parkinson's australia

# OUR IMPACT 2025·26

## National advocacy. Connection. Awareness.

PARKINSONS.ORG.AU

AMBASSADOR ROBYN WITH HUSBAND NOEL

OUR VISION

**To be the national voice & advocate for the Australian Parkinson's community.**

OUR PURPOSE

**To be responsive to the needs of people affected by Parkinson's through national advocacy, connection & awareness.**

# Our values

| | | |
|---|---|---|
| 01 | **Empowering** | We advocate and educate for better understanding and outcomes. |
| 02 | **Collaborative** | We work with our national and international partners to benefit the Parkinson's community. |
| 03 | **Inclusive** | We actively engage with the Parkinson's community, other neurological, health and disability organisations. |
| 04 | **Accountable** | We do what we say we will do. |
| 05 | **Empathetic** | We understand everyone's Parkinson's journey is different, and our work focuses on improving the lives of all people living with Parkinson's and their carers. |

## ACKNOWLEDGEMENT OF COUNTRY

**Parkinson's Australia acknowledges the Traditional Custodians of the lands and waters on which we work and live across Australia. We pay our respects to Elders past and present.**

Aboriginal and Torres Strait Islander people are disproportionately affected by chronic conditions and face significant barriers to diagnosis, treatment, and care, particularly in regional and remote communities. We are committed to working in genuine partnership with Aboriginal and Torres Strait Islander organisations, individuals, and communities to improve access to equitable, culturally safe Parkinson's services.

The insights of First Nations communities continue to shape our priorities, with our 2025/26 *Your Voice, Your Needs* national survey including dedicated engagement with Aboriginal and Torres Strait Islander communities.

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## WITH SUPPORT FROM


Australian Government
Department of Health, Disability and Ageing

Australian Government
Australian Digital Health Agency

A MESSAGE FROM OUR CHAIR

# Meaningful progress.

Welcome to Parkinson's Australia's Annual Report for 2025-26 - a year defined by meaningful progress, strengthened partnerships, and deepened commitment to more than 150,000 Australians living with Parkinson's.

This year we completed and reported on the Young Onset Parkinson's Exchange (YOPX), a landmark digital platform co-designed with the young onset community and funded through the Information, Linkages and Capacity Building (ILC) grant program. The YOPX platform stands as a model of what person-centred co-designed digital health infrastructure can achieve.

We also undertook our largest ever community consultation: the *Your Voice, Your Needs* national survey. The richness of these insights now underpins our service planning, policy advocacy, and funding applications for 2026 and beyond.

On behalf of the Board, I want to acknowledge the extraordinary dedication of our Parkinson's Australia team. Their tireless work, from securing new grant funding to leading national advocacy campaigns on NDIS, Support at Home, and Paraquat, reflects the deep commitment this organisation has to every person and family affected by Parkinson's.

I also extend my sincere thanks to my fellow Directors: Professor George Mellick, Professor David Blacker AM, Glen Booth, Heidi Clarris, Jen Harkness, Marcia Kimball, Sally Macdonald, and Steve Ferguson. Their counsel, expertise, and commitment have been invaluable throughout a full and rewarding year.

**Alison Perrott**

**CHAIR, PARKINSON'S AUSTRALIA LIMITED**

As we look to 2027, including our national conference in Sydney, I am proud of the platform Parkinson's Australia has built and excited by what lies ahead.

*Alison*

A MESSAGE FROM OUR CEO

# Punching above our weight.

OLIVIA AND HER YIAYIA

OLIVIA NASSARIS, CEO

*To my Yiayia (Greek for grandma) who passed with Parkinson's - being your end-of-life carer has always given me reason and purpose. I aim to make you proud.*

**Olivia Nassaris**

CEO, PARKINSON'S AUSTRALIA LIMITED

2025/26 has been one of the most active and impactful years in Parkinson's Australia's history. Across advocacy, digital health, research, and community engagement, our small but deeply committed team has punched well above our weight.

New funding from the Department of Health, Disability and Ageing under the Information, Advice and Referrals grants is allowing us to create information and support for groups that are too often forgotten. And we delivered another successful project with the Australian Digital Health Agency.

Our national survey, *Your Voice, Your Needs,* retumed 2,649 responses with a high rate of response from First Nations and culturally and linguistically diverse communities, which has produced the most comprehensive picture of the Parkinson's care experience in Australia to date. The findings are stark: Australians with Parkinson's experience fragmented care, workforce knowledge gaps, system navigation challenges, and geographic inequity. These insights now drive everything we do.

On the advocacy front, we continue to fight for people with Parkinson's within the NDIS legislative review. We are leading Aged Care reform advocacy through our Needs Not a Number campaign. And we are calling to Ban Paraquat, an agricultural herbicide linked to an increased risk of Parkinson's, which is banned in more than 70 countries.

We are also preparing for PANC27, the Parkinson's Australia National Conference, to be held in Sydney in May 2027. With an extraordinary lineup of international and Australian speakers already confirmed and the support of generous sponsors, PANC27 promises to be a landmark event for the Parkinson's community.

None of this work is possible without the people at the heart of it: the people living with Parkinson's, their families, and our dedicated staff, board, and partners.

Thank you.

*Olivia*

# National advocacy.

**We work tirelessly to amplify the voices of the Parkinson's community and advocate for improved support and recognition.**

AMBASSADOR DAMIEN LEITH LIVE ON AIR FOR WORLD PARKINSON'S DAY

**8**
SUBMISSIONS LED OR SUPPORTED

**559**
MEDIA MENTIONS IN 2025/26

**20,300+**
SIGNATURES ON OUR PARAQUAT PETITION

THE NATIONAL PEAK BODY

# Advocacy is central to our mission.

Parkinson's Australia is the national peak body for Parkinson's in Australia. We work to improve the lives of all Australians affected by Parkinson's, including people living with the condition, their families, carers, and the health professionals who form part of their care teams.

## 150,000 and expected to triple by 2050

The incidence of Parkinson's is expected to triple by 2050, placing immense pressure on the Australian health system and economy.

