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National Advocacy · Connection · Awareness

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Senate Standing Committees
on Community Affairs
PO Box 6100
Parliament House
Canberra ACT 2600

27 May 2026

Dear Committee Secretary,

Re: Submission to the Senate Community Affairs Legislation Committee NDIS Amendment (Securing the NDIS for Future Generations) Bill 2026

Parkinson's Australia welcomes the opportunity to make a submission to the Senate Community Affairs Legislation Committee on the NDIS Amendment (Securing the NDIS for Future Generations) Bill 2026.

Parkinson's Australia is the national voice and advocate for over 150,000 people living with Parkinson's, their families and carers, researchers, and health professionals.

We are committed to connecting our community through nationwide engagement, and we welcome open communication. We work to reduce the impact of Parkinson's by promoting awareness and best practice care, ensuring that people can maximise their opportunities to live well and maintain their independence.

We are available to provide oral evidence to the Committee and to meet with Senators and officials to discuss these concerns in further detail. We welcome the opportunity to work constructively with government to ensure that people with Parkinson's disease are not left behind by this reform.

Olivia Nassaris, Chief Executive Officer, Parkinson's Australia

EXECUTIVE SUMMARY

Parkinson's Australia calls on the Committee to recommend the following amendments:

Access

- The NDIS must retain the early intervention pathway for people with Young Onset Parkinson's who do not yet meet NDIS access criteria under the new Support Needs Assessment.

Support Needs Assessment

- Support needs assessors for people with Parkinson's disease must demonstrate specific competency in Parkinson's disease presentation, medication effects, and non-motor symptoms.
- The direct impairment link test must be interpreted to include all symptoms intrinsic to the Parkinson's disease process.
- Assessments must incorporate on-off medication fluctuations and be conducted across multiple time points or with explicit clinical evidence of fluctuation range.

Functional Capacity

- The functional capacity definition must require assessment across multiple time points and across the medication cycle for people with Parkinson's disease.
- Environmental context must be included in assessments of gait and falls risk where a person lives.
- Clinical specialist reports must be accepted as determinative evidence of functional capacity range, where a single assessment is insufficient to capture the condition's variability.

Change of Circumstance & Plan Reassessment

- For people with Parkinson's disease, documented acute events including falls with injury, hospitalisation, new diagnosis of Parkinson's disease dementia, loss of independent swallowing, or significant medication change should constitute automatic grounds for reassessment without requiring confirmation of ongoing change.
- The 90-day decision window must not apply to incurable neurodegenerative conditions, and the 21-day period should be maintained.
- Support coordinators and nominated representatives must retain the right to initiate reassessments on behalf of participants who lack the capacity to do so.

Automatic Plan Renewal & Loss of Capital Funding

- Where a plan renewed under section 50A previously included one-off capital funding, that funding must either be carried forward into the renewed plan or the participant must receive individual written notice of its removal with an automatic right to request reassessment for that item without being required to satisfy the significant-change threshold.
- Plan renewals that result in the removal of safety-critical equipment funding must be classified as reviewable decisions.

EXECUTIVE SUMMARY CONTINUED

Reasonable & Necessary Supports: Leasing & Informal Care Presumptions

- The leasing presumption in the amended reasonable and necessary test must be disapplied for participants with permanent, progressive, and incurable conditions.
- Assistive technology and home modifications required for long-term needs must be assessed for purchase, not defaulted to lease.
- Assessments of informal support sustainability must consider the full scope and intensity of the caring role and must not assume sustainability based solely on the absence of a formal declaration of breakdown.

All Possible Treatments Explored (Permanence)

- The legislation must explicitly state that symptomatic management, including dopaminergic therapy, does not constitute alleviation of the underlying impairment for the purposes of the permanence test.
- NDIA guidance must confirm that Parkinson's disease is a permanent impairment for NDIS purposes, regardless of treatment response.
- The definition of appropriate treatment must explicitly exclude experimental, investigational, and surgical interventions where individual clinical grounds exist for declining them.

The Priority Access Pathway

- The Priority Access Pathway should be enshrined in primary legislation, and its eligibility criteria should be defined by documented functional decline trajectory rather than solely by proximity to death. People with Atypical Parkinsonism or Parkinson's disease in advanced stages must have guaranteed access to rapid assessment and planning.

