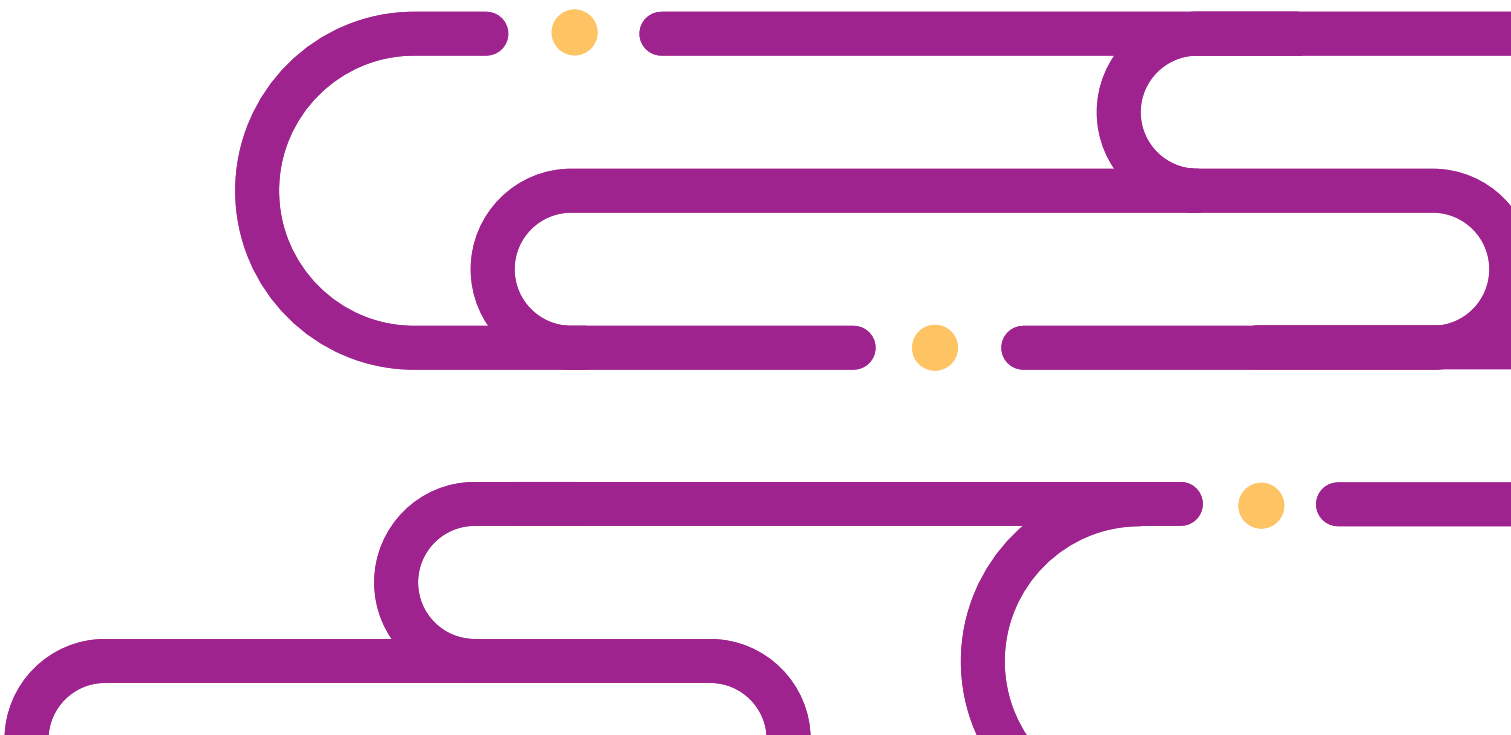


Pre-Budget Submission 2024-25

Proposal for a Lived Experience
Project, a National Awareness
Campaign & GP Education
Program



SUBJECT	Proposal for a National Awareness Campaign & GP Education Program		
TO	The Hon Mark Butler, Minister for Health and Aged Care		
FROM	Parkinson's Australia	DATE	25/01/2024

Parkinson's Australia is the national advocacy body representing people living with Parkinson's, their families and carers, as well as researchers and health professionals in the Parkinson's community. National advocacy. Connection. Awareness.