In August 2025 Parkinson's Australia organised with Senator Marielle Smith (ALP) to form the Parliamentary Friends of Parkinson's group for the newly elected parliament, with co-convenors Senator Wendy Askew (Liberal Party) and, for the first time, a third co-convenor, Senator David Pocock (Independent).

Through the Parliamentary Friends group and direct lobbying, we work to highlight to all sides of government that there are many contributing factors to prevalence, including an ageing population and environmental factors such as the use of Paraquat in agriculture. We are committed to strengthening the evidence base, in Australia and globally, that provides the foundation for understanding the causes and risk factors for developing Parkinson's.

CO-CONVENOR SENATOR DAVID POCOCK WITH OUR CHAIR, ALISON PERROTT

CEO OLIVIA NASSARIS WITH MINISTER FOR HEALTH, DISABILITY AND AGEING, MARK BUTLER

WITH SENATOR MARIELLE SMITH, CO-CONVENOR

WITH DR MIKE FREELANDER MP

## EVERY DONATION HELPS

Every donation helps us deliver trusted information, raise national awareness and advocate on behalf of the Parkinson's community. The generosity of new and repeat donors allows Parkinson's Australia to expand its reach and impact and supports our work to influence policy, improve services and drive change across health, disability and aged care systems.

# Standing up in a changing NDIS.

The NDIS Amendment (Getting the NDIS Back on Track) Bill 2024 moved through Federal Parliament in 2025/26, bringing significant changes to how the scheme assesses eligibility, determines reasonable and necessary supports, and interfaces with mainstream services including aged care.

Parkinson's Australia made multiple submissions to Parliament on behalf of the Parkinson's community, ensuring the experiences and needs of people living with Parkinson's were represented throughout the reform process.

Through its work with the Neurological Alliance Australia, we also wrote a sector-wide advocacy submission for reforms that recognise the needs of people living with progressive neurological conditions.

## Five things we called for:

**01**

Recognition of the fluctuating nature and impact of on/offs in the Support Needs Assessment, which will only assess the person in that moment in time, not across the day.

**02**

Maintain the Early Intervention pathway for people with young onset Parkinson's, allied health is evidenced to improve symptoms and slow the trajectory of the condition.

**03**

A functional capacity definition that captures the fluctuating nature of symptoms. Parkinson's

**04**

Remove the need for participants to have explored all possible treatments.

**05**

Reduced administrative burden on people with Parkinson's navigating the NDIS to conduct a change of circumstance when their needs inevitably change and functional capacity degenerates.

# A seat at the table... NDIA advisory group.

The Neurodegenerative, Palliative Care and Rare Diseases Advisory Group (NPRAG) was established in May 2024 to provide strategic advice to the National Disability Insurance Agency (NDIA) on issues related to participants with neurodegenerative, rare conditions, or those requiring palliative care.

The group's focus includes support needs assessments, part of the new way of planning for NDIS participants, and aims to ensure the process works for these cohorts and does not cause short-term or long-term disadvantage.

Our CEO is NPRAG co-chair, with a membership designed to reflect the diversity of the neurodegenerative disorder, palliative care and rare conditions communities.

## NPRAG MEMBERSHIP

**Parkinson's Australia**
**Neurological Alliance Australia**
**Mito Foundation**
**Emerge Australia**
**MS Australia**
**Young People in Nursing Homes Alliance**
**Rare Voices Australia**
**Palliative Care Australia**
**Huntington's Australia**
**Dementia Australia**
**Childhood Dementia Initiative**

## ADVOCACY WIN

*"Parkinson's Australia has provided invaluable advocacy and support as I navigated the complexities of the Administrative Review Tribunal. They gave practical advice and represented me during times when I was unable to advocate for myself or my loved one, Jinetta (pictured). I would not have been able to manage this difficult process without their compassion, guidance and ongoing support."*

SARA, whose change of circumstance was rejected and whose case was successfully challenged in the ART.

SUPPORT AT HOME · MY AGED CARE

# Over 65s Support at Home advocacy.

The new Aged Care Act came into effect in 2025, absorbing Home Care Packages into the new Support at Home program. While the reforms promise greater person-centred care, we identified serious concerns about implementation - particularly for people with progressive neurological conditions.

Our campaign calls on the Government to ensure that:

- Parkinson's-specific needs are recognised in Support at Home assessments.
- The assessment tool is fit for purpose and able to triage frailty, ageing and chronic conditions with human oversight, not purely a computer-generated algorithm.
- People with Parkinson's are not disadvantaged by fixed budget caps that cannot accommodate inevitable disease progression.
- The 88,000+ Australians assessed as eligible for a level of care actually have a package and services available to them.
- Transition from Community Home Support Packages to Support at Home is managed safely for existing recipients.

We wrote a detailed submission of the Support at Home rollout to the Department of Health, Disability and Ageing, highlighting the risk of service failures for people with complex neurological needs.

ADVOCACY WIN

## 135 days waiting...

*We shone a spotlight on Wayne's 135-day wait for a level 8 package, in the media and directly to the Health Minister's office. He received his package soon after.*

CAMPAIGN

# #Ban Paraquat

Paraquat is a widely used agricultural herbicide with strong scientific links to a higher risk of developing Parkinson's disease. It is already banned in more than 70 countries. In 2024, the Australian Pesticides and Veterinary Medicines Authority (APVMA) opened a consultation to review its usage. Parkinson's Australia wrote a submission to support a ban.

In the lead-up to the APVMA decision in late June 2026, our advocacy work intensified. We provided community voices to the review process, supported individuals to make submissions, and worked with world leading experts to coordinate a sector-wide response.

When the APVMA announced stronger restrictions and controls on the use of paraquat but failed to ban the chemical, our immediate response achieved more than 300 media appearances nationally over three days.

Parkinson's Australia has submitted a review of the decision with the Administrative Review Tribunal.

