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# National Parkinson's Action Plan

National Parkinson's Alliance

Australian Government
Department of Health, Disability and Ageing

Fight Parkinson's
Together we can

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parkinson's NSW
IN THIS TOGETHER

parkinson's QUEENSLAND
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UNIVERSITY of TASMANIA

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TASMANIA

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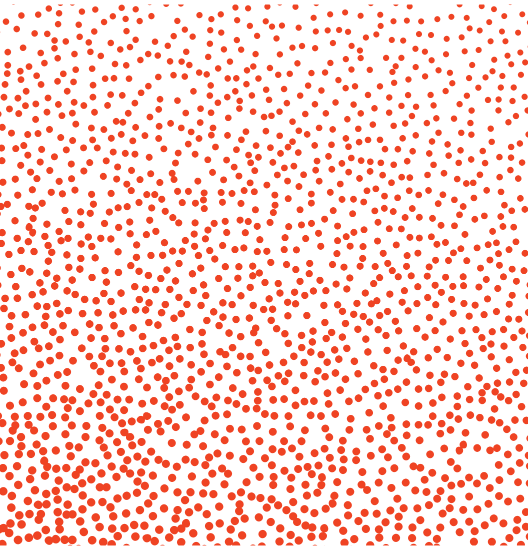
The National Parkinson's Action Plan is a result of people with Parkinson's making their voices heard regarding the urgent need for greater attention and funding to improve care and support for themselves, along with their families, carers, and supporters. The Federal Government acknowledged the importance of creating a national plan to address the needs of the Australian Parkinson's community and in response as part of the 2024-25 Federal budget, committed funding over two years to support the National Parkinson's Alliance (NPA) to develop Australia's first National Parkinson's Action Plan (NPAP).

The NPAP aims to support improved responses to the needs of more than 200,000 people living with Parkinson's over a 5-year timeframe. Regular reviews of the evidence supporting the action areas will be conducted throughout the NPAP's implementation. Over time, priority activities and implementation timeframes will be re-evaluated and updated to ensure efforts are focused efficiently, effectively, and where they are most needed.

The National Parkinson's Alliance thanks the Department of Health, Disability and Ageing for their partnership and support throughout the development of the National Parkinson's Action Plan.



# Acknowledgment

The National Parkinson's Alliance (NPA) acknowledges the Traditional Custodians of the lands and waters across which we gather – the first peoples of this nation – and pays its respects to Elders past and present. We recognise the enduring cultural, spiritual and scientific knowledge of Aboriginal and Torres Strait Islander peoples, and we commit to working in partnership, in spirit of care and shared purpose, as we collaborate across community, research, care, and policy for people with Parkinson's and related conditions.

We extend our thanks to everyone who contributed to the development of the National Parkinson's Action Plan (NPAP). This includes approximately 5,700 individuals with lived experience, their families, carers and support-persons, whose insights and perspectives have been invaluable.

We also acknowledge the clinicians, specialists, researchers, policy makers, advocates, and any other stakeholders who shared their expertise and dedication to inform the NPAP.

This collaborative effort reflects the collective commitment of all involved to create meaningful, effective, and inclusive outcomes for people with Parkinson's. Thank you for your contributions and the experiences you shared.

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# A note on language

Consultations with people with Parkinson’s identified diverse preferences on how they prefer to be referred to as a group. The term "Parkinson's" is used throughout the National Parkinson's Action Plan (NPAP) for simplicity, accessibility and to reflect preferences of the Parkinson’s community. The term “Parkinson’s” is only used when referring to the specific condition, particularly in medical, research, or government documents. Stakeholders often reflected that the term “Parkinson's disease” is misleading as it sounds like Parkinson’s is an infectious disease and may be associated with stigma.

The NPAP acknowledges Parkinson's may manifest differently between individuals, and that it encompasses a range of similar yet diverse symptoms and subtypes, including Young Onset Parkinson’s Disease (YOPD), forms of Atypical Parkinson’s and Parkinsonian conditions (e.g., Multiple System Atrophy (MSA), Progressive Supranuclear Palsy (PSP), Corticobasal syndrome (CBS), Dementia with Lewy Bodies (DLB)).

Additionally, consultation with those supporting people with Parkinson’s had different views on how they preferred to be referred to as a group. Some individuals identified with terms such as carer or caregiver, while others prefer terms like supporter, partner, or simply being described in relation to the person they support (e.g., spouse, sibling, or friend). For the purpose of the NPAP the term carer is used as an inclusive term to reflect individuals who provide unpaid support to a family member or friend.

# Key Terms

| Term | Definition |
|---|---|
| **Bradykinesia** | Slowness of movement with a reduced range of movement, making it harder to do everyday tasks like dressing or eating. |
| **Culturally and Linguistically Diverse (CALD)** | People or communities from different cultural backgrounds or who speak languages other than English. |
| **Corticobasal syndrome (CBS)** | A rare progressive brain disorder caused by the loss of nerve cells and shrinkage in multiple brain regions, including the cortex and basal ganglia. |
| **Dementia with Lewy Bodies (DLB)** | A progressive neurodegenerative disorder characterised by cognitive impairment, recurrent visual hallucinations and a movement disorder similar to that seen in Parkinson's. |
| **Dopamine Transporter Scan (DaTscan)** | A brain imaging test that helps assess dopamine signalling, which is reduced in Parkinson's. |
| **General Practitioners (GPs)** | General Practitioners (GPs) are primary care doctors who serve as the first point of contact for health care, offering diagnosis, treatment for a wide range of conditions, and long-term medical care. |
| **Motor symptoms** | Symptoms related to movement and physical coordination that can affect voluntary or involuntary movements, such as walking, posture, balance, and fine motor skills. |
| **Movement disorder specialist** | A medical doctor, typically a neurologist or geriatrician, who has specialised training and expertise in diagnosing and treating Parkinson's and other neurological conditions that affect movement. |
| **Multiple System Atrophy (MSA)** | A rare, progressive neurological condition where a loss of brain cells in the brainstem and cerebellum leads to diverse and widespread symptoms. |
| **My Aged Care** | Australian government's entry point for accessing government-funded aged care services or Australians aged 65 and over (or 50 and over for Aboriginal and Torres Strait Islander people). |

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| **Neurodegenerative disease (NDD)** | Refers to a group of progressive disorders characterised by the gradual degeneration and loss of function of nerve cells (neurons) in the brain or nervous system. Examples of NDDs include Alzheimer's disease, Parkinson's, Huntington's disease, and amyotrophic lateral sclerosis (ALS). |
| **National Disability Insurance Scheme (NDIS)** | An Australian government program that supports people with a permanent and significant disability that affects their ability to take part in everyday activities by providing funding to eligible people to gain more time with family and friends, greater independence, access to new skills, jobs, or volunteering in their community, and an improved quality of life. |
| **National Parkinson's Alliance (NPA)** | A collaboration of key stakeholders and leaders in the Australian Parkinson's community. |
| **National Parkinson's Action Plan (NPAP)** | The national strategy driving change to enhance the lives of people affected by Parkinson's across Australia. |
| **Non-motor symptoms (NMS)** | Symptoms that are not related to movement or motor control but are associated with underlying neurological or systemic conditions, often affecting various aspects of physical, emotional, and cognitive well-being. |
| **Postural instability** | Impaired balance and difficulty maintaining an upright posture, often leading to an increased risk of falls. |
| **Prodromal symptoms** | Early symptoms that appear before the full development of a condition, and in Parkinson's occur before noticeable motor symptoms develop. |
| **Progressive Supranuclear Palsy (PSP)** | A rare brain disorder causing damage to nerve cells and affecting movement, balance, speech, swallowing, vision, mood, behaviour, and thinking. |
| **Rigidity** | Increase in muscle tone, which makes it difficult for the limb or body to move freely that can feel like resistance or stiffness during movement. |
| **Sign** | An objective physical or medical indication of a condition observable by a healthcare professional (e.g., slow movements measured during an exam). |
| **Symptom** | A subjective experience reported by the patient, such as fatigue and pain. |
| **Tremor** | Unintentional, rhythmic, shaking movement, often most notable in the hands, arms, head, or legs, that occurs due to involuntary muscle contractions and relaxations. |
| **Young Onset Parkinson's Disease (YOPD)** | Parkinson's diagnosed before the age of 50. |

# A call to action

Parkinson's is a complex and diverse condition, affecting each person differently and requiring coordinated, multidisciplinary responses informed by both lived experience and scientific discovery. For too long Australia has had no national framework to integrate community insight, clinical care and research evidence into a coherent strategy for action.

The NPA came together to bridge this gap. By aligning people living with Parkinson's, leading researchers, clinicians, health organisations and policy partners, the NPA created a unified national voice – one that called for recognition, investment and coordinated reform.

Funded by the Australian Government, the first NPAP will drive change to enhance the lives of people affected by Parkinson's across Australia.

Informed by research, lived experience, and experts in Parkinson's, the NPAP sets a vision to create a future where everyone affected by Parkinson's has equitable access to quality care, support, research advancements, and hope for a cure.

# Ownership of the NPAP

The NPAP sets out key goals, priorities, and actions identified by the Parkinson's community to improve the health and wellbeing of Australians living with Parkinson's.

These actions are intended for consideration by a broad range of stakeholders, including all levels of government, non-government organisations, health services, industry, researchers, academics, and the wider community.

Implementation of any action remains at the discretion of each stakeholder, based on their responsibilities, governance arrangements, existing activities, and future directions.

# What is the ask?

The National Parkinson's Action Plan (NPAP) provides a significant opportunity to respond to the needs of people with Parkinson’s. Together we can drive meaningful change and deliver better outcomes and quality of life for people with Parkinson’s.

For **governments** at all levels to work together to collaborate, coordinate, support and invest in solutions that address critical challenges and system pressures to improve outcomes for the Parkinson’s community.

For **Parkinson’s organisations** and advocacy groups to work together to amplify their collective influence and provide leadership to raise awareness of Parkinson’s, to drive research advancements, improve services for people with Parkinson’s, their families and carers.

For the **Parkinson’s community** to engage with and help lead the implementation of the NPAP; continuing to raise their voices and offering insights and experience to advocate, shape and deliver the change required to better meet your needs and enable you to live the life you deserve.

For the **Australian community** to actively engage in understanding the daily experiences of people with Parkinson’s, helping to create inclusive and supportive environments where we embrace people with Parkinson’s.