We promote the best possible quality of life for people with Parkinson's. We advocate for the Parkinson's community on issues of national significance. We work to reduce the impact of Parkinson's by promoting best practice care to ensure that people can maximise their opportunities to live well and maintain their independence.

Our Objectives

- Seek out the stories and issues that people living with Parkinson's in different communities experience with diagnosis, stigma, access to care etc.
- Raise awareness about early warning signs and the motor and non-motor symptoms of Parkinson's, highlighting that Parkinson's is more than a tremor.
- Challenge the perception that Parkinson's is 'just an old person's condition', as approximately 20% of people diagnosed with Parkinson's are under 50 and are of working age.
- Raise awareness about Parkinson's being the fastest growing neurodegenerative condition in the world.
- Encourage those who have early warning signs and symptoms to seek an earlier diagnosis, which will educate General Practitioners (GPs), and other Allied Health Professionals (AHP) in Australia. This will help them to understand and recognise early warning signs and symptoms which will enable swifter referral pathways to Movement Disorder Specialists (MDS).

The Problem

1 in 308 people in Australia are living with Parkinson's.

Because of its chronic progressive nature, insidious onset, complicated and diverse motor and non-motor symptoms, Parkinson's is one of the most challenging diseases to provide care for. Parkinson's is a neurodegenerative condition that currently has no known cure. Parkinson's is more common than prostate, bowel and many other cancers that are considered National Health Priority Areas. Parkinson's is the most common Movement Disorder and had the second highest prevalence in 2005 compared to other neurological conditions, exceeded only by dementia (Deloitte Access Economics 2011).

People diagnosed with Parkinson's generally have four key clinical features: tremor, muscle rigidity, poverty of movement and loss of normal posture with a tendency for falls. Lesser known is the major impact on non-motor functions such as depression, anxiety, behavioural disturbances and cognitive impairment, sleep disorders, hallucinations, sensory deficits such as loss of smell and visual problems, and impaired speech. These early warning signs occur prior to the prodromal symptoms and can assist in an earlier diagnosis. Due to its complex symptoms, Parkinson's has a dramatic effect on a whole family.

There are over 150,000 people in Australia with Parkinson's, and another 1,000,000 people directly affected by Parkinson's including spouses/partners, siblings, offspring, friends and colleagues. Parkinson's prevalence increases threefold after the age of 65. The growth rate in the number of people living with Parkinson's is expected to continue to increase dramatically. It is estimated that the growth rate will average 4% per year, over the next 20 years.

Parkinson's presents a greater immediate pressure on the health system in Australia because of our ageing population. This extends to significant numbers of people with Parkinson's in regional, rural and remote areas which have a higher median age than metro areas.

Living well with Parkinson's requires the expertise and involvement of many Allied Health Professionals which begins with the General Practitioner being able to recognise early warning signs of Parkinson's to enable an early diagnosis.

The Solution:

1. A Lived Experience Project

2. A GP Education Program

3. National Awareness Campaign

Summary of the solution

An investment by the Federal Government to fund a lived experience project, a public awareness campaign and a GP education program will create the following outcomes.

Reaching out to hear the stories of people living with Parkinson's will determine the future policies and direction for the community and how care is accessed - especially those from RRR areas, CALD communities, Aboriginal communities, LGBTQIA+ community. These unique issues and experiences need to be told and heard for the first time.

Raising awareness of early warning signs will encourage people to seek professional help, which will lead to an earlier diagnosis. Early intervention leads to better management of the condition, for the individual, their families and loved ones, and the health system more broadly.