SUNRISE - OUR CEO AND SENATOR DAVID POCOCK ON WHY AUSTRALIA HASN'T BANNED PARAQUAT

ABC REGIONAL INVESTIGATIONS - ONE OF MORE THAN **331 MEDIA APPEARANCES IN THREE DAYS**

**331**
**MEDIA APPEARANCES**
**IN 3 DAYS**

| 194 | 50 | 44 | 36 | 7 |
|---|---|---|---|---|
| ONLINE | AM RADIO | TELEVISION | FM RADIO | NEWSPAPERS |

**20,300+** signatures on our Change.org petition and still growing.

SUBMISSIONS IN 2025/26

# Where change actually begins.

Most people see advocacy as media interviews, campaigns, petitions, or meetings with politicians. What they don't see is the hundreds of hours spent reading legislation, analysing policy, writing submissions, reviewing consultation papers, gathering evidence, consulting with the community, and drafting recommendations. That work is often where real change begins.

For Parkinson's Australia, submissions are one of the most important tools we have to influence decisions before they become law or policy.

When governments propose changes to the NDIS, aged care, Medicare, the PBS, environmental regulations, or healthcare funding, they ask organisations to provide feedback. If nobody explains how those changes will affect people living with Parkinson's, those impacts can be overlooked.

| | | |
|---|---|---|
| 01 | Submission to the National Disability Insurance Scheme Amendment (Securing the NDIS for Future Generations) Bill 2026 | NDIS |
| 02 | Supplementary submission to the NDIS (Securing the NDIS for Future Generations) Bill 2026 | NDIS |
| 03 | NAA & NPRAG submission to the NDIS Amendment (Securing the NDIS for Future Generations) Bill 2026 | NDIS |
| 04 | NDIS Rules: public consultation on the new framework planning submission | NDIS |
| 05 | Submission to the NDIS EAC review on EPs and smart home appliances | NDIS |
| 06 | RACGP Open Letter to Australia's Parliamentarians on Supporting People Living with Chronic Diseases 2026 | RACGP |
| 07 | AFDO submission endorsed by Parkinson's Australia: proposed new Commonwealth individual disability advocacy program- Disability Advocacy and Inclusion Reforms, Department of Health, Disability and Ageing | AFDO |
| 08 | Australian Society for Medical Research letter to the Minister to release MRFF funds 2026 | ASMR |

## RACGP OPEN LETTER PARLIAMENT HOUSE

**Longer consultations for people living with chronic conditions**

*With the RACGP President, backing the call for longer GP consultations - the difference between a rushed appointment and genuine Parkinson's care.*

ADVOCACY WIN

# VYALEV® is now on the PBS for advanced Parkinson's.

From 1 August 2025, Australians living with advanced Parkinson's have access to VYALEV®, a 24-hour levodopa-based infusion delivered subcutaneously via a wearable pump.

It is a major step forward for people experiencing severe motor fluctuations, and we are proud to have advocated for it. Throughout the process, consumer voices were vital in helping decision-makers understand the real impact of living with Parkinson's.

> *"We are delighted the Australian Government has made this treatment affordable and available for the* Parkinson's community."
>
> OLIVIA NASSARIS, CEO

As part of the same advocacy, we submitted to the Medical Services Advisory Committee supporting fluorodopa PET scans in cases of diagnostic doubt, and backed the public listing of MRI-guided focused ultrasound for Essential Tremor. We will continue to advocate for treatments and diagnostics to be available for our community.

PAULA BEFORE VYALEV®

PAULA AFTER VYALEV®

*"After being housebound for five years I've regained my mobility and independence. I hope this listing gives other Australians the same chance to regain quality of life."*

PAULA - LIVING WITH YOUNG ONSET FOR OVER 30 YEARS, VYALEV® TRIAL PARTICIPANT

*"Oral medications have begun to lose their efficacy for me. This new treatment will mean I can be a better dad, a better husband, and stay in the workforce longer."*

CRAIG - LIVING WITH YOUNG ONSET PARKINSON'S

## WHY THIS MATTERS

*Someone in Australia is diagnosed every 27 minutes. Parkinson's is the fastest-growing neurological condition in the world and it does not only affect older people.*

**20%**
DIAGNOSED UNDER 50

**20%**
OF WORKING AGE

A NEW PATIENT-ADVOCACY ORGANISATION

# Essential Tremor Australia

More than 300,000 Australians are living with Essential Tremor (ET). Essential Tremor Australia was launched in 2025 to provide information, advocacy and support for people living with the condition. Until its establishment there was no Australian patient advocacy organisation, despite ET being the most common movement disorder in the world.

Nichole, also known as 'Shaky Nan' as named by her granddaughter, has documented her life as an 'ET-er' online for five years and was key in the creation of the ET Lived Experience Advisory Group. Essential Tremor Australia launched on Nichole's 54th birthday and has built a community from zero, with a social media presence, newsletter and an advisory group established to advocate, connect and grow awareness.

> **"...the organisation was needed so that others with ET, especially children, can learn to live well with the condition and not go through the bullying and stigma I've experienced throughout my life."**
>
> NICHOLE, ET LIVED EXPERIENCE ADVISORY GROUP

CELEBRATING THE LAUNCH OUTSIDE PARLIAMENT HOUSE, CANBERRA WITH ET AMBASSADOR, NICHOLE

WITH THE MINISTER FOR HEALTH, DISABILITY AND AGEING, MARK BUTLER

## OUR ADVISORY GROUP

**OUR ET ADVISORY GROUP REPRESENTS A WIDE RANGE OF AGES AND EXPERIENCES FROM ACROSS AUSTRALIA. THEY HAD THE MAMMOTH TASK OF REVIEWING THE WEBSITE CONTENT BEFORE THE LAUNCH.**

## OUR IMPACT - FROM ZERO AT OCTOBER 2025 LAUNCH

| | | |
|---|---|---|
| FACEBOOK | **122k** | views 2.9k interactions |
| INSTAGRAM | **17.3k** | views 542 interactions |
| LINKEDIN | **3.65k** | impressions 173 reactions |
| EMAIL | **750** | subscribers 4 newsletters |
| WEBSITE | **9.7k** | visits 1.7k to “I have ET” |
| ADVISORY GROUP | **7** | meetings |

### A GLIMPSE INTO THE FUTURE

On 24 October 2026 in Sydney, the Essential Tremor Australia Inaugural Annual Conference will mark a historic milestone: the first time Australians living with ET come together as a community, a dedicated space where people with ET, their carers, and healthcare professionals can connect, learn, and be heard.