# The NPAP sets out the following actions:

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| **Tackle stigma, improve awareness and ensure access to accurate information** | • Raise the profile of Parkinson's across Australia to foster understanding and reduce stigma.<br>• Develop a centralised information hub to enable access to accurate and current information on Parkinson’s (e.g., Parkinson’s symptoms, treatments, lifestyle advice, services, community resources, and latest research findings).<br>• Raise awareness of Parkinson’s through developing targeted information for distribution to locations accessible to people in their everyday lives. |
| **Strengthen prevention strategies to delay onset and improve understanding of risk and disease progression** | • Develop an evidence base to deepen understanding of Parkinson’s causes, risk factors, and progression.<br>• Promote safety by educating at-risk cohorts about protective measures.<br>• Develop guidelines and adjust regulatory requirements to address known environmental and occupational risk factors. |
| **Improve accurate and timely diagnosis and post diagnostic care** | • Implement standardised, nationwide guidelines and tools to ensure consistency and accuracy in diagnosing Parkinson’s across Australia.<br>• Establish advice and navigational support services to enable timely and appropriate post diagnostic care and support.<br>• Recognise and strengthen the role of peer support in supporting people with Parkinson’s in their care journeys. |
| **Improve clinical care, treatment pathways and coordination of care** | • Strengthen equitable access to health care and treatment for Parkinson’s across Australia.<br>• Establish national guidelines and evidence-based care models specific to Parkinson’s care.<br>• Enable people with Parkinson’s to be active partners in their care and treatment. |
| **Build capacity and capability of the healthcare workforce** | • Develop a national workforce strategy targeted at building the capacity and capability of the health and social care workforce. |
| **Improve data and maximise the impact of research** | • Develop a national Parkinson’s research strategy to enable a coordinated approach to maximise the impact of research. |

# Purpose

**The National Parkinson's Action Plan (NPAP) is Australia’s first Parkinson’s Action Plan. Grounded in lived experience and evidence-based research, it sets out a plan for improving the lives and care of people with Parkinson’s in Australia.**

## Responding to the Needs of the Parkinson’s Community

People with Parkinson’s have made their voices heard regarding the urgent need for greater attention and funding to improve care and support for themselves, along with their families, carers, and supporters. It acknowledges the unique challenges people with Parkinson’s face daily and calls for action to address the unmet needs of the Parkinson’s community. This will be delivered through informing Federal and State government policy, as well as strategies and initiatives in health, disability, aged care and research. The aim is to ensure people with Parkinson’s and their families receive fair and equitable access to services and benefit from strategic investment in research and care.

The Federal Government acknowledged the ongoing need for, and importance of, a national plan to address the needs of the Australian Parkinson’s community. In response, as part of the 2024-25 Federal budget, the Federal Government committed funding over two years to support the development of Australia’s first NPAP. Consequently, the National Parkinson's Alliance (NPA) was tasked with its development.

The NPAP aims to support improved responses to the needs of the Parkinson’s community over a five-year timeframe. Regular reviews of the evidence supporting the action areas will be conducted throughout the NPAP's implementation. Over time, priority activities and implementation timeframes will be re-evaluated and updated to ensure efforts are focused efficiently, effectively, and where they are most needed.

# The National Parkinson's Alliance

The NPA was founded on a shared commitment to transform the future for people with Parkinson's and related conditions, through the power of collaboration between the community, clinicians, researchers and government. The NPA is composed of key stakeholders and leaders from the Australian Parkinson's community. It brings together leading Parkinson's organisations from across each state and territory, as well as universities and research institutions, to work collaboratively to help shape policies, strategies, and initiatives that aim to improve the lives of individuals affected by Parkinson's across Australia.

Its membership is drawn from:

- Fight Parkinson's
- Neuroscience Research Australia (NeuRA)
- Parkinson's New South Wales (PNSW)
- Parkinson's Queensland (PQld)
- Parkinson's Tasmania (PTas)
- Parkinson's Western Australia (Parkinson's WA)
- Shake It Up Foundation Australia
- The Hospital Research Foundation Group (Parkinson's SA, NT & ACT)
- University of Tasmania (UTAS)
- Walter and Eliza Hall Institute of Medical Research (WEHI)
- Wings for Parkinson's

# Developing Australia's first National Parkinson's Action Plan

The NPAP has been developed through an inclusive process bringing together input from stakeholders through national consultations and evidence from a detailed literature review and policy scan. The resultant NPAP is grounded in evidence-based research and lived experiences.  A summary of the approach is provided below with more detail on the methodology and the insights that emerged provided in Appendix A and Appendix B.

# Literature Review and Policy Scan

A literature review was conducted to provide a global perspective on key issues impacting people with Parkinson's, and effective interventions including approaches, gaps and opportunities for improvement. In addition, an environmental scan of the Australian policy context was conducted to understand government direction in response to people with Parkinson's.

To inform the literature and policy review, 233 documents were reviewed and prioritised based on the extent they addressed the research topics and objectives, their currency, and their presence in peer-reviewed journals or publications recognised by experts and institutions.

# National Consultation Process

National consultation aimed at capturing the diverse perspectives of the Parkinson's community, representing various regions, cultural backgrounds, genders, and age groups was central to the development process. This included people with Parkinson's, their families, carers and supporters, professionals such as clinicians, researchers, allied health workers, and Parkinson's nurses.

The consultation explored key areas of concern and opportunity, such as:

- Reducing stigma
- Promoting earlier detection and empathetic diagnosis
- Enhancing the education and capacity of the sector workforce
- Improving access to multidisciplinary, evidence-based care
- Advancing research and clinical trials.

## Stakeholders consulted

In total, we engaged more than 5,700 people with Parkinson's, their families, and carers through in-person and virtual consultations and surveys, including:

- 717 individuals from across the country through in-person, virtual, or phone consultations; and
- 5,029 responses to a national survey.

The survey captured key concerns, expectations, and recommendations from a broad audience, allowing for a more detailed understanding of the concerns that matter most to the Parkinson's community. Through this quantitative data, combined with qualitative input from the consultations, a holistic picture of the Parkinson's experience emerged.

Expert input was also obtained from research professionals, key organisations, and members of the National Parkinson's Alliance (NPA) .

A wide range of healthcare professionals contributed their expertise, including:

| | |
|---|---|
| **Medical Specialists** | • Neurologists (incl. Movement Disorder Specialists)<br>• Geriatricians (incl. Movement Disorder Specialists)<br>• Other Physicians |
| **Primary Care** | • General Practitioners (GPs)<br>• Pharmacists<br>• Optometrists |
| **Nursing** | • Parkinson's / Movement Disorder Nurses<br>• Clinical Nurse Consultants<br>• Community / Generalist Nurses<br>• Aged Care Nurses |
| **Allied Health Professionals** | • Physiotherapists<br>• Exercise Physiologists<br>• Occupational Therapists<br>• Speech Pathologists<br>• Dietitians<br>• Psychologists<br>• Counsellors<br>• Social Workers |
| **System Navigation & Coordination** | • Care Coordinators |
| **Research** | • Researchers |

As a result, the National Parkinson's Action Plan (NPAP) addresses the priorities of the Parkinson's community focused on health and social care system improvements, providing a roadmap for meaningful, long-term change for all those affected by Parkinson's in Australia.

# About Parkinson’s

Parkinson’s is a complex and progressive neurodegenerative condition commonly associated with challenges in controlling movement. These movement symptoms are caused by the death of cells in the brain that produce dopamine. Dopamine is important in ensuring smooth and coordinated movements, so people with Parkinson’s may start to notice their movements becoming slower, their muscles feeling stiff, and balancing being harder.

The speed at which Parkinson’s develops differs from person to person, with many experiencing non-motor symptoms (e.g., constipation, chronic pain, sleep disturbances, or a decreased sense of smell) long before the more commonly recognised motor symptoms become noticeable. These non-motor symptoms can persist for years and might often be overlooked or not initially associated with Parkinson's. While Parkinson's is the most common type of parkinsonism, there are other related conditions such as:

- Progressive Supranuclear Palsy (PSP)
- Multiple System Atrophy (MSA)
- Corticobasal syndrome (CBS)
- Dementia with Lewy bodies (DLB)
- Drug-induced parkinsonism
- Vascular parkinsonism

In most cases, there are no obvious causes for these conditions, which are likely due to a combination of environmental and genetic risk factors. There is no cure, but regular treatment, such as medications that increase dopamine to the brain and movement therapies, can help improve symptoms.

Confirming the diagnosis for parkinsonism can be difficult because early symptoms of conditions like Parkinson's and other parkinsonian disorders often look very similar. With there being no single test that can definitively diagnose parkinsonism disorders, diagnosis relies on specialist clinicians taking a medical history and carrying out a physical examination to identify the signs and symptoms of Parkinson’s.

Many other countries have access to supportive tests like a Dopamine Transporter Scan (DaTscan), that helps clinicians support a diagnosis of Parkinson's (or other neurodegenerative parkinsonism's such as PSP, MSA etc) by visualising dopamine system health, showing if dopamine producing cells are dying off. In Australia, there is currently no approved diagnostic test or clinically accessible biomarkers to clearly identify parkinsonism’s or to track progression.

# Signs and Symptoms of Parkinson's

Parkinson's presents through a wide range of signs and symptoms that evolve over time.

## Early Symptoms (Prodromal Symptoms)

In the years or even decades before movement symptoms appear many people with Parkinson's experience "early warning signs" called prodromal symptoms. This may include constipation, a loss of sense of smell, depression, or vivid dreams. These early signs are often non-specific and may not be recognised as part of the earliest stages of Parkinson's. Many also report subtle changes like smaller handwriting, a weaker voice, or a stiff shoulder that were only understood in hindsight as early Parkinson's symptoms.

## Movement Symptoms (Motor Symptoms)

As Parkinson's develops, it starts to affect movement in noticeable ways.
The four main motor signs are:

1: Bradykinesia (slowness of movement with a reduced range of movement, making it harder to do everyday tasks like dressing or eating);

2: Rigidity (stiffness causing discomfort and limiting flexibility);

3: Tremors (involuntary shaking, often starting in one hand or arm, and usually when at rest); and

4: Postural instability (trouble with balance and coordination, making it easier to fall or feel unsteady while standing or moving)

In order to receive a formal diagnosis, an individual needs bradykinesia along with at least one of the following: tremors, rigidity, or postural instability. Other common movement challenges include difficulty walking, shuffling steps, smaller handwriting, diminished facial expression, and trouble with speech or swallowing.

## Non-Movement Symptoms (Non-Motor Symptoms)

Parkinson's also causes many symptoms that do not involve movement, such as constipation, dizziness, fatigue, and poor sleep. Many people with Parkinson's also experience anxiety, depression, or memory and cognitive problems, which, may progress to dementia. For many people with Parkinson's non-motor symptoms have a big impact on their quality of life, sometimes even more so than the motor symptoms.

# Who is Affected by Parkinson’s?

While the exact causes of Parkinson's are not fully understood, a combination of genetic and environmental factors, such as ageing and exposure to toxins (e.g., through pesticides, herbicides, industrial solvents, and heavy metals), is believed to contribute to its development. Despite the causes being somewhat unknown and complex to determine, certain groups face unique challenges and are sometimes heavily impacted. Below is a list of priority population groups who experience varied impacts or barriers:

- **People with Young Onset Parkinson's Disease (YOPD)** refers to those diagnosed before 50 years old. YOPD accounts for a growing proportion of the Parkinson’s community and can bring additional challenges such as balancing work and family responsibilities.
- **People living in regional, rural and remote areas** often experience delays in diagnosis and treatment due to limited access to healthcare professionals, support services, and community resources.
- **Women** with Parkinson’s may experience different symptoms, responses to treatment, or challenges in accessing treatments, such as deep brain stimulation.
- **Culturally and Linguistically Diverse (CALD) communities** may encounter language barriers, cultural stigma, or difficulty accessing tailored healthcare services.
- **First Nations peoples** may face unique challenges around culturally safe care and equitable access to resources.
- **People with intellectual disability, autism, or acquired brain injuries** are the priority population, not people with a disability. Research indicates people with autism are at a higher risk of developing Parkinson's and the Royal Commission into violence, abuse, neglect and exploitation of people with disability found that people with disability face multiple barriers to accessing healthcare.