Ministerial Power, Control Over Pricing & Determinations

- Support determinations under section 34A must include individual notification, an individual impact assessment for participants in affected categories, and a right of merits review.
- Pricing instruments must remain subject to Senate disallowance.
- An independent clinical advisory panel must inform all pricing decisions affecting neurological condition participants.

New framework plan budgets

- New framework plan budgets set under Schedule 4 must be required to meet the actual cost of the funded supports for participants with complex neurological conditions.
- Where the budget-setting method produces an amount below the real-world cost of a participant's assessed and approved supports, the participant must have a right to seek individual review of the funding amount.
- The legislative acknowledgement that plan funding may fall below actual cost must not be used to insulate systematically inadequate budgets from challenge.

INTRODUCTION

Parkinson's disease is the fastest-growing neurological condition in the world. Over 150 000 people are living with Parkinson's in Australia, and that number is predicted to triple by 2050. It is progressive, incurable, and has numerous complex motor and non-motor symptoms. While many people live with Parkinson's for decades, the condition inevitably worsens over time. No treatment halts or reverses the underlying neurodegeneration. The rate of progression varies significantly between individuals, and this is where Early Intervention is vital for people living with Young Onset Parkinson's (YOP).

People living with a diagnosis of Parkinson's who access the NDIS typically do so under the Early Intervention pathway. The proposed changes to access mean that the majority of people living with YOP won't be accepted onto NDIS, despite having a neurodegenerative disease with no known cure.

Funding early intervention for Young Onset Parkinson's prevents a cascade of compounding economic losses. By keeping both patients and their carers in the workforce, reducing the reliance on welfare, and proactively preventing expensive emergency hospitalisations, early intervention strategies offer a highly favourable return on government investment.

We acknowledge the importance of fiscal responsibility in scheme management and support measures that improve integrity and reduce fraud. However, we are deeply concerned that several provisions in this Bill, taken together, will impose substantial new barriers on people with Young Onset Parkinson's at precisely the point in their disease course when they can least afford them.

The impact extends beyond the person living with YOP. Caregivers, most often partners, adult children, or other family members, frequently reduce their working hours or leave the workforce entirely as the demands of caregiving increase. The financial consequences of this are significant and lasting, including reduced lifetime earnings, superannuation, and retirement security.

The personal consequences are equally serious. Caregivers of people with Parkinson's disease report high rates of depression, anxiety, social isolation, and physical health deterioration as a direct result of their caring role. When the NDIS fails to provide adequate, timely, and flexible support to the person with Parkinson's disease, it is the caregiver who absorbs the shortfall at cost to their own health, financial security, and wellbeing.

A scheme that reduces or delays support for participants with Parkinson's disease does not save money; it transfers the cost invisibly onto unpaid caregivers and ultimately onto the health and social welfare systems that will support those caregivers when they can no longer cope.

LACK OF EARLY INTERVENTION FOR YOUNG ONSET PARKINSON'S, WHERE EVIDENCE-BASED INTERVENTION REDUCES SYMPTOMS & TRAJECTORY

The evidence base for exercise and allied health intervention in Parkinson's disease is among the strongest in neurology. Regular, intensive, neurologically targeted therapies including physiotherapy, exercise physiology, speech pathology, occupational therapy, dietetics, counselling and psychotherapy have been shown to slow motor progression, improve balance and gait, reduce falls, maintain cognitive function, and improve quality of life. Early and sustained access to these interventions is clinically critical and saves our health system money in the long-term.

The NDIS has been an important enabler of early access to allied health supports for people with Parkinson's disease. Access to publicly funded outpatient rehabilitation programs only occurs after a catastrophic event, such as a fall has taken place. The proposed Support Needs Assessment risks excluding people with YOP from NDIS on the basis that they aren't displaying symptoms yet would benefit from evidence-based Parkinson's-specific exercise and therapy programs to manage symptoms and slow the trajectory of the disease.

People with newly diagnosed Parkinson's disease who are still in paid employment, managing their own household, and not yet significantly disabled are unlikely to meet NDIS access criteria under either the current or proposed frameworks. However, this is precisely the period during which exercise and allied health intervention have the greatest impact on trajectory.