# Connection.

**We bring together people living with Parkinson's, families and healthcare professionals to ensure best practice care, support and independence.**

**12**
NATIONAL ROUNDTABLES

**515**
ROUNDTABLE PARTICIPANTS

**2,649**
VOICES IN YOUR VOICE, YOUR NEEDS SURVEY

OUR COMMUNITY · VIRTUAL

# National Roundtables.

**12**
ROUNDTABLES HELD ACROSS 2025/26

**515**
TOTAL PARTICIPANTS

Held monthly, online, our National Roundtables are a space for open conversation where we listen to lived experiences, share advocacy updates, and explore how to better support the Parkinson's community. Being online removes the distance barrier for regional, rural and remote Australia.

OUR COMMUNITY · FACE-TO-FACE

# Bringing the community into one room.

The key to connection is our national face-to-face conference, held every two years. After a 10-year hiatus, PANC25 brought together people living with Parkinson's, carers, researchers, specialists and allied health professionals with local and international experts in Canberra.

PANC27 runs 16-18 May 2027 at the International Convention Centre in Sydney and is set to be even bigger. The theme Now + Future focuses on evidence-based practice and technology in treatment and care.

EQUITY & ACCESS — PANC PRICING

**$1,200**
TRUE COST PER DELEGATE

→

**$220**
TICKET FOR A PERSON WITH PARKINSON'S OR A CARER

We subsidise registration so people with Parkinson's and carers can access high-quality education and connection.

THE "YELLOW SHIRTS" - VOLUNTEERS WHO MADE DELEGATES FEEL WELCOME AT PANC25

# Co-design is not a method. It's how we work.

Every one of our Lived Experience Advisory Groups practises co-design, co-creation and co-delivery embedded in every project and activity we undertake. Perspectives from people living with Parkinson's, carers and health professionals shape our advocacy and our responses.

**Young Onset Parkinson's eXchange**

YOPX LIVED EXPERIENCE ADVISORY GROUP

**Parkinson's Disease Education eXchange**

PDEX ADVISORY GROUP

**Intersecting Voices**

PROJECT ADVISORY GROUPS: RRR, WOMEN, FIRST NATIONS, LGBTQIA, CALD

**Conference Committee PANC27**

CONFERENCE ADVISORY GROUP

**Essential Tremor Australia**

ET LIVED EXPERIENCE ADVISORY GROUP

YOPX LIVED EXPERIENCE ADVISORY GROUP

# Your connection to the source of truth.

**Our Information Hub holds the most up-to-date information on Parkinson's in Australia.**

Everything we produce is reviewed by researchers, clinicians, subject matter experts and peak bodies, then co-branded to underline our experience, expertise, authoritativeness and trustworthiness.

We pride ourselves on co-writing and producing information with experts in the relevant fields, the reason the community trusts it.

## BEHIND THE INFORMATION HUB

### Tina Gillespie

CONTENT STRATEGIST & LIVED EXPERIENCE ADVOCATE

Tina shapes what the Hub says and how it says it, co-writing every title with clinicians and subject matter experts, then testing the language against her own lived experience of Parkinson's. That dual role is why the Hub reads as practical rather than clinical.

THE LIVE WELL WITH PARKINSON'S SERIES, CO-PRODUCED WITH SUBJECT MATTER EXPERTS

## Live Well with Parkinson's. An ever-expanding series:

- Live Well with Parkinson's
- Palliative Care and Parkinson's
- Occupational Therapy for Parkinson's

Occupational Therapy Australia

Palliative Care Australia
Matters of life and death

PRODUCTIVE & MUTUALLY BENEFICIAL PARTNERSHIPS

# We don't do any of this alone.

We collaborate with key organisations, health professionals and policymakers to increase understanding of the impacts of Parkinson's - co-producing articles and infosheets, co-writing and endorsing submissions and campaigns, and supporting research applications and trials to ensure best-practice care. Thank you to everyone who took the time to co-produce advice, information, campaigns and submissions with us.

## GOVERNMENT AGENCIES

Department of Health, Disability and Ageing. Australian Digital Health Agency. NDIA's Neurodegenerative, Palliative Care and Rare Diseases Advisory Group (NPRAG). Healthdirect Australia (information partner Essential Tremor Australia & Parkinson's Australia).

## UNIVERSITIES

Flinders University Griffith University. La Trobe University. RMIT University. Swinburne University of Technology. The University of Melbourne. The University of Newcastle. The University of Queensland. University of Tasmania. UNSW Sydney.

## ORGANISATIONS & COLLABORATORS

Accessible Product Design Alliance
Advance Care Planning Australia
Assistive for All
Australasian Neuroscience Nurses Association
Australia New Zealand Academy of Special Needs Dentistry
Australia New Zealand Falls Prevention Society
Australian Association of Social Workers
Australian Federation of Disability Organisations
Australian General Practice Accreditation
Australian Healthcare and Hospitals Association
Australian Parkinson's Genetic Study
Australian Patient Advocacy Alliance
BD PureWick
BlakAbility
Carers Australia
Centre for Culture, Equity and Health
CFEP Surveys
Chakra Foundation Australia
CI-ISAC Australia
CMAX Clinical Research
Consumers Health Forum of Australia
Continence Health Australia
Dietitians Australia volunteer APD, Amy Neill (Parkinson Diet)
Exercise & Sports Science Australia
Garvan Institute of Medical Research - Australian Parkinson's Mission
Global Alliance to End Parkinson's Disease
Go Gentle Australia
Griefline
International Hyperhidrosis Society
Invisible Disabilities Australia
LGBTIQ+ Health Australia
Medicines Australia
MND Australia
Movement Disorders Society of Australia and New Zealand - Clinical Trials Network
My Moves Matter
National Rural Health Alliance
Neuroscience Research Australia
Neurological Alliance Australia
Occupational Therapy Australia
Palliative Care Australia
Parkinson's Europe
Parkinson's Foundation (USA)
Parkinson's New Zealand
Parkinson's WA
Patient Voice Initiative
PD Avengers
Pharmacy Guild Australia
Serina Therapies
Shake It Up Australia Foundation
Sleep Health Foundation Australia
Speech Pathology Australia
SwalTech
Symbyx Biome
Tasmanian Parkinson's Project
The Royal Australian College of General Practitioners
Urological Society of Australia and New Zealand
Wicking Dementia Centre
World Parkinson's Coalition