In addition to people with Parkinson’s, it is important to recognise the critical role of family members and loved ones in providing informal care, as well as the profound impact it has on their lives. These carers are often responsible for helping with mobility, administering medications, coordinating medical appointments, assisting with personal care, preparing meals, managing household tasks, and providing emotional support. Carer burden can have a big impact on a person’s life. It can leave them feeling tired, stressed, and emotionally worn out. Caring for someone full time often means less time for their own needs, which can lead to feeling alone, burned out, and even health problems.

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Yin, W., Reichenberg, A., Schnaider Beeri, M., Levine, S.Z., Ludvigsson, J.F., Figee, M., and Sandin, S. (2025), Risk of Parkinson Disease in Individuals With Autism Spectrum Disorder. JAMA Neurol. 1;82(7): 687-695
Mai, A.S., Yau, C.E., Tseng, F.S., Foo, Q.X.J., Wang, D.Q. and Tan, E.-K. (2023), Linking autism spectrum disorders and parkinsonism: clinical and genetic association. Ann Clin Transl Neurol, 10: 484-496.

# Where are we now?

Parkinson’s is increasingly recognised as a growing global health challenge. A paper by leading international researchers Dorsey and Bloem titled 'The Parkinson Pandemic - A Call to Action’ predicted the number of people with Parkinson’s globally will double from 6.9 million in 2015 to 14.2 million in 2040.

Published Australian prevalence estimates for Parkinson’s derived from administrative and prescribing datasets should be interpreted as conservative lower-bound estimates rather than measures of total community burden. In Victoria, prevalence estimates reported by Ayton et al. (2019) used medication-treated Parkinson’s as a proxy for case ascertainment and identified a prevalence of approximately 0.85%, reflecting individuals who are diagnosed and receiving pharmacological therapy.

At a national level, analysis of Pharmaceutical Benefits Scheme data by Evans et al. (2024) estimated that 154 850 unique patients in Australia are treated with levodopa (the mainstay of treatment for Parkinson's), explicitly excluding individuals managed solely with dopamine agonists as well as those not receiving antiparkinsonian medications. While these prescribing datasets provide robust, real-world evidence on treated Parkinson’s within Australia, they are inherently unable to capture individuals in the prodromal phase, those with early or mild disease who have not yet commenced pharmacotherapy, or individuals who remain undiagnosed. As a result, prevalence estimates derived from medication data systematically underestimate the true population burden of Parkinson’s.

When an allowance is made for these limitations and we incorporate ageing demographics and prodromal disease duration it is reasonable and evidence-based to cite a national estimate of approximately 200,000 Australians living with Parkinson’s. This figure should be interpreted as a projected estimate of total prevalence — encompassing diagnosed, undiagnosed, and prodromal disease — rather than a count of individuals currently captured within prescribing or treatment datasets alone.

The lack of a single source of truth for the prevalence of Parkinson’s in Australia illustrates the importance of creating reliable ongoing measures of Parkinson’s so resources can be allocated effectively and efficiently.

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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

Ayton, D., et al., Parkinson’s disease prevalence and the association with rurality and agricultural determinants. Parkinsonism Relat Disord, 2019. 61: pp. 198-202. https://pubmed.ncbi.nlm.nih.gov/30377035/

Evans, A., Waterhouse, B., et al., Levodopa use in Australia: an analysis of Pharmaceutical Benefits Scheme 10% data. BMJ Neurol Open. 2024.

The rising prevalence of Parkinson’s is placing increasing pressure on healthcare resources, community support systems, and broader social services. These pressures are making it harder for people with Parkinson’s to manage their health and wellbeing. Addressing this urgent issue requires a clear and transformative Action Plan to promote a coordinated approach to research, services, and support to meet the needs of the Parkinson’s community.

Below is an overview of the current state of Parkinson’s in Australia, capturing insights shared by individuals with Parkinson’s, their families and carers. It highlights the key challenges, gaps, and priorities that need to be addressed to make meaningful improvements for the Parkinson’s community.

# Awareness and Understanding

Awareness and understanding of Parkinson’s across Australian communities remains limited. Misconceptions persist, with many people viewing Parkinson’s as an "old person’s disease" or exclusively associating the condition with tremors. This narrow understanding not only overlooks the diverse range of people affected but also harms older people by reinforcing views that minimise their symptoms, delay diagnosis, and diminish expectations for their quality of life.

Unlike other chronic conditions, Australia has seen limited national campaigns or coordinated advocacy initiatives to address these misunderstandings and break down harmful stereotypes. Efforts to raise awareness about symptoms, causes, and risk factors, have been somewhat siloed with information rarely extending to high-risk groups, such as farmers exposed to pesticides and industrial workers, or those with specific challenges such as people with Young Onset Parkinson's Disease (YOPD).

Community events, media portrayals, and modern digital platforms remain underutilised to reach wider audiences. Many of these platforms often fail to consider the needs of Culturally and Linguistically Diverse (CALD) communities, Aboriginal and/or Torres Strait Islander peoples, or people from regional and remote areas, leaving these groups underserved.

## What does the Parkinson’s community want?

- **Access to accurate information about Parkinson’s to build both basic understanding and more advanced knowledge.**
- **To challenge stereotypes to reduce stigma.**
- **Information targeted for high-risk groups (farmers, industrial workers).**
- **Tailored materials for diverse cohorts, such as Aboriginal and/or Torres Strait Islander communities and CALD communities.**
- **Parkinson’s to have a public profile across Australia.**

# Early Diagnosis

Early diagnosis is essential to improving outcomes for people with Parkinson’s, but diagnosing the condition remains a major challenge.

Key barriers identified include:

- Limited awareness and recognition of early Parkinson’s symptoms amongst the public and healthcare providers.
- A lack of nationally consistent diagnostic guidelines and tools tailored to the Australian context.
- Long delays caused by a shortage of neurologists or geriatricians who have undergone additional training in movement disorders, particularly in regional and remote areas.
- A lack of support at the time of diagnosis.

For women and people with YOPD, symptoms are more often misdiagnosed as depressive or psychogenic conditions, or dismissed as unrelated conditions, leading to longer delays in receiving appropriate care. People in rural and remote areas face additional challenges, including travel costs, waitlists for fly-in-fly-out specialists, and reduced access to neurologists and geriatricians and general multidisciplinary care. Additionally, for people from CALD communities, barriers often relate to language difficulties, limited interpreter availability, and a lack of culturally appropriate or translated health information.

## What does the Parkinson’s community want?

- **GPs and primary healthcare workers to recognise early motor and non-motor symptoms.**
- **Standardised diagnostic guidelines and tools to ensure consistency in diagnosis and treatment pathways.**
- **Access to movement disorder specialists, particularly in regional or remote areas.**
- **Resources to address the specific language and communication needs of CALD communities.**

# Clinical Care

Once diagnosed, people with Parkinson's often face insufficient, fragmented and inconsistent care. There are no national evidence-based clinical guidelines, with care pathways and services differing widely across regions, leading to unequal access to treatment and therapies.

Parkinson's nurses play a crucial role in coordinating care, providing education and managing symptoms. However, there are very few specialised Parkinson's nurses in Australia, and access varies depending on location and inconsistent funding arrangements. Clinical workforce shortages extend to neurologists, physiotherapists, and other allied health professionals, many of whom lack specific training in Parkinson's care.

Additionally, hospitals and aged care settings often lack the necessary knowledge to provide appropriate care, leading to delays in accessing time critical medication or not receiving interventions to manage symptoms.

## What does the Parkinson's community want?

**Clinical care guidelines tailored to the Australian health care system.**

**Greater access to nurses and allied health professionals.**

**Tailored training pathways for specialists, nurses and allied health professionals.**

**Better integration of care between healthcare, aged care, and disability service systems to provide joined up support.**

# Navigating Care and Support Systems

Navigating the complex system of supports and services for Parkinson's remains difficult, with many people with Parkinson's and their carers unable to find clear or centralised information. There is no single source of trusted guidance on available supports, symptom management, or treatment options. Rural and Culturally and Linguistically Diverse (CALD) communities face additional inequities, including language barriers, cultural stigma, and lower health literacy levels.

People accessing government programs like the National Disability Insurance Scheme (NDIS) or My Aged Care report significant challenges navigating these systems, including long delays, burdensome paperwork, varied outcomes and assessors who lack Parkinson's-specific knowledge.

## What does the Parkinson’s community want?

- **Information hub or "one-stop shop" for Parkinson’s resources.**
- **Support to navigate the different service systems and financial support to find and access the right services earlier.**
- **Government service systems that work better together, streamlining access to the NDIS and My Aged Care services.**

# Research and Data

Compared to conditions such as dementia, research into Parkinson’s in Australia is underfunded and fragmented, with little national coordination. There is an urgent need for a comprehensive study on the prevalence, distribution and economic burden of Parkinson’s in Australia. Additionally, research into new treatments that stop or slow progression is a recognised priority for those living with Parkinson's. In addition, risk factors, such as exposure to pesticides and other chemicals remain under explored, leaving prevention strategies underdeveloped.

Collaboration across states and research institutions is limited, and Australia is underrepresented in global research networks. Not having a national registry prevents the collection of critical data on symptoms, outcomes, and treatments.

Attracting industry to conduct clinical trials would enable the Australian Parkinson’s community to access cutting-edge new treatments.

## What does the Parkinson’s community want?

- **Accelerated and collaborative research into advanced treatments to slow disease progression and, ultimately, develop a cure.**
- **An understanding of the number of people with Parkinson’s in Australia, and factors that can increase the risk of developing Parkinson’s, to support prevention and early identification, guide research, improve availability of support services, and ensure policy and advocacy are informed by accurate data.**
- **More definitive understanding of the occupational, environmental, and genetic risk factors.**
- **Greater understanding of the social and economic cost of Parkinson’s to inform return on any investment.**
- **A clear strategy to translate research findings into meaningful treatments or prevention strategies, including approaches to prevent, stop or slow progression.**
- **A program of clinical trials to support cutting edge new treatments, with greater access for priority cohorts (e.g., women, CALD communities, and rural, regional and remote communities).**

# Other National Plans

There are a range of National Plans and Frameworks that have already been developed, and which are important references for this National Parkinson's Action Plan (NPAP) to ensure there continues to be alignment across health and wellbeing-related plans across Australia.

## The National Strategic Framework for Chronic Conditions 2026-2035

The National Strategic Framework for Chronic Conditions 2026-2035 (the Framework) sets out an approach to one of Australia's most significant health challenges, chronic conditions. These conditions account for the majority of the country's disease burden and are associated with approximately 90% of all deaths. Nearly two in five Australians live with multiple chronic conditions, highlighting the need for a coordinated and forward-looking response.

This includes neurological diseases such as Parkinson's, which are captured within the Framework's overarching policy direction, through strategies aimed at prevention, early detection and the management of chronic conditions.