Early diagnosis means the person can actively participate in non-pharmacological solutions such as exercise, hydration and nutrition that is clinically proven to assist to slow the progression of Parkinson's and improve their overall quality of life. Ultimately this may lead to reduced risk of falls, continued participation in the workforce, social and community connection, and decrease cost to the health system through less presentations to emergency departments, people living in their homes for longer and shorter lengths of stay for planned admissions.

A \$2 million dollar investment over two years would ensure consultation with people living with and affected by Parkinson's, the creation and distribution of a National Awareness Campaign and an Education Campaign that will upskill GPs and AHPs in how to ensure that someone lives well with Parkinson's.

The immediate outcomes for people living with Parkinson's:

- Improve the management of symptoms and quality of life
- Provide information and education regarding early intervention options
- Provide supporting information for access to NDIS, MAC and other future programs such as Support at Home
- Provide information and support regarding advanced care directives
- Reduce hospital admissions and length of stay for necessary admissions
- Delay entry in residential care and reduce the need for costly medical consultations and interventions
- Assist in managing the very wide, complex and idiosyncratic medication regimes of individuals which is essential as access to a neurologist is usually annual or bi-annual.

The expected outcomes for the Australian Health System:

- Increased education regarding treatment options
- Reduced unplanned admissions
- Reduced bed days
- Avoided re-admissions
- Improved patient experience for end-of-life care
- Provided multidisciplinary care
- Enabled self-management
- Supported Carers, reduced Carer burnout

1. Lived Experience Project \$250k

The National story of Parkinson's has never been told. The first step is for people living with Parkinson's and their families to tell their stories and distil their priorities. This will entail reaching out nationally for the first time by focus groups in urban, RRR areas, accessing those in CALD communities, partnering with indigenous organisations and particularly aboriginal health organisations, enabling LGBTQIA+ communities to express their unique experience and concerns about their treatment and care. To this end resources are needed for travel and staff support for the policies developed to reflect what the people lived experience so that people living with Parkinson's can be reassured that their voices are being heard.

2. GP Education Program \$800k

Parkinson's Australia recognises the need for endorsed, consistent and up-to-date information and education for GPs and Allied Health Professionals. This is to ensure the earliest possible diagnosis of Parkinson's, which leads to the confident implementation of evidence-based treatment and management options.

It is proposed that Parkinson's Australia leads the development of comprehensive education material and resources for health professionals, drawing on the latest scientific evidence and where appropriate, international resources; guided by the needs of people with Parkinson's.

The GP Education Program seeks to:

- Enhance recognition of the early signs of Parkinson's and the benefits of early intervention
- Ensure health professionals are up-to-date with the latest evidence-based management of Parkinson's
- Enhance the understanding and treatment of both motor and non-motor symptoms
- Reduce the lengthy and uncertain pathway to diagnosis for people with Parkinson's
- Improve overall health and wellbeing outcomes for people with Parkinson's

Guiding Principles

The GP Education Program will be guided by:

- Parkinson's Australia Strategic Plan/State Strategic Plans
- Parkinson's educational resources being utilised internationally
- The expertise of Parkinson's Nurse Educators across Australia
- 'Champions' working in the individual health professions
- The experiences of people living with Parkinson's

Development of Resources

The development of educational resources for the GP Education Program will draw on a key set of information gathering tools, designed to efficiently consolidate:

- The latest scientific evidence in Parkinson's management
- The latest advancements in online CPD (Continuing Professional Development) health education
- The latest advice from CPD accreditation organisations
- The perspectives and needs of people with Parkinson's
- The perspectives of training bodies including the National Prescribing Service

Workforce Considerations

- Australians access general practice more than any other part of the health system (RACGP General Practice Health of the Nation Report 2020)
- 37,472 GPs working in Australia in 2019
- 52% of the FTE GP workforce is overseas trained
- 74.5% of GPs work in the major cities
- 90% of the Australian population visits their GP at least once each year

Evidence-Based Outcomes

[Parkinson's disease: patient and general practitioner perspectives on the role of primary care — PubMed \(nih.gov\)](#)

Conclusion: Patients and GPs see a limited role for the GP in early-stage Parkinson's Disease (PD) care because of patient autonomy and GPs lack of specific knowledge and skills. However, GPs should feel more confident of the added value of their generalist approach to care for patients with a complex chronic disorder as PD. If generalist and specialized care reinforce each other, PD patients benefit.

