evidence-based therapies people with Parkinson's will have significantly greater disability, lower quality of life, more hospital admissions and subsequently greater costs to health, disability and aged care systems. In contrast to conditions like dementia that have a range of specific services and programs funded by governments, services and programs for people with Parkinson's are limited, and not embedded in government policy or strategy.

In 2017, the estimated mean annual cost per person living with Parkinson's to the Australian health care system was \$32,556, and the burden to society was an additional \$45,000 per annum per person.^{vii} The largest component of health system costs was for hospitalisation (69% of total costs), and the costs for people with moderate to severe disease were almost 4 times those with moderate disease (\$63,569 versus \$17,537).^{viii}

Significant Priority Area for Investment

National Parkinson's Action Plan

Strategy to address the unmet needs of the Parkinson's community

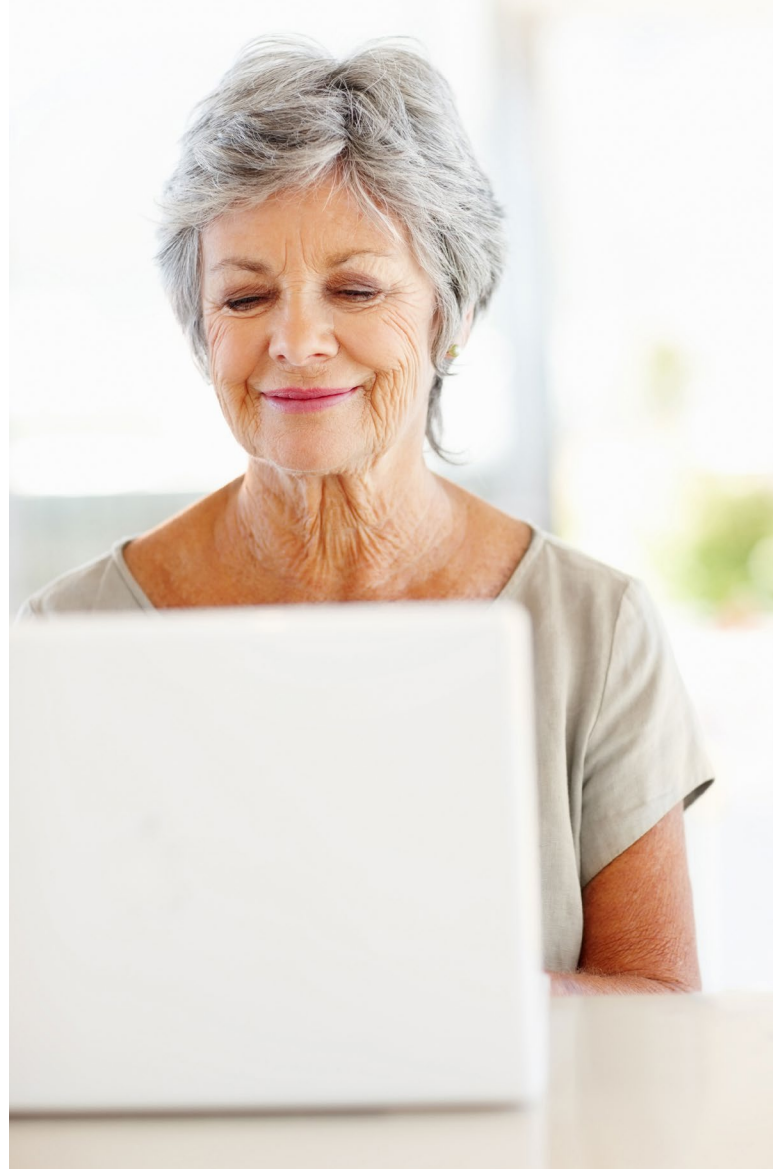
The alliance is seeking investment to develop a National Parkinson's Action Plan.

This strategy to address the unmet needs of the Parkinson's community will inform Federal and State government policy, strategies and initiatives in health, disability, aged care and research to ensure people living with Parkinson's and their families receive fair and equitable access and benefit from strategic investment in research. This will support improved integration of the needs of the Parkinson's community into current and future systems of support and care.