This Framework provides high-level, overarching guidance to support a comprehensive, multisectoral effort focused on prevention, early intervention and equitable health care. It promotes collaboration across governments, sectors and communities to reduce the impact of chronic conditions and improve health and wellbeing for all Australians. The Framework outlines shared objectives, principles and priority areas to guide the development of policies, strategies and services across all levels of government. It is primarily directed at policymakers and is designed to support consistent, evidence-based decision-making. While it informs national efforts, it does not prescribe detailed actions or timelines. Instead, it provides a foundation for collective action and long-term reform across Australia's health system.

# National Preventative Health Strategy 2021-2030

The National Preventive Health Strategy (the Strategy) aims to provide more balance to the health system by enhancing the focus on prevention and by building systems-based change over a 10-year period.

While the Strategy does not specifically address neurological conditions or Parkinson's, it places greater emphasis on broad-based health promotion and prevention programs, which are consistent with Priority Actions to improve awareness and strengthen prevention strategies for Parkinson's.

# The National Agreement on Closing the Gap and National Aboriginal and Torres Strait Islander Health Plan 2021–2031

There is significant alignment between the Priority Actions set out to improve outcomes for people living with Parkinson's, including First Nations people, and the Priority Reform Areas in the National Agreement on Closing the Gap and the National Aboriginal and Torres Strait Islander Health Plan 2021–31. This alignment means the following for the NPAP:

- Awareness raising, strengthening prevention, diagnosis of Parkinson's and access to care and supports should be done in partnership with Aboriginal Community Controlled Health Organisations (ACCHOs) and Aboriginal Community Controlled Organisations (ACCOs), recognising the importance of self-determination and an ACCO-led approach.

- Working in partnership with First Nations communities on training and education programs, and information resources.

- Increasing the capacity and capability of the workforce associated with First Nations communities.

- Improving data, research and translation of evidence on Parkinson's in First Nations people, through engagement with the community and the workforce, appropriate disaggregation of data, and increased reach of clinical trials and participatory research projects within First Nations communities.

# What does the future look like?

## What follows is a vision for a better future for people with Parkinson’s

It’s 2036, and life with Parkinson’s in Australia feels different now — familiar in its challenges but supported in every direction.

There is no longer the uncertainty that once came with diagnosis, or the fear of navigating the system alone.

The National Parkinson's Action Plan (NPAP) changed that — putting people with Parkinson’s and their families at the centre and building everything else around them.

## A New Beginning

At 50, Australians can now receive a simple early detection test as part of their routine health check — a quick test developed through research. If early signs of Parkinson’s are detected, the follow-up is immediate. A team of health professionals is there ready to support the person right from the start through providing information and education, treatment plans and emotional support before symptoms start to interfere with daily life.

People know what Parkinson’s is, how it might affect them, and what they can do right away. Families are included, with guidance on how to adapt, plan, and stay active together.

Early information and support have removed so much of the fear that once came with uncertainty — and early action is preventing complications, stopping progression, and reducing health costs across the system.

## Preventing Parkinson’s

After years of community-led research, the connection between environment, genetics, and Parkinson’s became clear — and Australia acted. Government reforms phased out or tightly **regulated chemicals once linked to neurological harm**. Environmental monitoring is routine, **protecting air, water, and soil in agricultural and industrial regions** to support healthier communities.

Workplace standards focus on how to **reduce exposure risks and protect workers'** neurological health.

Past sites of toxic exposure have been identified and actions taken to address risks to the public.

At the same time, national health campaigns promote **brain-protective living** — supporting exercise, healthy diets, sleep, and stress management as part of everyday prevention.

Families with known genetic risk have access to voluntary counselling and early testing, giving them the knowledge to act sooner. As a result, the rate of new Parkinson's diagnoses has slowed. Environmentally linked cases have declined, and people are living longer, healthier, happier lives.

# Care That Moves With Life

Every person with Parkinson's now has a **personalised care plan** and a **team built around them** — shared between their General Practitioner (GP), neurologist, geriatrician, nurse, and allied health professionals, all trained in Parkinson's. Appointments and reviews are automatically coordinated, and care records travel with the person, not the other way around.

At home, technologies such as **wearable sensors and smart devices** quietly track movement, sleep, and speech. Both the person and their care team receive updates. When small changes appear, proactive messages arrive: People take an active and informed role in these conversations, adjusting routines before problems escalate.

Early intervention has become the norm, leading to slower disease progression, a reduction in falls, hospital admissions, and unnecessary costs while improving health, independence and quality of life.

New treatments are available, made possible through investment in research and improved access to international clinical trials. These treatments stop or slow disease progression.

# Communities That Stay Connected

Across Australia, support is available when people need it — not just during clinic hours. Programs are flexible and shaped around individuals and families, with sessions running early mornings, evenings, and weekends.

Local and online programs offer strength and balance training, tai chi, speech and voice workshops, and wellbeing sessions — all based on research and delivered by trained professionals.

Family-focus workshops help partners and carers learn strategies that fit their daily routines. Education for health professionals happens within communities too, so learning is local and responsive. Therapists and support teams are easy to reach, and community and clinical care now reinforce one another.

# Research That Includes Everyone

Research has become one of Australia's greatest strengths.

Over the past decade, sustained **government investment** has transformed how Parkinson's research is coordinated and delivered — from the laboratory to the clinic, and into everyday life.

The **National Parkinson's Research Program** brought together people with Parkinson's, families, scientists, clinicians, and policymakers in a shared mission.

Funding now supports the full research pipeline:

- **Basic research** uncovering the biological causes and mechanisms of Parkinson's.
- **Clinical research** developing new therapies and models of care.
- **Translational research** that ensures discoveries move quickly from trials into practice.

Australia's network of **Clinical Trial Centres** operates in every state and territory, connected through a **National Clinical Trial Network** that shares data, infrastructure, and ethics frameworks.

This collaboration has accelerated innovation — giving Australians early access to emerging therapies and international partnerships.

At the centre of it all is the **National Parkinson's Registry — open to all researchers.** The registry integrates clinical data, lived experience, and longitudinal outcomes, allowing researchers to identify trends, design studies, and measure what truly improves quality of life.

Linked internationally, it ensures discoveries made in Australia contribute to global understanding — and global findings return swiftly to benefit Australians.

Research priorities are shaped by people with Parkinson's, ensuring every study is grounded in what matters most to those living the experience.

This ecosystem has made Australia a recognised leader in Parkinson's discovery — advancing prevention, accelerating therapies, and bringing the hope of a cure within reach.

# Families and Carers Supported

Families and carers are recognised as partners in care.

They access online information, education, respite programs, and wellbeing grants that support both practical and emotional needs.

**Digital coaching network**s connect carers across the country, providing shared learning and support. Families say the biggest change isn't just the services — it's the culture.

They feel seen, heard, and valued. The system recognises that when carers are supported, everyone does better.

# A Society That Understands

By 2036, understanding Parkinson's has become part of Australian life.

Because of early detection and better management, many people continue working, volunteering, and contributing to their communities for longer.

Workplaces routinely provide flexible arrangements and adaptive technology.

Schools teach brain health and neurological awareness from an early age.

People with Parkinson's are visible in leadership, advocacy, and research.

The stigma that once created silence has faded.

We no longer need to explain Parkinson's — people simply understand.

# Australia Leading the Way

Australia's integrated model of prevention, research, and person-centred care is now recognised globally.

The **National Parkinson's Action Plan (NPAP)**, community-driven research, and workforce training programs are shared internationally as examples of what's possible when science and lived experience work together.

# The Plan to Take us to the Future

We acknowledge the significant challenges faced by people with Parkinson’s and their carers and are committed to taking action to address these issues. To guide these efforts, a clear vision statement, along with five guiding principles have been developed to underpin and drive the National Parkinson's Action Plan (NPAP). These principles provide a strong and unified foundation, ensuring that every initiative is strategically aligned with shared goals and values, enabling a focused and effective response to the needs of those impacted by Parkinson’s.

## Vision Statement

A future where everyone affected by Parkinson’s has equitable access to quality care, support, research advancements, and hope for a cure.

## Principles

1. **Respect for Human Rights:** The dignity and rights of all people with Parkinson’s are upheld and realised in all aspects of care and support, ensuring their voices are central to decision-making.
2. **Person-centred:** The unique characteristics, needs, and experiences of people with Parkinson's are recognised, ensuring they are partners in their care, and approaches are co-designed to be fit-for-purpose.
3. **Evidence-based:** The latest research and data is used to deepen understanding, and ensure timely, effective, and contemporary management and interventions.
4. **Effective systems:** Integration, coordination and collaboration across health and social service systems improves outcomes for people with Parkinson’s and their carers.
5. **Improve community awareness and reduce stigma:** There is a reduction in stigma through public awareness and, improved understanding surrounding Parkinson’s within the community, ensuring people with Parkinson’s are treated with dignity and respect.

**Vision**

A future where everyone affected by Parkinson’s has equitable access to quality care, support, research advancements, and hope for a cure.

**Respect for Human Rights**

**Person-centred**

**Evidence-based**

**Effective systems**

**Improve community awareness and reduce stigma**

Tackle stigma, improve awareness and ensure access to accurate information

Strengthen prevention strategies to delay onset and improve understanding of risk and disease progression

Build capacity and capability of the healthcare workforce

Improve data and maximise the impact of research

Improve clinical care, treatment pathways and coordination of care

Improve accurate and timely diagnosis and post diagnosis care and support

# Priority Action 1 – Tackle stigma, improve awareness and ensure access to accurate information

## What we hope to achieve

By fostering a greater understanding of Parkinson's within Australian communities we will reduce misconceptions and biases with the aim to shift attitudes, promote inclusion and reduce discrimination through public education and cultural change. We will have improved access to accurate information that will empower people with Parkinson's, their families and communities to access the knowledge they need when they need it. Ultimately, we seek to build a more supportive, inclusive and informed society.

## Why is this important?

To combat the stigma and harmful stereotypes surrounding Parkinson's, it is essential to promote greater understanding and awareness of the condition. By addressing common misconceptions and stereotypes, we can ensure people with Parkinson's receive the acceptance, early help, and resources they need to navigate life with confidence.

**"When I mention to people that I have Parkinson's, they always look down at my hands expecting a tremor. But that's not really an issue for me, more around balance and gait. But I found it quite troubling, that unless I have the shakes, I don't 'really have Parkinson's'." – Person with Parkinson's**

To fill knowledge gaps, many currently turn to the internet for help but often find scattered and inconsistent information. This makes it difficult for people with Parkinson's, carers, and even healthcare professionals to access reliable and up-to-date information. Providing accurate information is the first step in a strong integrated support model for people with Parkinson's.

For most people with Parkinson's, the aim is to maintain a fulfilling and active life, with many striving to continue their daily routines. This is especially true for those with Young Onset Parkinson's Disease (YOPD), as many want and need to stay in the workforce. To support people with Parkinson's in sustaining their employment longer, small yet impactful adjustments can make a significant difference. Parkinson's friendly spaces will empower people with Parkinson's to fully participate and thrive, unlocking their potential.

**“You're completely ignored because it's seen as an older person’s disease." – Young Person with Parkinson’s**

Increasing awareness of Parkinson’s and challenging misinformation will not only make life easier for people with Parkinson's but also support building a more compassionate and understanding society. This will ensure people with Parkinson’s feel understood and supported to pave the way for a society that genuinely values the experiences of everyone affected by Parkinson’s.