**Thank you**

To every collaborator named on this page, the government agencies, universities, peak bodies, dietitians, researchers and community organisations who gave their time and expertise this year. Your co-produced advice, information, campaigns and submissions make our work possible, and make it better.

PDEX
Parkinson's Disease Education Exchange

+

Australian Government
Department of Health, Disability and Ageing

# A national care model starts here.

Funded by the Department of Health, Disability and Ageing, Parkinson's Disease Education Exchange has provided the starting point for a national Parkinson's care model. We continue to work with neurologists, GPs and Australian health professional peak bodies to guide planning and care coordination, such as assembling a care team.

With our research partners we are approaching workforce challenges in regional, rural and remote areas in innovative ways, moving outside conventional assessment with remote, objective measurement and diagnostic tools.

The *Your Voice, Your Needs* national survey, the most comprehensive picture of Parkinson's care experiences in Australia, sits within this program of work, and its findings now direct where the care model goes next.

## WHAT PDEX BRINGS TOGETHER

- → Neurologists, GPs and allied health peak bodies guiding a shared model of care.
- → Care-team planning and coordination tools for people newly diagnosed.
- → Remote, objective measurement and diagnostic tools for regional, rural and remote Australia.
- → The Your Voice, Your Needs evidence base with 2,649 responses shaping the priorities.

**2,649**
SURVEY RESPONSES

**264**
PAM™ RESPONSES

**All 8**
STATES & TERRITORIES REPRESENTED

**1,000+**
VOLUNTEERED FOR ONE-ON-ONES AND FOCUS GROUPS

**More than a thousand people offered to tell us more about their needs in person.**

We are speaking to every single one. Each conversation, one-on-one interviews and focus groups through 2026, deepens the survey evidence and directs where the national care model goes next.

# The findings are stark.

The survey explored access to healthcare, experiences with GPs and specialists, the challenges of living with Parkinson's, and support and information needs. The findings provide an evidence base for service planning, policy development and targeted education.

## Where people turn for information

**67.7%** Internet search

**59.5%** Specialists

**50.8%** Parkinson's Australia or state

**27.7%** Only 27.7% turn to their GP...a telling gap

Younger respondents rely heavily on digital and social channels, while older respondents rely more on specialists and printed materials.

**264** PATIENT ACTIVATION MEASURE (PAM™) RESPONSES

### WHAT IS PATIENT ACTIVATION?

Hibbard and others (2005), define the Patient Activation Measure as, "an individual's knowledge, skill, and confidence for self-management." The more activated a person is, the more empowered and engaged they are in their health care and wellbeing.

It is a behavioural concept: a positive change in activation leads to positive change in a variety of self-care behaviours, improving health outcomes and reducing costs across the healthcare system.

Parkinson's Australia is aiming to measure 250 PAMs across each year to test the impact of our education.

HIBBARD, J.H., MAHONEY, E.R., STOCKARD, J. AND TUSLER, M. (2005), DEVELOPMENT AND TESTING OF A SHORT FORM OF THE PATIENT ACTIVATION MEASURE.

### GEOGRAPHIC INEQUITY

People in regional and remote areas consistently report greater unmet need, particularly for local specialist services, healthcare professional training, and improved technology access. The findings reinforce the importance of digital-first service delivery and targeted outreach to the regions.

### PRIORITY POPULATIONS

Aboriginal and Torres Strait Islander and Culturally and Linguistically Diverse (CALD) respondents reported higher needs across most categories, including mental health support and service navigation. These insights will directly inform the focus group and interview phase of the Improving Health Outcomes project, which will prioritise First Nations peoples, CALD communities, and regional and remote Australians.

National Community Survey

# YOUR VOICE, YOUR NEEDS

## PARKINSON'S CARE IN AUSTRALIA

Key insights from the National Survey

2,649 respondents | People living with Parkinson's, carers and families

PDEX
Parkinson's Disease Education Exchange

### OVERALL KEY INSIGHT

**Parkinson's care is valued — but access, coordination and support remain inconsistent.**

### CHALLENGES PEOPLE FACE

- 57.3% Mental health / emotional wellbeing
- 29.1% Access to services
- 28.7% Cost of care
- 28.1% Social isolation
- 25–26% Daily living, relationships & understanding

→ Challenges extend beyond clinical care

### ACCESS & TIMELINESS OF CARE

55 / 100
Access is moderately difficult

36.6%
experience delays

Delays are higher for:

- Under 30 — 41.2%
- Remote areas — 40.2%
- Priority populations — up to 38.2%

→ Access is harder for younger people and outside metropolitan areas

### SUPPORT NEEDS & SERVICE GAPS

- 72.9% Understanding symptoms
- 68.8% Medication & treatment
- 59.9% Daily living support
- 49.2% Mental health support
- 47.0% Help navigating services