The funding of a National Parkinson's Action Plan will seek to identify and address policy gaps, strategies and initiatives in areas including:

- Stigma and lack of knowledge about Parkinson's in the community
- Health and social care to support people living with Parkinson's and their carers
- Equitable access to current and new therapies and treatments
- Prevention and mitigation strategies for Parkinson's
- Investment in research to better understand causes, mechanisms and progression, with a focus on disease-modifying therapies, health and social care and treatment of Parkinson's

A **National Summit to End Parkinson's** will be held in Canberra in March 2024, preceding World Parkinson's Month. The summit will provide an update on global progress to end Parkinson's and the key areas and initiatives required to support a new agenda for the Australian Parkinson's community through the development of a National Parkinson's Action Plan.





Community Engagement

The National Parkinson's Alliance is committed to a transparent and inclusive process that involves people living with Parkinson's, caregivers, clinicians, researchers, and community representatives.

By actively engaging with these stakeholders, the Alliance aims to gain a comprehensive understanding of the challenges faced by individuals living with Parkinson's and their families, ensuring that the National Action Plan is tailored to meet their specific needs.

National consultation and engagement will focus on people living with Parkinson's, their carers and families. The consultancy will be committed to understanding the individual perspectives of those living with Parkinson's and their families. Clinicians and researchers in the field will provide insight into system supports, their gaps and opportunities.

A comprehensive literature review will unearth valuable insights into key aspects such as stigma, treatment modalities, therapies, and the overall caregiving landscape for Parkinson's patients. This literary exploration will extend beyond national boundaries, encompassing a global perspective on Parkinson's to ensure a holistic understanding.

Moreover, the research team will conduct an in-depth analysis of clinical care methodologies, aiming to identify gaps and opportunities for improvement. By adopting a patient-centric viewpoint and synthesising information from a myriad of sources, the consultancy aspires to contribute to a more nuanced and compassionate approach to Parkinson's care, thereby enhancing the quality of life for those affected by this complex neurodegenerative condition.



Financial Support

To achieve its objectives, the National Parkinson's Alliance requires federal investment to develop the National Parkinson's Action Plan.

The funding will be utilised to develop a National Parkinson's Action Plan. The project will conduct a nationwide consultancy, evaluating the current needs and requirements of individuals living with Parkinson's. This data will inform the development of a comprehensive Action Plan, outlining strategies and priorities for research, treatment, and support services. A detailed National Action Plan Scope of Works is included as Appendix 1 of this submission.

The investment to support the development of the National Action Plan is \$400,000 and will be delivered within twelve months.

Project Outline

- **STAGE 1:**

Assess the national and international empirical evidence

- **STAGE 2:**

Assess the Australian policy context via an environmental scan of Australia's policies effecting people living with Parkinson's, identify the key concepts, gaps in the evidence, and identify what should/not be included in scope and why.

- **STAGE 3:**

Consult via a national survey and focus groups of (a) people with Parkinson's, (b) family members and carers and about the key concepts and guiding principles.

- **STAGE 4:**

Consolidate data and undertake a stakeholder analysis.

- **STAGE 5:**

Consult with clinical experts and researchers on the outcomes of the stakeholder analysis to inform recommendations

- **STAGE 6:**

Prepare a final evidenced-based National Parkinson's Action Plan report including recommendations relating to government policy, strategy and initiatives to support better outcomes for people living with Parkinson's

Conclusion

Parkinson's is a significant public health and community challenge, and a comprehensive, nationally coordinated response is urgently needed and long overdue.

The National Parkinson's Alliance, born out of the community's dedication, is poised to lead the development of a National Action Plan.

Federal funding is crucial to ensuring the success of this initiative, paving the way for a future where individuals living with Parkinson's and their families can access the services, treatments, therapies, research investments and supports they need to thrive.

National Advocacy

The landscape surrounding Parkinson's advocacy and support has evolved significantly in the past 18 months, and urgent action is needed to address the complex challenges faced by those living with Parkinson's in Australia. The formation of the National Parkinson's Alliance was driven by a genuine need to lead real change and create a more effective and responsive framework with, and for, the Parkinson's community in Australia.