**A lack of information was seen a barrier to accessing services and supports by over a third of survey respondents.**

# Actions to tackle stigma, improve awareness and ensure access to accurate information

| | |
|---|---|
| **1. Raise the profile of Parkinson's across Australia to foster understanding and reduce stigma** | a. Develop and implement a national multi-modal, multi-year campaign to provide accurate, reliable and accessible information about Parkinson's that addresses common misconceptions and builds general community understanding.<br>b. Provide health professionals and support workers with clear and accurate information on Parkinson’s to ensure consistent communication and to minimise inadvertently contributing to stigma and misconceptions.<br>c. Provide resources that people with Parkinson's can share with those around them (i.e. family, friends, employers, etc) to support education on what Parkinson’s is, its symptoms, and how individuals and employers can support someone with Parkinson’s. |
| **2. Develop a centralised information hub to enable access to accurate and current information on Parkinson’s** | a. Parkinson’s organisations to work together to design and implement a centralised information hub to enable access to accurate and current information on Parkinson’s.<br>b. Parkinson’s information is to be made available in a variety of formats such as plain English, Auslan, easy read, videos and other languages. |
| **3. Raise awareness of Parkinson’s through developing targeted information for distribution to locations accessible to people in their everyday lives** | a. Improve understanding of Parkinson's through ongoing dissemination of accurate and accessible information targeted at multiple levels - the public, community organisations, healthcare professionals, educational institutions (including, primary, secondary and tertiary) and workplaces.<br>b. Promote awareness and guidance for employers to enable inclusion and supports for people with Parkinson's in the workplace, particularly for high-risk workplace environments. |

Actions within Priority Action 1 should ensure that First Nations, Culturally and Linguistically Diverse (CALD) and other priority groups are considered in the design, development and testing of resources and information, to make sure they are accessible to all.

# Priority Action 2 – Strengthen prevention strategies to delay onset and improve understanding of risk and disease progression

## What we hope to achieve

Through strengthening prevention strategies, we will enhance understanding of the key risk factors associated with Parkinson's. This information can be used to drive policy change and enable informed decision making around lifestyle choices and treatment options to improve overall quality of life, reduce disease burden and improve outcomes.

## Why is this important?

To prevent Parkinson's we first need to understand the causes and risk. We already know environmental influences, exposure to toxins, genetic factors and head injuries increase the risk of developing Parkinson's. Through leveraging global research and applying it to the Australian context we can uncover new approaches for risk reduction, devise preventative measures, and develop targeted strategies to protect those most at risk. This knowledge will pave the way for earlier interventions and improved approaches to delay the onset and progression of Parkinson's.

**"I was a farmer. I used chemicals and sprays - I thought we were careful, but I've found out other farmers have Parkinson's too. There's a pattern there." – Person with Parkinson's**

The link between toxin exposure and Parkinson's is well-documented, with certain chemicals like pesticides, herbicides, industrial solvents, and heavy metals significantly increasing the risk of the disease by causing neuronal damage, highlighting the need for stricter regulations and preventive measures.

> **Half of all survey respondents reported exposure to notable risks, through farming proximity and exposure to chemical products, herbicides, pesticides and commercial cleaning products based on where they lived or worked.**

There is a growing body of evidence that links sports-related injuries, particularly head injuries, to an increased risk of developing Parkinson’s. To better protect our athletes, we need to understand how approaches to training and improvements in protective gear can be used to minimise this risk.

Various genetic mutations are known to increase the risk of Parkinson's and often lead to Young Onset Parkinson's Disease (YOPD). However, more needs to be understood about how individuals are genetically predisposed to Parkinson’s, in what ways and where exposure to other risk factors may be a catalyst. Equally we need to understand more about how genetic factors can be impacted by exposure to other risk factors, such as toxins, head injuries and lifestyle.

Research has shown lifestyle factors, such as diet, physical activity and substances, influence the risk of developing Parkinson’s in different ways. Regular exercise and a healthy diet are commonly known to reduce risk and delay symptom progression, whilst limited exercise and unhealthy diet may contribute to symptom onset.

We want to equip people with the tools to make informed choices to mitigate risks. Through scientific research, review of guidance and regulations, and clear advice for those at risk we can foster greater collective action to reduce the burden of Parkinson’s on individuals, families, and communities.

# Actions to strengthen prevention strategies to delay onset and improve understanding of risk and disease progression

| | |
|---|---|
| **1. Develop an evidence base to deepen understanding of Parkinson’s causes, risk factors, and progression** | a. Undertake research to strengthen understanding of the potential causes of Parkinson's including environmental factors (i.e., toxins exposure), head injuries (i.e., sport, instances of violence), lifestyle (i.e., drug usage, diet) and genetic predisposition.<br>b. Uplift findings from global research and determine how findings can be translated to better understand risk factors and the progression of Parkinson's in Australia. |
| **2. Promote safety by educating at-risk cohorts about protective measures** | a. Develop targeted information and education programs tailored to at-risk populations aimed at addressing protective measures.<br>b. Partner with relevant industries (e.g., industrial, sporting, etc) to identify and implement appropriate protections to minimise the impacts of at-risk activities. |
| **3. Develop guidelines and adjust regulatory requirements to address known environmental and occupational risk factors** | a. Undertake a review of regulatory approaches to identify opportunities to actively reduce exposure to environmental toxins and minimise risk factors for Parkinson’s.<br>b. Develop safe use guidelines and practical tools to protect workers handling identified hazardous substances and monitor compliance in industries that work with these substances.<br>c. Advocate for stricter regulations on the use of chemicals linked to Parkinson’s, such as certain pesticides and industrial solvents. |

# Priority Action 3 – Improve accurate and timely diagnosis and post diagnostic care

## What we hope to achieve

Through improved access to appropriate diagnostic services and standardised tools and post-diagnostic care we will ensure timely and accurate diagnosis of Parkinson's. Early access to a multidisciplinary team, proactive interventions and tailored support will enhance quality of life to enable better symptom management and promote long-term health and wellbeing outcomes. Post diagnosis, we will provide people with personalised support to navigate the complexities of the service system, providing them with tailored information and support to access appropriate services and manage their condition, including the option to access peer support if desired.

## Why is this important?

To best support people with Parkinson's early in their journey we need to focus on supporting a more timely and accurate diagnostic process. Delivering an accurate and timely diagnosis provides the best chance to slow symptom progression and maintain quality of life. By focusing on better education for clinicians and communities on the 'hidden' symptoms of Parkinson's we can help people 'connect the dots' sooner and ensure they receive timely support.

**"I feel lucky that my GP referred me to a neurologist quickly, and I was diagnosed within a month. I've heard others have waited years." – Person with Parkinson's**

Through establishing national guidelines and tools for diagnosing and treating Parkinson's in Australia we empower people with Parkinson's and their carers to navigate their diagnostic journey with greater confidence and optimism. Standardised processes will support greater certainty on next steps, reduce delays in seeking support, improve early intervention, and promote equitable access to care across Australia. Standardised processes should also integrate existing best practice diagnostic tools for specific cohorts, such as the Comprehensive Health Assessment Program.

**“I was told ‘you’ve got Parkinson’s, here’s some medication, come back and see me in six months. I needed more.” – Person with Parkinson’s**

To accompany guidelines there needs to be appropriate support to help people with Parkinson’s to understand their condition and how they can best manage symptoms in a way that suits their lifestyle. This also means making sure that Australia’s First Nations and Culturally and Linguistically Diverse (CALD) communities have access to culturally appropriate care and resources, promoting equal access to information and support following diagnosis, and Aboriginal Community Controlled Health Organisations (ACCHO) and Aboriginal Community Controlled Organisations (ACCO) are part of the diagnostic and clinical management pathways for First Nations people.

This plays a key role in ensuring that interventions and treatments are tailored to meet the unique needs of each person with Parkinson’s.

> **Over one third of survey respondents took more than a year to be diagnosed, with over a quarter taking two years or more.**

People with Parkinson’s need comprehensive support that includes access to information, peer networks, psychosocial support, financial resources, and multidisciplinary clinical expertise. More specifically at time of diagnosis, they require access to professionals that can help them manage the emotional impact and adjustment to the diagnosis and provide guidance during the initial stages of managing the condition. It is critical that people receive post-diagnosis support and assistance to navigate the complexities of the service system, empowering them with practical knowledge to manage their condition, access care and make informed decisions.

In addition, recognising early the value of peer support networks in the care journey is key to ensuring people with Parkinson’s have the necessary support and supporters to help them actively manage their Parkinson’s journey.

# Actions to improve accurate and timely diagnosis and post diagnostic care

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|---|---|
| **1. Implement standardised, nationwide guidelines and tools to ensure consistency and accuracy in diagnosing Parkinson's across Australia** | a. Develop national standardised diagnostic guidelines and tools for Parkinson's to confirm Parkinson's diagnosis and exclude other disorders.<br>b. Provide targeted education and training for General Practitioners (GPs), geriatricians, allied health professionals, and pharmacists to improve recognition of early Parkinson's symptoms.<br>c. Work with state, territory and federal governments to ensure accurate information on Parkinson's is available on health information websites related to movement and neurological conditions. |
| **2. Establish advice and navigational support services to enable timely and appropriate post diagnostic care and support** | a. Design, fund and implement a national Parkinson's navigator approach to provide tailored advice and support to enable service access (including multidisciplinary care) for people with Parkinson's post diagnosis.<br>b. Develop information resources to support people post diagnosis providing practical information and knowledge to manage their condition, access care and make informed decisions, including resources tailored to First Nations and CALD communities. |
| **3. Recognise and strengthen the role of peer support in supporting people with Parkinson's in their care journeys** | a. Grow new and strengthen existing in-person peer-led support group networks for individuals with Parkinson's to share experiences.<br>b. Establish dedicated, moderated online forums or social media groups for people with Parkinson's and their carers to connect virtually, share experiences, and access accurate information. |

# Priority Action 4 – Improve clinical care, treatment pathways and coordination of care

## What we hope to achieve

Enhanced clinical care and clear treatment pathways will create stronger coordination from diagnosis to improve quality of life for people with Parkinson's. By partnering with care providers in a way that is actively guided by people with Parkinson's and their carers, we will optimise treatment outcomes, foster better communication and enable collaboration to deliver more efficient care management. It will incorporate the unique wants and needs of every person with Parkinson's.

## Why is this important?

People with Parkinson's need coordinated support from a range of care disciplines to access clear treatment plans and appropriately manage their symptoms. Care systems must be designed to eliminate barriers, such as long wait times, funding challenges, and fragmented communication, by fostering an integrated approach that prioritises timely and equitable access to treatment and resources.

Through improving access to multidisciplinary care we will enhance health outcomes, reduce system inefficiencies, and provide equitable, person-centred, and seamless support. Increasing access to Parkinson's nurses and allied healthcare, and working with states and territories to improve access and pathways, will ensure we respond to the unique needs of everyone with Parkinson's.

> **Survey results showed a lack of information about available services (29%) and difficulty understanding health resources (24%), highlighting significant gaps in connecting individuals with the support they require.**

By developing clear, standardised clinical care guidelines and multidisciplinary models of care, we can define what high-quality care should look like. It will guarantee the healthcare system is equipped to meet the growing demand for care to improve outcomes and quality of life.