<https://bmchealthservres.biomedcentral.com/articles/10.1186/s12913-022-07503-7>

PD diagnosis and treatment practices: The majority of respondents in both geriatricians and GPs groups reported having confidence in making the diagnosis of PD, with no significance difference noted (69.8% of GPs and 78.8% of geriatricians, $p =$

0.38) (Table 2).

Geriatricians were more comfortable in initiating dopamine replacement therapy (DRT) for patients they had diagnosed with PD, as compared to GPs (OR = 11.8 [95% CI: 3.54–39.3], $p < 0.001$). When asked further about why they may not feel comfortable with starting the treatment, GPs were more likely to report that they were unfamiliar with the types and/or doses of PD medications as compared to geriatricians (OR 7.14 [2.58–19.8], $p < 0.001$). GPs were more likely to report being uncomfortable with providing PD education (OR 8.64 [2.84–26.3], $p < 0.001$), and their patients were more likely to request a neurologist confirmation before initiation of the treatment (OR 6.94 [1.94–24.8], $p = 0.003$).

Increasing public awareness and GP and allied health education improves the quality of life for people living with Parkinson's. In simple terms, better care and treatment keeps people out of hospitals and residential care. It enables people with Parkinson's to stay in the workforce longer, continue to live independently in their own homes, increase productivity and savings, and reduce the demand for care.

Royal Australian College of General Practitioners (RACGP)

New processes for approving CPD education activities have been introduced by The Royal Australian College of General Practitioners (RACGP), to strengthen the educational rigour of CPD, and to ensure that activities focus on high quality education suited to the professional development needs of GPs. The advice from RACGP to GPs when choosing an education activity for CPD Points is to: "Consider your current and future scope of practice and choose high-quality education resources or activities that will enhance or develop new skills and knowledge within your defined scope."

Australian College of Rural and Remote Medicine (ACRRM)

The Australian College of Rural and Remote Medicine (ACRRM) offers its Professional Development Program to Australian GPs regardless of location. ACCRM is also utilising new criteria to assess activities for accreditation as follows:

1. Does the educational activity help to update knowledge and skills, review performance and/ or measure outcomes?
2. Does the activity relate to the College's Primary Curriculum?
3. Does the educational event/activity have clear, specific learning objectives?
4. Are the planned educational strategies based on adult learning principles?
5. Does the application show that some impact evaluation (changes in knowledge, skill, attitude, practice or patient outcome) is planned?

National Prescribing Service

The National Prescribing Service offers CPD points for GPs, as well as education material on the "Management of Parkinson's Disease," and this is currently based on research papers on Parkinson's medications that are more than 10 years old. These can be found at <https://www.nps.org.au/australian-prescriber/articles/management-of-parkinsons-disease>

The former CEO of the National Prescribing Service, Professor Steve Morris has recently been appointed to the CEO of the Pharmaceutical Society of Australia and would be an ideal (and approachable) contact to provide insight into medication prescribing issues that could potentially be addressed with updated educational materials.

3. National Awareness Campaign \$950k

Who will build and run the awareness campaign?

Parkinson's Australia has been working on a concept with Dee Madigan and the team from Campaign Edge who have created a detailed proposal for a national awareness campaign. We approached Campaign Edge as they have already developed a very successful Dementia Australia awareness campaign.