ⁱ 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. <https://doi.org/10.3233/JPD-181474>

ⁱⁱ Ayton, D., Ayton, S., Barker, A. L., Bush, A. I., & Warren, N. (2019). Parkinson's disease prevalence and the association with rurality and agricultural determinants. *Parkinsonism & related disorders*, 61, 198–202. <https://doi.org/10.1016/j.parkreldis.2018.10.026>

ⁱⁱⁱ Bohingamu Mudiyansele, S., Watts, J. J., Abimanyi-Ochom, J., Lane, L., Murphy, A. T., Morris, M. E., & Iansek, R. (2017). Cost of Living with Parkinson's Disease over 12 Months in Australia: A Prospective Cohort Study. *Parkinson's disease*, 2017, 5932675. <https://doi.org/10.1155/2017/5932675>

^{iv} Ball, N., Teo, W. P., Chandra, S., & Chapman, J. (2019). Parkinson's Disease and the Environment. *Frontiers in neurology*, 10, 218. <https://doi.org/10.3389/fneur.2019.00218>

^v Ayton, D., Ayton, S., Barker, A. L., Bush, A. I., & Warren, N. (2019). Parkinson's disease prevalence and the association with rurality and agricultural determinants. *Parkinsonism & related disorders*, 61, 198–202. <https://doi.org/10.1016/j.parkreldis.2018.10.026>

^{vi} PAN International Consolidated List of Banned Pesticides 6th edition, May 2022, Pesticide Action Network (PAN), accessed from <https://pan-international.org/pan-international-consolidated-list-of-banned-pesticides/>

^{vii} Bohingamu Mudiyansele, S., Watts, J. J., Abimanyi-Ochom, J., Lane, L., Murphy, A. T., Morris, M. E., & Iansek, R. (2017). Cost of Living with Parkinson's Disease over 12 Months in Australia: A Prospective Cohort Study. *Parkinson's disease*, 2017, 5932675. <https://doi.org/10.1155/2017/5932675>

^{viii} Bohingamu Mudiyansele, S., Watts, J. J., Abimanyi-Ochom, J., Lane, L., Murphy, A. T., Morris, M. E., & Iansek, R. (2017). Cost of Living with Parkinson's Disease over 12 Months in Australia: A Prospective Cohort Study. *Parkinson's disease*, 2017, 5932675. <https://doi.org/10.1155/2017/5932675>

Appendix 1 – National Parkinson’s Action Plan

Scope of Works

National Parkinson’s Alliance

AIM: To develop an evidence-based report to understand the experiences and unmet needs of the Parkinson’s community in Australia

KEY OUTCOMES

The report will provide:

- Clear definitions of: People living with Parkinson’s, diverse cohorts of people in need of special attention, treatment contexts, types of intervention (e.g., primary prevention, early intervention, response).
- Guiding principles to underpin the Action Plan
- Guiding principles to inform policy makers, service providers, and researchers who work with people with Parkinson’s and their family carers.
- Identification of what should be in/out of scope and rationale for inclusion/exclusion.
- Budget and timeline to deliver National Parkinson’s Action Plan

Stage 1: Assess the international empirical evidence

Conduct an evaluation of existing literature that examine the key concepts relevant to health and welfare for people with Parkinson’s. The purpose of this review will be to:

1. Identify the key concepts, including:

- Health and social care to support people living with Parkinson’s and their carers
- Equitable access to current and new therapies and treatments
- Specific needs of indigenous people with Parkinson’s
- Prevention and mitigation strategies for Parkinson’s
- Investment in research to better understand causes, mechanisms and progression, with a focus on disease-modifying therapies, health and social care and treatment of Parkinson’s
- Cohorts of the Parkinson’s community in need of special attention
- Treatment contexts (e.g. primary care, community, hospital, residential aged care, rural areas), types of intervention (e.g. primary prevention, early intervention, response), intersections with related domains (e.g. comorbidities, carer welfare)
- Stigma and lack of knowledge about Parkinson’s in the community

2. Identify the evidence-gaps.

3. Identify what should be in/out of scope and rationale for inclusion/exclusion.

Our proposed criteria for the review search is as follows (this may be subject to later revision as we further scope the field):

Population: Adults with a diagnosis of Parkinson’s, Lewy Body Dementia and/or Atypical Parkinson’s diagnosis and their family and care providers.