**“Every aspect of care with Parkinson’s could be better improved with better guidelines and evidence-based approaches, but Parkinson’s nurses are the linchpin to delivering tailored support.” - Clinician**

We need to ensure that every person living with Parkinson’s has access to the guidance and support they need to navigate the complexities of the health, disability and aged care systems. Currently, these systems do not provide equitable access, funding and support to the Parkinson’s community, with the progressive, fluctuating and complex nature of symptoms not being recognised. To achieve greater equity, service systems need to ensure people with Parkinson’s have consistent, timely, and appropriate access to support that is tailored to their needs, particularly access to treatments and therapies. This will ensure people with Parkinson’s get the personalised support they deserve.

**“I see a neurologist who comes in to visit every 6 months. I don’t even know if there are any physios in the area.” – Person with Parkinson’s**

# Actions to improve clinical care, treatment pathways and coordination of care

| | |
|---|---|
| **1. Strengthen equitable access to health care and treatment for Parkinson's across Australia** | a. Establish hub-and-spoke models to improve access to specialist care that includes movement disorder nurses, General Practitioners (GPs), allied health professionals, geriatricians and neurologists in regional, rural and remote communities. |
| | b. Embed the Parkinson's nurse model to support clinical care and treatment pathways, with consideration for approaches to increase access to Parkinson's nurses across Australia. |
| | c. Advocate for increased funding and policy initiatives to recruit, train, and retain allied health professionals to meet the growing demand for multidisciplinary support in Parkinson's care. |
| | d. Support approaches to establish telehealth and virtual care services tailored for regional, rural and remote locations to enable better access to care and treatment. |
| | e. Establish streamlined access pathways to adjacent service systems (i.e., the National Disability Insurance Scheme (NDIS), My Aged Care) to reduce administrative burdens and expedite processes, ensuring timely and less complex access to funding and care. |
| **2. Establish national guidelines and evidence-based care models specific to Parkinson's care** | a. Develop national care models for treating and managing Parkinson's that incorporate holistic and multidisciplinary approaches to support effective planning and care coordination. |
| | b. Develop evidence-based minimum clinical guidelines for Parkinson's care, covering the continuum of diagnosis, treatment pathways, ongoing management, and transitions between care stages. |
| | c. Ensure all hospital and health care facilities have access and are aware of Parkinson's clinical guidelines. |
| **3. Enable people with Parkinson's to be active partners in their care and treatment** | a. Improve health literacy of people with Parkinson's and their carers. |

# Priority Action 5 – Build capacity and capability of the healthcare workforce

## What we hope to achieve

A skilled and compassionate healthcare workforce that is equipped with the knowledge, skills, resources and training to provide compassionate, evidence-based and tailored care. Multidisciplinary clinical networks will be standard to support a more integrated and effective system that adapts to the unique needs of people with Parkinson's to deliver better outcomes.

## Why is this important?

There are workforce shortages across all key aspects of Parkinson's care, and addressing workforce gaps is key to a system that is better equipped to meet the unique needs of people with Parkinson's.

To effectively support people with Parkinson's we will prioritise Parkinson's-specific education and training for all healthcare professionals to foster a deeper understanding of the condition and its complexities. We need to equip healthcare workers with sufficient information to implement effective treatment strategies to provide earlier interventions, better care, fewer hospitalisations, and improved outcomes for people with Parkinson's.

**"Training is fundamental, we need to effectively train our juniors for succession with more structured and secure training pathways." - Clinician**

We will inspire and train a new generation of healthcare professionals to specialise in Parkinson's care. To do this, it is essential to break down misconceptions and ensure healthcare workers see focusing on Parkinson's as a rewarding career. Better pathways are needed to ensure a pipeline of skilled professionals. Equally, continuous funding for Parkinson's specific roles, such as Parkinson's nurses and allied health professionals is essential to making the field more attractive and to meet the growing demands. Paired together, it can build a more sustainable workforce by reducing burnout through increasing the workforce and appropriate training.

> **Survey insights show a significant gap in the utilisation of specialties, including speech pathologists, occupational therapists, geriatricians, and mental health professionals, with 46% to 80% of people with Parkinson's reporting that they 'don't have one'.**

By strengthening the workforce and enhancing the foundational understanding of Parkinson's care across all relevant professionals, care systems will be better equipped to provide integrated, high-quality, and patient-centred care. Bridging these workforce gaps will not only improve outcomes for people with Parkinson's but will also empower healthcare workers to feel more confident and effective in their roles.

# Actions to build capacity and capability of the healthcare workforce

**Develop a national workforce strategy targeted at building the capacity and capability of the health and social care workforce**

a. Develop a national workforce strategy to support capability uplift and increase the number of Parkinson's specialists across Australia.

b. Develop Parkinson's specific training for the primary care workforce (including General Practitioners (GPs), nurses and allied health workforce), as well as the broader aged care and disability support workforces to better meet the needs of people with Parkinson's.

c. Establish training pathways for health and social care workers through certifications and short courses that provide credentials to encourage participation in Parkinson's care, and specific pathways for workers from First Nations, Culturally and Linguistically Diverse (CALD) and other diverse communities.

d. Work with educational institutions such as universities to develop education pathways, starting at an undergraduate level, to encourage an interest in Parkinson's as a career pathway.

# Priority Action 6 - Improve data and maximise the impact of research

## What we hope to achieve

Evidence-based decision making through improved data collection that maximises the impact of research and can one day stop the progression of Parkinson's. By building a stronger understanding of the number of people with Parkinson's and the impacts, we strengthen Australia's connection to global efforts, enabling effective policymaking and supporting strategic resourcing to improve outcomes for people with Parkinson's.

## Why is this important?

People with Parkinson's want a cure, and research is how we will get there. Research, evidence, and data must guide everything we do to better understand Parkinson's, its causes, prevention, diagnosis, management, and treatment. Research offers hope and is essential for making progress for everyone affected by Parkinson's.

To achieve real breakthroughs, research into Parkinson's and movement disorders needs to be prioritised. We will establish a more connected research system that fosters and values collaboration between researchers, healthcare professionals, and people with Parkinson's. This will prioritise the sharing of data, insights, and resources, enabling innovative approaches to accelerate discoveries and translate findings into practical solutions.

**"The current infrastructure is failing Parkinson's research. It's not considered a National Health Priority, but it should be."**
**- Researcher**

The number of people with Parkinson's in Australia is unknown, meaning it is challenging to understand where the greatest impact can be achieved. A National Parkinson's registry will help us better understand the number of people with Parkinson's and which communities are most impacted. This will ensure more targeted interventions, equitable resource distribution, and improved support for those affected. By centralising information, the registry will also facilitate research efforts, policy development, attract clinical trials, and advocacy initiatives to address the challenges of Parkinson's more effectively.

**“What gets measured gets managed. Right now, we fail to measure even the most basic aspects of Parkinson’s: how many people have it and how many are developing it. Not surprisingly, the condition is out of control. We don’t know how many people actually have Parkinson’s – not for the world, any country, any state or province, or any city.”**
**- Ray Dorsey, MD and Michael S. Okun, The Parkinson's Plan: A New Path to Prevention and Treatment**

With an ageing population and more people being diagnosed with Parkinson’s every year, research is more urgent than ever.
To create meaningful change, we need to make Parkinson’s research a national priority. By taking a strategic and collaborative approach, we can increase funding, speed up progress, improve care and quality of life, promote innovation and access to innovative technologies, and move closer to prevention and, one day, a cure.

# Actions to improve data and maximise the impact of research

| | |
|---|---|
| **Develop a national Parkinson’s research strategy to enable a coordinated approach to maximise the impact of research** | a. Establish a national registry to collect data on Parkinson's incidents, demographics and outcomes, and to enable clinical trials.<br>b. Work with the Australian Bureau of Statistics to have Parkinson’s listed as a long-term health condition within the 2031 census.<br>c. Undertake an updated prevalence study of Parkinson’s in Australia.<br>d. Undertake social and economic impact analysis to understand the cost of Parkinson’s, informing policy and investment, and drive improved social and economic outcomes through a strong evidence base.<br>e. Establish coordinated Parkinson’s-focused research networks comprising people with Parkinson’s, researchers, healthcare providers, government institutions, and not for profit organisations.<br>f. Advocate for increased and prioritised funding for research into Parkinson’s, including coordinated approaches to maximising the impact of research funding.<br>g. Define and embed best practice research approaches to recruit underrepresented groups to participate in research (including clinical trials), such as different racial, ethnic, socio-economic, and geographical populations.<br>h. Define approaches to embed global research and how it can be applied within the Australian context to increase sample sizes and diversity for more comprehensive results.<br>i. Review best global practice on causes of Parkinson’s and mitigation approaches, including consideration for toxic chemicals. |

# Next steps

To maintain the momentum generated through the development of the National Parkinson's Action Plan (NPAP), the next phase will focus on developing an Implementation Plan and Evaluation Framework. A number of priority actions are required to support this work.

- Establish the National Parkinson's Alliance (NPA) as the primary point of contact for engagement with the Parkinson's sector, ensuring clear, consistent communication and representation in relation to the NPAP and its implementation.

- Collaborate with all levels of government and the broader health system to strengthen understanding of the NPAP.

- Develop a Governance and Responsibilities Framework to clearly define roles, decision-making processes and accountability mechanisms for implementing the NPAP.

- Develop a Measurement and Reporting Framework to monitor and track progress against the NPAP, supporting transparency and accountability.

# Appendix A: Summary of the stakeholder engagement approach to inform the National Parkinson’s Action Plan

## Overview / Approach to Developing the Plan

In developing the National Parkinson's Action Plan (NPAP), a detailed literature review and policy scan spanning 233 documents was conducted. A national consultation process gathered insights from 717 stakeholders, and 5,029 survey responses were received through a national survey. Findings have been synthesised and distilled to form Australia’s first National Parkinson's Action Plan (NPAP).

The below diagram summarises the activities undertaken to build an evidence base to inform the NPAP, grounded in the lived experiences of Australian’s living with and/or supporting someone with Parkinson’s. It aimed to systematically identify gaps in care, prioritise needs, and recommend actionable strategies for improving Parkinson’s in Australia.

# Literature Review and Policy Scan

## Literature review

The aim of the literature review was to provide a global perspective on key issues impacting people with Parkinson’s, and effective interventions including approaches, gaps and opportunities for improvement. The literature review was conducted to assess the international evidence available regarding Parkinson’s, treatment and care models. It was guided by reviewing publicly available peer-reviewed and empirical evidence, as well as documentation (publicly or privately available) provided by the National Parkinson's Alliance (NPA).

The literature review included research on the following key areas:

- Epidemiology, including prevalence;
- Symptoms, diagnosis and intervention;
- Treatment and therapy;
- Investment, funding, research trials and costs associated with Parkinson’s; and
- Lived experience of people with Parkinson’s, carers and family members.

## Policy scan

An environmental scan of the Australian policy context was conducted to address the needs of people living with Parkinson’s. Policies at both the state and federal levels were analysed, using documents that are either publicly available or provided by the NPA. The aim of this scan was to understand existing policies and national strategies related to Parkinson’s and to identify gaps in the policy landscape.

Focus topics and documents analysed for the policy scan included:

- Parkinson’s submissions, policies, strategies and frameworks, including Parkinson’s specific strategies, government submissions, national insurance schemes and research investment; and
- Sector adjacent submissions, strategies and frameworks, including strategies to address Parkinson’s adjacent disorders and Royal Commissions.