We need our target audience to recognise and understand the signs of common symptoms of Parkinson's. We want them to question if they, a family member or close friend are affected by those symptoms, and to seek more information and ultimately advice from a health professional.

Target Audience

- Broad Australian public
- Skewed to 30 - 60-year-olds
- Even male / female skew
- National campaign across all States and Territories

Audience Campaign Goals

What do we want the target audience to learn and action, and what do we want the outcome to be?

- **Learn:** Parkinson's is now the fastest growing neurodegenerative condition in Australia (and the world) with a broad range of symptoms that are lesser known such as depression, anxiety and apathy, Parkinson's can affect people at all ages and all ethnicities. Increase knowledge of early warning signs of Parkinson's.
- **Action:** Seek advice from GP or other AHP if they recognise early warning signs and symptoms in themselves or loved ones to assist with an early diagnosis and provide continuous care throughout the journey of living with Parkinson's.
- **Outcome:** Early diagnosis, early intervention including an inter-disciplinary allied health professional team and focus on exercise, nutrition and hydration.

Audience Journey

- Exposure to creative TV, Radio, Press & digital environments.
- Click through to a dedicated campaign website with long form content, resources and downloads, plus a dedicated 1800 or 1300 line, either managed by Parkinson's Australia and our associates or outsourced, to answer queries over the phone.
- Develop a remarketing list to keep connected with users through ongoing content.

Proven Ability to Deliver

Parkinson's Australia has delivered a successful \$1.57m Information, Linkages and Capacity Building grant and extension to continue to enhance the YOP-X app.

The Young Onset Parkinson's Exchange (YOP-X) app and website is a world first information portal and resource hub supporting people with young onset Parkinson's. Developed as a living lab model, the experiences, ideas, knowledge and daily needs of people with young onset Parkinson's have underpinned all app and website content, with more than 250 individual stories and experiences shaping tools and resources. YOP-X also provides a fast track for people with young onset Parkinson's to collect and collate information relevant to their NDIS applications.

The Young Onset Parkinson's Exchange now sits within the top four Google listings for Parkinson's, and has narrowed the gap between diagnosis and access to targeted and appropriate information and support. Prior to the launch of the Young Onset Parkinson's Exchange, a new diagnosis of Parkinson's often meant sifting through websites targeting the over 65 age group, with many of these set up outside of Australia and mostly offering confronting information for later stage Parkinson's. As the Young Onset Parkinson's Exchange has compartmentalised information within pillars for access when a user is ready, YOP-X resources are sitting parallel to stages along the Parkinson's journey to provide targeted assistance, whether it be around maintaining employment, sex and relationship issues, mental health or sleep concerns.

The NDIS Wallet is the first of its kind and is the most utilised function of the YOP-X app, accessed 3861 times and assisting users to consolidate data for their NDIS applications. Aside from the NDIS Wallet, the most accessed areas of the YOP-X app offer daily activities to work through including strength and balance exercise videos accessed 3281 times, mental health tools accessed 3108 times, and sleep tools accessed 2823 times.

As you can see, for targeted investment, we are offering a comprehensive suite of healthcare solutions for, and engagement with, people impacted by the fastest growing, incurable, neurodegenerative condition in the world. Our impact will have ripple effects across the wellbeing of people living with Parkinson's and that of their loved ones; saves money and time in the healthcare system through upskilling GPs; and will bring much needed awareness around early signs of this complex and impactful condition to ensure longer quality of life of all those affected.

Thank you for taking the time to review our submission,



Olivia Nassaris

National Advocate and Changemaker (CEO), Parkinson's Australia



Parkinson's Australia Ltd
Email info@parkinsons.org.au
Phone 0407 703 328
ACN 671 516 822
ABN 46 011 714 078
parkinsons.org.au



Postal Address
PO Box 270, Browns Plains
BC, QLD 4118

Registered Office
Suite 6, 32 Thesiger Ct,
Deakin, ACT 2600