Inclusion: accurate and early diagnosis, prevention, and brain health as part of the broader neurological umbrella for alignment with both state and federal government policy

Exclusion criteria: Studies excluding people with a Parkinson’s diagnosis, not an evidence synthesis (i.e. not a systematic, rapid, or scoping review), not in the English language, not peer-reviewed.

Perform a literature search of academic databases using targeted keywords. Apply the inclusion and exclusion criteria specified above, and first examine abstracts to identify those relevant to the review. Conduct a full text review and appraise articles for quality. Categorise studies according to geographical location, treatment context, types of intervention, intersections with related domains, participants, method and focus. Synthesise findings to address the aims cited above. The review will likely be structured into sections addressing the key concepts; however this may be subject to change once the full data extraction plan has been developed (which will be done in consultation with the NPAPT).

Key outcomes of Stage 1:

- Identify the key concepts
- Identify the evidence-gaps.

Appendix 1 – National Parkinson’s Action Plan

Scope of Works

National Parkinson’s Alliance

Stage 2:

Assess the Australian policy context

Concurrently, undertake an environmental scan of Australian policy and funding landscape to capture how different state and territories are meeting the needs of people living with a Parkinson’s diagnosis.

This will be done by performing a broader search and exploration of relevant websites, and scanning of citations and mentions across the relevant literature as well as by interviews with key State and Federal government policy-makers and regulators.

Healthcare involves a diversity of approaches, including through aged care providers, funding models, integrated/multidisciplinary teams, government, NGO or private initiatives, research collaborations between schools or universities, holistic care providers, and accommodation models and more.

Key outcomes of Stage 2:

- Identify what should be in/out of scope and rationale for inclusion/exclusion.

Stage 3:

Focus groups with people living with Parkinson’s, family carers, and service providers

Undertake focus groups across Australia, comprising a total of approximately 300 face to face, and 900 tele interviews.

Recruitment will target:

- Participants with a relevant diagnosis, their family carers and those who work to support people with Parkinson’s
- Participants who live with various progression and presentation of condition
- Participant who are diversified by gender, ethnicity, Indigenous status, LGBTQIA+, and location.

Stage 4:

In-depth interviews with people living with Parkinson’s and their family carers

Interviews of, diverse people who have lived experience of managing their condition and who have used health services in the past 12 months (including inpatient, outpatient, community social services). Wherever possible, we will seek to diversify participants based on gender, ethnicity, Indigenous status, LGBTQIA+, and location.

The focus groups (Stage 3) and in-depth interviews (Stage 4) will focus on the key concepts; guiding principles that should underpin the Action Plan; guiding principles to inform policy makers, service providers, and researchers; and what should be in/out of scope and rationale for inclusion/exclusion.

Where relevant, focus groups and interviews will be conducted with support from an interpreter, in the respective community languages. We will attempt to undertake the focus groups and interviews face-to-face, but should this not be possible, we will undertake them online.

Focus groups and in-depth interviews will be audio-recorded, transcribed, and thematically analysed. This data will provide a range of different and diverse communities’ experiences with Australia’s health systems, identify what really matters to them, and what is important to include/exclude in the National Parkinson’s Action Plan.

Key outcomes of Stage 3 and 4:

- Identify the key concepts
- Guiding principles to underpin the Action Plan
- Guiding principles to inform policy makers, service providers, and researchers who work with and for people with Parkinson’s.
- Identification of what should be in/out of scope and rationale for inclusion/exclusion.

Stage 5:

Stakeholder analysis

Synthesising the data from the literature review, environmental scan, focus groups, and in-depth interviews to draft the final report defining the key concepts, guiding principles, and what is/not in scope for the NPAP.

The National Parkinson’s Alliance will review the final report, provide critical feedback on the key concepts, and endorse the guidelines.

Key outcomes of Stage 5:

- Endorsement of the Key concepts, Guiding principles to underpin the Action Plan, Guiding principles to inform policy makers, service providers, and researchers who work with older people, and what is in/out of scope and rationale for inclusion/exclusion.

Stage 6:

Final report

The report will be finalised and handed to the National Parkinson’s Alliance in the next 12 months.

Key outcome of Stage 6:

- Present Action Plan to Federal and State Ministers for Health, Members of Parliamentary Friends of Parkinson’s and other relevant Government agencies for endorsement.