# Approach to reviewing documents

To inform the literature and policy review, 233 documents were reviewed and prioritised based on the extent they addressed the research topics and objectives, their publication date or currency, and their presence in peer-reviewed journals or publications recognised by experts and authoritative institutions.

A preliminary review of titles and abstracts was conducted to assess relevance and eliminate less pertinent studies, with a focus on peer-reviewed studies published between 2020 and 2025, while earlier studies were included as needed for a strong evidence base.

Once the applicability and relevance of the research and policy were identified, the literature was reviewed in greater detail and applied for the purposes of the review. This thorough review process ensured that the most relevant, up-to-date, and authoritative sources were utilised to inform the findings and recommendations.

# Consultation Approach

Following completion of the literature review and policy scan, a large national consultation process was undertaken with both people with Parkinson's, their families and unpaid carers, clinicians, researchers, and other professionals working in the Parkinson's sector. This consultation included:

- A national online survey and a series of workshops and phone interviews to gather input from people with Parkinson's, their family members and carers on their experience with Parkinson's, to understand their priorities, challenges, and perspectives for the National Parkinson's Action Plan (NPAP).
- A series of virtual workshops and interviews with clinicians, researchers and other professionals to gather their perspectives on current challenges and areas for improvement for people with Parkinson's in Australia, based on their professional experience.
- Interviews and written responses from federal, state and territory government to gather their views and perspectives on policy, funding, and support systems for improving services, systems and support for managing Parkinson's.

# Detailed consultation approach

To guide the approach for stakeholder consultations, findings from the literature review and policy scan were used to identify gaps in existing knowledge about Parkinson's. These efforts focused on highlighting areas where research and information were limited, providing a foundation for the development of targeted consultation guides. These guides were tailored to facilitate meaningful engagement with each specific stakeholder group, ensuring their unique perspectives, experiences and priorities were captured.

A key consideration in the design of the consultation approach was to ensure it was accessible, enabling people with Parkinson's to have their voices heard regardless of the progression of their Parkinson's. This was ensured by enabling consultation to occur in a range of formats, including in-person, over the phone and virtually via MS Teams. The plan aimed to maximise the value of stakeholder input by ensuring a clear and focused methodology for engagement while allowing flexibility to adapt as new insights and opportunities emerged. A high-level overview of this approach is outlined below.

# Engagement approach

Consultation sought to gather stakeholder perspectives on the challenges, needs, and priorities of the Parkinson's community to understand challenges and opportunities in:

- Reducing stigma associated with Parkinson's;
- Enhancing the education and capability of the health, disability, and aged care workforce;
- Promoting earlier detection and diagnosis with empathetic delivery and access to multidisciplinary teams;
- Improving access to and coordination of evidence-based healthcare, resources, supports, and treatments;
- Enhancing prevention strategies for Parkinson's;
- Collecting better data on Parkinson's prevalence and monitoring of practise gaps;
- Advancing treatments and therapies informed by data, with increased access to clinical trials; and
- Securing greater funding for Parkinson's research and translating current findings into practise.

Prior to consultation, where virtual consultations occurred, stakeholders were provided with a consultation guide that included background on the project, reason for engagement and questions. At these sessions, consulted stakeholders had the opportunity to provide their views and reflections on the questions posed.

# Recruitment approach

The following stakeholders were engaged in the consultation process:

- **People with Parkinson's (including Atypical Parkinson's).**
- **Carers and supporters of people with Parkinson's.**
- **Clinicians (incl. neurologists, geriatricians and General Practitioners (GPs), nurses).**
- **Researchers (incl. clinician researchers).**
- **Allied Health Workers (including psychologists, pharmacists, optometrists, physiotherapists, speech pathologists, occupational therapists, social workers, dieticians, counsellors).**
- **Parkinson's nurses.**
- **Paid care workers (incl. care coordinators).**
- **Professional peak employees.**
- **Federal, state and territory government representatives.**

Contributions were gathered from participants across all states and territories through various formats, as outlined in the table below.

| Cohort | Engagement approach | Recruitment approach |
|---|---|---|
| People living with Parkinson's, family members, and carers | In-person workshops | Each National Parkinson's Alliance (NPA) member organisation and other Parkinson's peak bodies in each state and territory utilised their communication channels to recruit participants, with the majority relying on local support groups to support recruitment and participation. |
| | Virtual workshops | Individuals who completed the online survey were provided the option to nominate themselves to participate in consultation. Of these individuals, participants were randomly selected and provided the opportunity to participate in a virtual workshop. Where individuals had previously been nominated to attend an in-person session but were no longer available they were provided the opportunity to participate virtually. |
| | One-on-one interviews | Individuals who completed the online survey were provided the option to nominate themselves to participate in consultation. Of these individuals, participants were randomly selected and provided the opportunity to participate in a one-on-one interview. |
| Clinicians, research experts and peak body representatives | Virtual workshops | Each NPA member organisation and other Parkinson's peak bodies in each state and territory utilised their communication channels to recruit participants. Where possible, professional peak bodies were recruited to utilise their communication channels to recruit participants. |
| | One-on-one interviews | Each NPA member organisation and other Parkinson's peak bodies in each state and territory utilised their communication channels to recruit participants. Where possible, professional peak bodies were recruited to utilise their communication channels to recruit participants. |
| | Focus groups | Each NPA member organisation and other Parkinson's peak bodies in each state and territory utilised their communication channels to recruit participants. Where possible, professional peak bodies were recruited to utilise their communication channels to recruit participants. |
| Government | Virtual interviews or written submissions | Federal, state and territory governments were provided the opportunity to participate in a virtual interview or provide a written response to support in informing the National Parkinson's Action Plan (NPAP). A combination of virtual interview or written response was offered to maximise participation and input. |

# Appendix B: Summary of research findings to inform the National Parkinson’s Action Plan

This section offers an overview of the key research conducted to guide the development of the National Parkinson's Action Plan (NPAP), highlighting critical findings and insights that shaped its formulation and focus areas.

## Prevalence of Parkinson’s

The research community agrees Parkinson’s is the fastest-growing neurological disorder with varying prevalence estimates in Australia. This is influenced by inconsistent diagnostic criteria and reporting methods. However, it is known prevalence varies by region due to industrial and environmental factors, with East Asia projected to see the highest increase by 2050.

With a national estimate of approximately 200,000[1,2] Australians living with Parkinson’s disease, this highlights the pressing need for updated prevalence studies and standardised reporting frameworks to better capture the scale and geographic distribution of Parkinson’s in Australia and inform policy and healthcare planning.

## Prevention of Parkinson’s

Parkinson’s is a complex condition, and despite a range of research, the causes are not fully understood. The long prodromal period before symptoms appear, the variability of symptoms and the various environmental exposures that affect the disease development and progression create complexities in understanding prevention approaches.

Environmental exposures significantly contribute to Parkinson’s development and progression. Pesticides are the strongest risk factor, particularly with prolonged exposure in agriculture. Living in areas with high air pollution and working in occupations involving solvent exposure also increase the risk due to neurotoxic effects.

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[1] Ayton, D., et al., Parkinson’s disease prevalence and the association with rurality and agricultural determinants. Parkinsonism Related Disorders, 2019. 61: pp. 198-202. https://pubmed.ncbi.nlm.nih.gov/30377035/

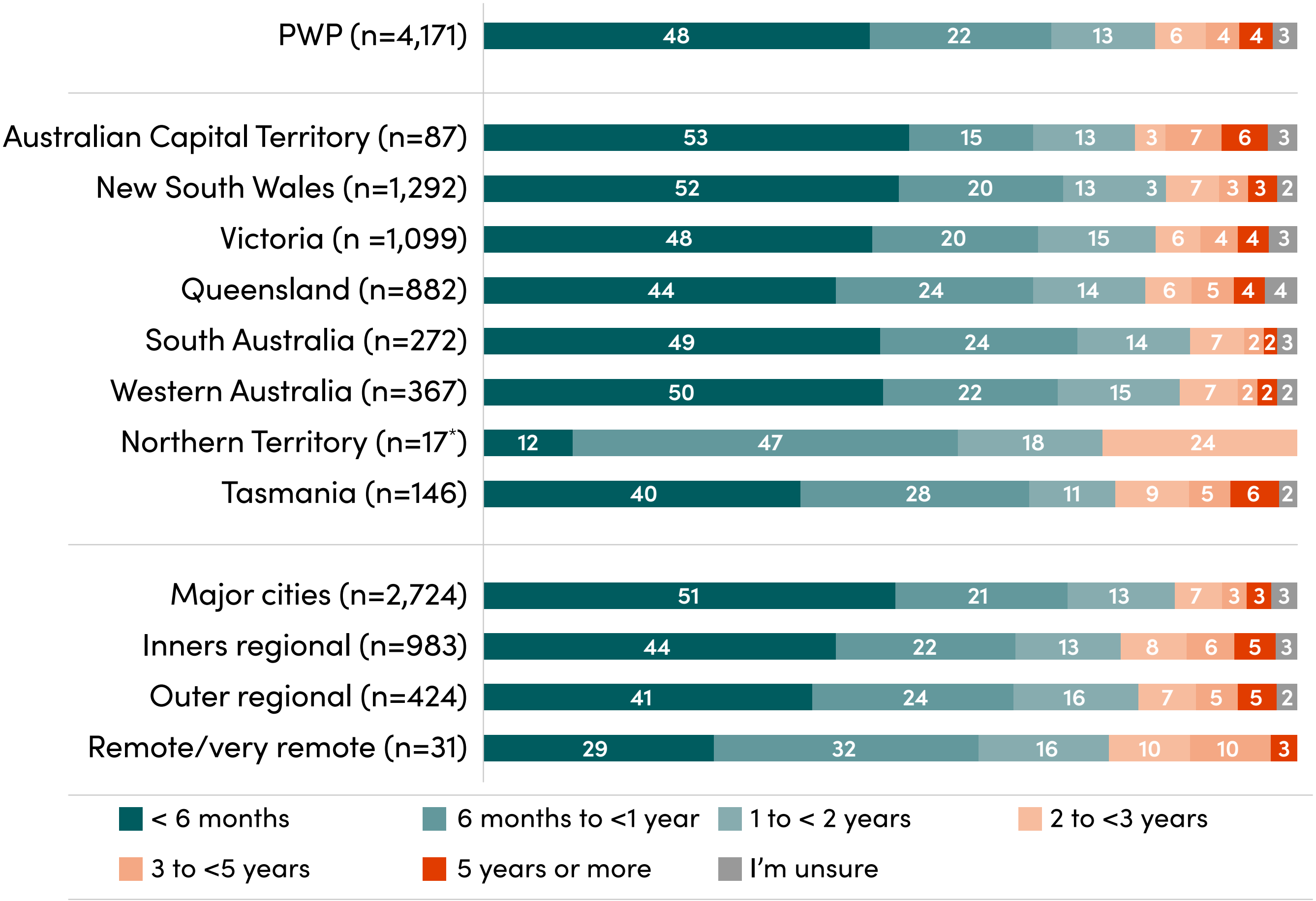
[2] Evans, A., Waterhouse, B., et al., Levodopa use in Australia: an analysis of Pharmaceutical Benefits Scheme 10% data. BMJ Neurol Open. 2024. https://pubmed.ncbi.nlm.nih.gov/38268755/

Despite these findings, the existing literature linking environmental exposures, epigenetic regulation, and disease outcomes in humans remains limited, pointing to the need for further research to better understand these mechanisms and their long-term impact on Parkinson's.