→ Support needs extend beyond clinical care

### GP KNOWLEDGE & INFORMATION

76.1%
say GPs need more Parkinson's training

58 / 100
confidence in GP understanding

69.2%
confidence in information accuracy

→ GP capability is a key driver of care quality

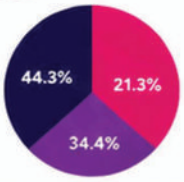
### NAVIGATION & INFORMATION

- 67.7% Internet
- 59.5% Specialists
- 50.8% Organisations

47.0%
still need help navigating services

→ Information exists — but navigation remains difficult

### CULTURAL SAFETY & ACCESSIBILITY




- 44.3% Services are culturally safe
- 34.4% Unsure
- 21.3% Services are not culturally safe

→ Cultural safety is not consistently embedded

### DIFFERENCES ACROSS GROUPS

**GENDER**

Mental health: Women 51.5% | Men 41.4%
Carer burden: Women 44.5% | Men 31.1%
Financial stress: Women 38.2% | Men 20.7%

→ Women experience higher cumulative burden

**AGE (PARKINSON'S JOURNEY)**

- Younger (<30): Highest mental health & navigation needs
- 45–64: High needs across multiple domains
- 65+: Greater reliance on daily living support

→ Needs shift from complexity to daily support over time

**PRIORITY POPULATIONS**

- Lower confidence in GP understanding
- Higher mental health needs (59.5%)
- Higher financial needs (47.6%)

→ Nigher support needs and lower confidence in care

**REGIONAL & REMOTE**

- Lower GP confidence
- Reduced access to services
- Higher navigation burden

→ Access challenges increase outside metropolitan areas

### WHAT NEEDS TO CHANGE

- Strengthen GP capability
- Improve care coordination
- Expand mental health & carer support
- Deliver stage-specific support
- Improve regional access
- Embed culturally safe care

**Without better coordination and support, patients and carers will continue to carry the burden of navigating a complex system.**

## INFORMATION, LINKAGES AND CAPACITY BUILDING GRANT

young onset parkinson's exchange

Australian Government
Department of Health, Disability and Ageing

### A national digital hub co-designed with people diagnosed under 65.

The final report for the Young Onset Parkinson's Exchange (YOPX) ILC grant was lodged in March 2026, marking the completion of a landmark project that has transformed how younger Australians with Parkinson's access information and support.

The YOPX website and app were co-designed with people living with young onset Parkinson's and delivered as a national, digital information and support hub tailored to people diagnosed under 65. Addressing the specific life-stage challenges their older counterparts do not face, including employment disruption, parenting and relationship changes, financial stress, and NDIS navigation.

The YOPX website and app were successfully developed and delivered. The platform provides curated, evidence-informed content, lived-experience insights, and step-by-step guidance. It also functions as a workforce education tool, improving understanding of young onset Parkinson's among NDIS staff and allied health professionals.

By co-designing content with the community and embedding real-world tools, the project met its objectives of improving access to relevant information, reducing isolation, and strengthening capacity for participation in work, family, and community life.

### WHAT MADE IT WORK

The co-design approach was the project's defining strength. Grounding content in lived experience ensured the platform is relevant, practical, and trusted by the young onset community. The integration with the YOPX app strengthened usability and positioned both tools as consumer and workforce resources.

The NDIS-focused content proved particularly valuable, with clear, structured guidance responding to a well-documented gap in the system. The breadth of resources spanning employment, relationships, mental health, and symptom management reflects a whole-of-life rather than purely medical approach.

### LOOKING AHEAD

Changes to the NDIS legislation and their trickle down to policy and practice will mean the app requires information updates covering access and eligibility, the process from applying, what makes an effective plan, and how to use it.

# Key themes addressed by YOPX.

- Early diagnosis and navigating a health system not designed for younger people
- Parenting while living with Parkinson's, and caring for ageing parents simultaneously
- NDIS access. Understanding eligibility, documenting functional impact, and communicating needs
- Employment security, workplace allowances for disability, financial stress, and career disruption
- Relationship issues, including the impact of diagnosis, sex and intimacy
- Geographic inequity. The digital platform was deliberately designed for national reach and connecting the RRR community

## Social media, website, app and resources

| Facebook @YOPXAUSTRALIA | Instagram @YOPXAUSTRALIA | Resources PUBLISHED THIS YEAR |
|---|---|---|
| **593k** views | **106.3k** views | **133** YOPX articles |
| **1.1k** interactions | **577** interactions | **25** noticeboard posts |
| **432** followers | **304** followers | **25** videos in the YouTube playlist |
| **YOPX App** | **YOPX Website** | **23,645** YOPX video views |
| **13,000+** app users | **35,000** website users | |
| **7,327** Australian app users | | |

parkinson's australia + Australian Government Australian Digital Health Agency

PARTNERSHIP · YEAR TWO

# Digital health, peer to peer.

Parkinson's Australia and the Australian Digital Health Agency have collaborated on a program of work aimed at increasing the uptake and effective use of the Agency's digital health technologies among people living with Parkinson's and their carers. The partnership has been grounded in a commitment to understanding the real barriers to access, as well as addressing them through resources and initiatives designed with lived experience at the centre.

Underpinning this work has been a sustained focus on awareness: developing targeted, relevant information and building capability across the Parkinson's community at a national level, ensuring that key digital health tools reach the people who need them most.

Building on those foundations, year two focused on further community engagement, with a focus on peer-led education. People with lived experience of Parkinson's were trained and supported to facilitate peer-to-peer learning sessions within their communities, improving awareness and adoption of digital health tools.

**Parkinson's Australia is excited to continue this partnership with the Australian Digital Health Agency in 2026/27.**

## WHAT MADE IT WORK

The involvement of lived experience presenters (digital champions) proved a genuine strength, their personal stories built trust and resonated with participants in ways conventional health resources cannot.

A particular highlight was **David Varidel**, whose natural ability as a presenter and his authentic belief in the tools made him an outstanding contributor to the Parkinson's videos and digital health sessions.