# Diagnosis

Research demonstrated there are challenges in attaining an accurate and timely diagnosis, particularly for those who experience barriers to accessing care (e.g., geographical challenges, language barriers, cohorts underrepresented in research). Given the range of symptoms associated with Parkinson's there are often delays in diagnosis because of the overlap with other disorders, both neurodegenerative and otherwise. In Australia, challenges to accessing a diagnosis are often attributed to challenges in accessing healthcare professionals, misunderstanding of symptoms, incorrect diagnosis or motor symptoms not presenting from the outset. Both consultation and survey responses highlighted these challenges, particularly for those in regional, rural and remote areas.

**Figure 1: Length of time to get diagnosis - by state and location (%)**



**Source: National Parkinson's Action Plan Survey Findings (2025)**

There is currently no accessible diagnostic test that can definitively diagnose Parkinson's; diagnosis relies on clinical evaluation and identifying characteristic motor features. This approach heavily depends on subjective assessments by clinicians and patient self-reporting, which can result in diagnostic inaccuracies, particularly in the early stages. However, there are a range of promising advancements in diagnostic testing and use of biomarkers in blood, spinal fluid, and imaging techniques. Further research and validation are required to ensure their reliability and accessibility, particularly in diverse and resource-limited settings, before they can be integrated into clinical practise.

# Parkinson’s specific guidelines and frameworks

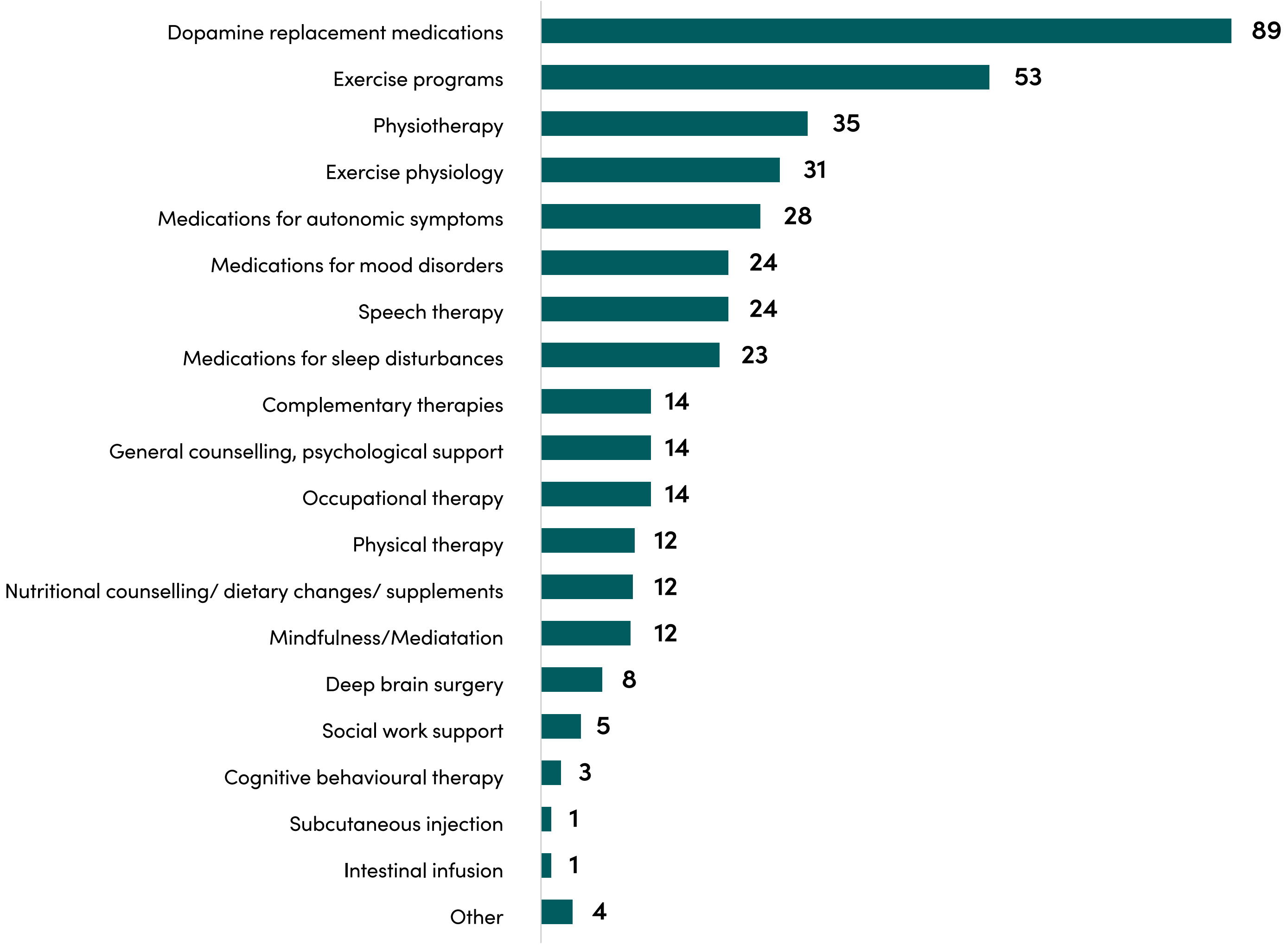
Some state and territory government health services and Parkinson’s peak bodies have supported the testing and implementation of multidisciplinary approaches through hub-and-spoke style models led by Parkinson’s nurses to strengthen connections and pathways to other services. Additionally, whilst countries such as the US and UK have strong frameworks and guidelines in place, often used by Australian clinicians, they are not tailored to the nuances of Australian healthcare systems. Developing Australian specific guidance on Parkinson’s was seen as a core opportunity for many stakeholders, and there are opportunities to build on existing efforts for other neurodegenerative conditions.

# Parkinson’s care and treatment

The ultimate goal of treating Parkinson’s is to find a cure. However, until that occurs the most common medical interventions include medication and surgery. Whilst there are treatments to manage motor symptoms and improve quality of life, there are currently no approved medications or therapies that slow or stop progression of Parkinson’s.

Non-pharmacological treatments, such as exercise and physical therapy, are beneficial in early-stage Parkinson’s to support the management of symptoms. Additionally, research has identified the effective application of multidisciplinary care can support better Parkinson’s management through reduced complications and healthcare costs. Since the needs and preferences of people with Parkinson’s vary, it is critical to personalise non-pharmacological interventions based on individual circumstances. Combining these therapies with pharmacological treatments frequently provides the best outcomes for managing Parkinson’s. This was supported in consultation, with many clinicians and people with Parkinson’s expressing the empowerment that comes from having a care team that has tailored support to meet your needs. Additionally, outputs from the survey highlighted the broad range of support being accessed by people with Parkinson's to improve their quality of life.

## Figure 2: Most beneficial treatments to manage Parkinson's symptoms (%)



**Source: National Parkinson's Action Plan Survey Findings (2025)**

Providing comprehensive specialist care and integrating health systems along a continuum of service in low-resource areas is particularly challenging. In rural, regional, and remote areas of Australia, delays in treatment and diagnoses have been found to adversely affect treatment and patient outcomes. While technological advancements have improved healthcare accessibility in rural, regional, and remote areas, the application of telehealth services for movement disorders, such as Parkinson's, remains limited in Australia. This was supported by consultation findings, with many reflecting on the varying levels of access to services and inconsistencies in care delivery across rural, regional and remote areas.

# Carers

Limited research exists on the impact of caring for people with Parkinson's, but it is evident that carers face a wide range of challenges that affect their physical, mental, and social well-being. As Parkinson's progression entails increasingly complex and debilitating symptoms, caregivers often take on significant responsibilities, including assisting with daily living activities, managing medications, attending medical appointments, and navigating healthcare systems. These duties can lead to physical exhaustion, emotional stress, and social isolation, as carers may have limited time to focus on their own health, hobbies, or personal relationships.

Research and consultation have highlighted the critical role carers play in supporting individuals with Parkinson's. However, it is equally important for carers to prioritise their own physical and emotional well-being to ensure they can provide sustained and effective care for their loved ones. Without adequate support, carers risk burnout, which can hinder their ability to meet the complex and evolving needs of the person they are caring for.

# Cost of Parkinson's

There are limited Australian studies that calculate the cost to an Australian living with Parkinson's, with the most recent 2014 estimates showing a per person a lifetime cost of $191,300 or $14,513 per year.[3] Other countries have conducted further research, with the US estimating a total economic burden of $51.9 billion.[4]

The high cost of Parkinson's supports and ongoing requirement for support to manage symptoms means people with Parkinson's are often reliant on funding available through Medicare, the Pharmaceutical Benefits Scheme, the National Disability Insurance Scheme (NDIS) and/or My Aged Care. However, stakeholders have highlighted that the varying structures and eligibility criteria of these schemes can result in inequities in access to and availability of key supports. For instance, individuals under the age of 65 may qualify for NDIS funding, which often provides more robust and comprehensive resources, while those over 65 must seek support through the My Aged Care system, which is often perceived as less tailored to the needs of people with Parkinson's. Similarly, while Medicare and the Pharmaceutical Benefits Scheme offer some financial relief for medications and treatments, gaps remain for those requiring specialised therapies, assistive technologies, or broader care services.

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[3] Deloitte Access Economics (2015).

[4] Yang, W., Hamilton, J. L., Kopil, C., Beck, J. C., Tanner, C. M., Albin, R. L., Ray Dorsey, E., Dahodwala, N., Cintina, I., Hogan, P., & Thompson, T. (2020). Current and projected future economic burden of Parkinson's disease in the U.S. NPJ Parkinson's disease, 6, 15.

# The Parkinson’s policy landscape

The policy landscape regarding Parkinson’s in Australia is evolving, with recent government reviews and submissions focusing on expanding pharmaceutical benefits and Medicare rebates, and the sector calling for the banning of harmful substances like paraquat. However, Australia does not have any specific government frameworks aimed at addressing Parkinson’s. With no overarching policy or framework dedicated specifically to addressing Parkinson’s, it often falls within broader neurological or chronic disease policies.

Globally, there is limited legislation specific to Parkinson’s. However, the United States has implemented the National Plan to End Parkinson’s Act, which is one of the first national plans to encourage a coordinated approach to support the development of treatments, promote early diagnosis, and understand the impact on health and international coordination.

# Research

The literature and policy review revealed, there is substantial investment into research globally. This is largely driven by developed countries focused on disease cause biomarkers, disease monitoring (including neuroimaging) and genetic testing. However, it also revealed Australia does not have the same level of focus, with a range of gaps to support contextualising known evidence within Australia, such as understanding the epidemiology of Parkinson’s, environmental risk factors, pain management, gene-environment interactions, and fundamental and complex causes of Parkinson’s. This was supported in consultation, where it was reflected there is a greater opportunity for Australia to invest in research, particularly in understanding the personal and economic burden of Parkinson’s.

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