DAVID VARIDEL DEMONSTRATING THE 1800MEDICARE APP

# Awareness.

**Accurate information reduces stigma.
So do relatable stories from people living
with Parkinson's and the people who love them.**

**559**
MEDIA MENTIONS

**1M**
FACEBOOK VIEWS

**380k**
YOUTUBE VIEWS

**10,269**
EMAIL SUBSCRIBERS

# A year of being heard.

**559**
TOTAL MEDIA MENTIONS IN 2025/26

## Where the coverage landed

| | |
|---|---|
| ONLINE | 291 |
| TELEVISION | 28 |
| AM RADIO | 28 |
| FM RADIO | 28 |
| NEWSPAPER | 28 |
| MAGAZINE | 1 |

### SUBMISSIONS BY PARTNER

**8** submissions led or supported across the year, five of them on the NDIS alone.

| 5 | 1 | 1 | 1 |
|---|---|---|---|
| NDIS | RACGP | AFDO | ASMR |

**Community members like Sandi, pictured on A Current Affair, put a human face to the numbers. Sharing their story on national television reaches audiences no media release can.**

## Our channels, by the numbers

FACEBOOK
**1M views**
9.3k interactions
6,483 followers

INSTAGRAM
**111k views**
3.6k interactions
414 followers

LINKEDIN
**54,680**
1,232 reactions
1,999 followers

EMAIL
**10,269**
subscribers
17 newsletters

WEBSITE
**1.1M views**
168k users
information hub

ROUNDTABLES
**12**
roundtables
515 participants

CAMPAIGN • SEVEN WEEKS • MULTICHANNEL

# Fighting stigma: I Am More Than My Parkinson's.

The campaign ran for seven weeks across the end of the financial year - a focused initiative designed to raise the national profile of Parkinson's, foster deeper community understanding, and meaningfully reduce the stigma that so often shadows a diagnosis.

At its heart was Robyn Higgins, 71, living a full, active life eleven years on from her diagnosis. Her voice threaded authentically through every touchpoint, challenging the entrenched image of Parkinson's as an "old person's condition" defined by decline. Today she still travels, goes to the gym, performs a three-minute dead hang, and laughs with her husband and friends.

A series of emails reached our database of more than 10,000 subscribers, each building on Robyn's journey, from the shock of diagnosis to the discovery of community, specialists and allied health support. Social posts across YouTube, Instagram and Facebook extended that reach with shareable, stigma-challenging content.

The campaign reinforced our top ten tips for living well with Parkinson's and our belief that exercise is crucial to early intervention and wellbeing. It also demonstrated our commitment to reducing stigma associated with a diagnosis.

> **"Parkinson's felt like a word that meant the end of the life I knew."**
>
> Robyn reframed that narrative entirely... evidence that with the right support and a positive attitude you can live well with Parkinson's.

**These didn't just help me manage Parkinson's, they helped me stay "me."**

*ROBYN HIGGINS, CAMPAIGN AMBASSADOR*

**ROBYN HIGGINS - 11 YEARS ON FROM DIAGNOSIS & STILL HOLDING A 3-MIN DEAD HANG**

# Free, trusted & always on.

Our YouTube channel now hosts more than 125 videos and has grown to almost 1,900 subscribers. Educational content remains the most valued, with several videos attracting more than 10,000 views. The channel provides free access to evidence-based information, conference presentations, advocacy updates, podcasts and lived experience stories, extending our reach well beyond face-to-face events and supporting equitable access to trusted information across Australia and the globe.

**125+**
VIDEOS PUBLISHED

**1,900**
SUBSCRIBERS

**380k**
YOUTUBE VIEWS THIS FINANCIAL YEAR

## Most viewed this year

| | |
|---|---|
| What Successful People with Parkinson's Do to Maximise Wellbeing \| Dr Laurie Mischley (PANC25) | **16,000** |
| Parkinson's & the bladder \| Dr Ashani Couchman, Neuro-urologist | **11,000** |
| Constipation & Parkinson's \| Sue Williams, Movement Disorder CNC | **6,300** |
| Parkinson's eXchange Podcast EP2 \| Gaia Forlani | **6,200** |

**PARKINSON'S EXCHANGE PODCAST**

### Real conversations. Real community.

The podcast brings together Australians living with Parkinson's, care partners and experts to share honest experiences and perspectives. Each episode explores how Parkinson's looks different for everyone, and why lived experience is essential to better information, support and connection. Hosted by our Ambassador Damien Leith and CEO Olivia Nassaris.

**FILMING THE PARKINSON'S EXCHANGE PODCAST WITH GUESTS ANN & REX**

# Stories do the heavy lifting.

We have engaged high-profile ambassadors including former Australian cricket captain Allan Border, who is living with Parkinson's, and singer-songwriter Damien Leith, whose father had Parkinson's. Our lived experience ambassadors are out in the media too, sharing personal stories that shed light on Parkinson's.

### BARMY ARMY VS MOSMAN CRICKET CLUB

## $20,000

In January 2026, Mosman Cricket Club and the Barmy Army met at the Allan Border Oval for a Charity T20 showdown. Allan Border did the coin toss on the ground that bears his name, a deeply personal dimension to a day that raised almost $20,000 for Parkinson's research. Both organisations now have their sights on making it a permanent fixture, with the next Ashes series as the perfect backdrop.

**THE BARMY ARMY AND MOSMAN CRICKET CLUB PRESENT THE PROCEEDS TO PARKINSON'S AUSTRALIA AMBASSADOR ALLAN BORDER AT THE ALLAN BORDER OVAL**

### JOIN OUR LIFEBLOOD TEAM

We're inviting you to donate blood with us as part of the Parkinson's Australia team. Ask your family and friends to join!

**8.3M**

**AUSTRALIANS WILL NEED BLOOD IN THEIR LIFETIME**

**48,000**

**HOSPITALISATIONS OF PEOPLE WITH PARKINSON'S IN 2019-20**

### WHY IT MATTERS

Over 8.3 million Australians will need blood in their lifetime. While Parkinson's itself doesn't typically require regular blood transfusions, many people living with Parkinson's are older and often face hospitalisations for related conditions: infections, surgeries, or falls that may require blood products.

**DAMIEN LEITH, PARKINSON'S AUSTRALIA AMBASSADOR, GIVING BLOOD AS PART OF THE PARKINSON'S AUSTRALIA LIFEBLOOD TEAM**

# Community fundraising.

Supporters raised funds through Facebook birthday fundraisers, workplace initiatives, endurance challenges, bake sales, morning teas and community events of every size. Every dollar came from someone who decided that Parkinson's mattered enough to act.

### Kim

Duo Rottnest Channel Swim in honour of her Dad

### Vicky & SureDeploy

City2Surf for team Parkinson's

### Justin

3,000km Tour Aotearoa ride, in support of friends living with Parkinson's

### Many more

Facebook birthday fundraisers, bake sales, morning teas and self-led challenges

## Jack's Backyard Ultra for Parkinson's

**$10,470**

"I am attempting to run 160km in 24 hours for my mum, who was diagnosed with Parkinson's disease six years ago. This incurable disease impacts my mum's daily life, a life she so richly deserves to live to the fullest. I am raising money towards a cure for this horrible disease."

## Meg's Parkinson's Fundraiser

**$1,440**

"I'm shaving my head and fundraising for Parkinson's Australia. This is for Pa, the best sort of grandad you can have. This is also for Ga, the loving care that she gave him. Please donate or share to help Parkinson's Australia continue to educate and support all those affected."

## Running Mt Kosciuszko for Dad

**$2,900**

"Dad was a passionate trail runner, and | want to honour him by racing the Kosci 50, a 50km ultra up and through Mt Kosciuszko. To think how inspirational Dad was living with Parkinson's, running an ultra during that time is simply incredible. There's nothing going to stop me."

# Governed with care.

Parkinson's Australia Limited is a company limited by guarantee, incorporated under the Corporations Act 2001 and the Australian Charities and Not-for-profits Commission Act 2012. The Board of Directors holds ultimate responsibility for governance and meets four times per year, twice online and twice face-to-face.

## Three standing committees

### ARF

**Audit, Risk and Finance**

Chaired by Glen Booth. Meets four times per year to review financial reports, budgets, risk registers and audit arrangements.

### NRG

**Nominations, Remuneration and Governance**

Chaired by Alison Perrott. Oversees CEO and Board appointments, performance, remuneration and governance policy.

### SHIPS

**Sponsorships, Partnerships and Industry Stakeholders**

Chaired by Sally Macdonald. Manages strategic partnership and sponsorship relationships.

# A skills-based board with lived experience

Our Directors are appointed for the skills the organisation needs including governance, clinical and research expertise, finance, law, communications and health policy. Almost every member also brings lived experience of Parkinson's, as a person living with the condition, a carer or a family member. The combination of skills and lived experience keeps our decisions both rigorous and grounded in the reality of the community we serve. It is why they give their time to this work.

## Our Directors

**Alison Perrott**
DIRECTOR & CHAIR

Grandmother lived with Parkinson's; Aunt lives with Parkinson's

**Jen Harkness**
DIRECTOR & DEPUTY CHAIR

Lives with young-onset Parkinson's

**Prof George Mellick**
DIRECTOR

Uncle lives with Parkinson's

**Prof David Blacker AM**
DIRECTOR

Lives with Parkinson's

**Glen Booth**
DIRECTOR
ARF CHAIR

Father lived with Parkinson's

**Heidi Clarris**
DIRECTOR

Mother lived with MS

**Marcia Kimball**
DIRECTOR

Husband lives with Parkinson's

**Sally Macdonald**
DIRECTOR
SHIPS CHAIR

Grandfather and father lived with Parkinson's and Lewy Body Dementia

**Steve Ferguson**
DIRECTOR

Mother-in-law and brother-in-law live with Parkinson's

**Olivia Nassaris**
CHIEF EXECUTIVE OFFICER

Yiayia lived with Parkinson's

SECTION 05

# Well funded. Well governed.

## Your support ensures Parkinson's Australia is well-funded, financially stable, and equipped to achieve long-term success.

| PROFIT AND LOSS · YEAR ENDED 30 JUNE 2026 | |
|---|---|
| **TRADING INCOME** | |
| Donations, memberships & bequests | 998,493 |
| Corporate & conference income | 24,500 |
| Project income | 997,974 |
| **Total trading income** | **2,020,967** |
| **OTHER INCOME** | |
| **Total other income** | **9,763** |
| **OPERATING EXPENSES** | |
| Admin expenses | 89,642 |
| Office expenses | 16,913 |
| Travel & conferences | 32,927 |
| Payroll expenses | 565,191 |
| Project expenses | 626,808 |
| Other expenses | 598 |
| **Total operating expenses** | **1,332,079** |
| **Net profit** | **698,651** |

| BALANCE SHEET · AS AT 30 JUNE 2026 | |
|---|---|
| **ASSETS** | |
| Cash at bank | 1,509,257 |
| Accounts receivable | 48,500 |
| Sundry debtors | 34,098 |
| Term deposits | 758,961 |
| Prepaid expenses | 14,577 |
| **Total current assets** | **2,365,393** |
| Investments (shares) — non-current | 158,485 |
| **Total assets** | **2,523,879** |
| **LIABILITIES** | |
| Credit card & accounts payable | 30,759 |
| Project liabilities | 317,740 |
| ATO liabilities | 14,758 |
| Payroll liabilities | 36,337 |
| **Total liabilities** | **399,594** |
| **Net assets** | **2,124,285** |
| **EQUITY** | |
| Current year earnings | 698,651 |
| Other comprehensive income | 13,100 |
| Retained earnings | 1,412,535 |
| **Total equity** | **2,124,285** |

Figures in AUD, rounded to the nearest dollar. The figures in these tables are an indicative view of PAL finances as at 30 June 2026. Full audited statements will be available on the ACNC website following the Annual General Meeting on 5 November 2026.

parkinson's australia

**From the smallest donation or when you like and share our content - as a charity that relies on your generosity to do what we do, we appreciate your support.**

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