The Bill does not address how these people will access evidence-based early intervention. The Foundational Supports framework, as currently described, is unlikely to provide the intensity or specialisation required, and programs such as Thriving Kids obviously do not address the needs of our cohort.

There is no clarity in the Bill about what supports will be available for people with Parkinson's disease who do not yet meet NDIS access criteria, but whose condition is on a trajectory toward significant disability. The gap between health system coverage (episodic, acute, clinical) and the NDIS (significant and permanent disability) is precisely where early intervention needs to sit. The Bill does not resolve this gap, and the proposed Foundational Supports system is not designed or resourced to fill it for a condition requiring the intensity and specialisation of Parkinson's-specific allied health intervention.

BEST PRACTICE EVIDENCE ON HOW TO IMPROVE SYMPTOMS & SLOW THE PROGRESSION OF A WHOLE-BODY, NEURODEGENERATIVE, INCURABLE, CHRONIC DISEASE

Management must focus on a proactive, neuroprotective, and multidisciplinary approach. It must be noted that this individual approach to managing symptoms has a large body of evidence-based interventions proven in multiple research papers from around the world. Citations for dot points are organised by specialty topic in the reference section at the end of this document.

Multidisciplinary care teams & PD

Parkinson's is a whole-body disorder that affects movement, mood, cognition, sleep, vision, communication, swallowing, and nutrition. No single clinician can manage all domains. A coordinated multidisciplinary team (care team) addresses the full risk profile, including falls, hospitalisation, and functional decline.

- Early, proactive referral to allied health is recommended, not delayed until decline.
- Specialised allied health care reduces complications associated with Parkinson's and supports daily function.
- Multidisciplinary care is required due to the complexity of combined motor and non-motor symptoms.
- Teams should include a minimum of neurology, physiotherapy, occupational therapy, speech pathology, psychology, dietetics, and nursing.
- Evidence shows that multimodal rehabilitation (physio + OT + speech + psychology) improves motor scores (UPDRS), gait, and quality of life compared to standard care.
- Integrated care is associated with improvements in activities of daily living and quality of life.

Mental health & maintaining independence

Because YOP strikes during prime career and family-building years, holistic care is essential. Maintaining independence requires coordinated physical and mental health care. Depression, anxiety, and apathy are common clinical symptoms in Parkinson's, with a higher impact on younger people. These non-motor symptoms are disease-related and linked to changes in brain chemistry, not just a reaction to diagnosis. They reduce motivation, decision-making, and daily function. Untreated mental health symptoms also increase falls risk and functional decline. Mental health directly affects motivation, adherence to therapy, and safe decision-making. Integrated care improves long-term independence.

- Depression and apathy reduce physical activity, attention, and engagement in safe behaviours, contributing to instability and loss of independence.
- Cognitive Behavioural Therapy (CBT) improves depression and anxiety in Parkinson's, reduces symptom severity and improves coping and daily function.
- Peer support reduces isolation, improves self-management, and supports emotional regulation, particularly in younger cohorts managing work and family.
- Structured workplace support helps people maintain productivity, manage fatigue, and adapt tasks to changing capacity.
- Early workplace adjustments extend career participation. Flexible hours, task modification, and ergonomic changes allow people with YOP to maintain employment and financial independence for longer.
- Engaging in vocational rehabilitation counselling and seeking early workplace accommodations allows individuals with YOP to manage their physical symptoms while preserving their careers and independence for a longer duration.

Physiotherapy & exercise physiology

One size does not fit all. Both exercise and physiotherapy should be carefully prescribed for each individual with Parkinson's disease, taking their impairments, disease severity, fall risk, progression trajectory and goals into account. As an individual's disease progresses over time, their exercise and physiotherapy programs will need to be reviewed and updated to meet their changing needs and ensure their safety. (18) These outcomes translate into reduced reliance on acute care services and delayed progression to higher levels of support. It is essential for early intervention and wellbeing.

Why you need both

Regular engagement with Accredited Exercise Physiologist (AEPs) ensures tailored, safe, and effective exercise programs that address Parkinson's-specific challenges, such as gait, balance, rigidity, fatigue, constipation, apathy, mood and motor fluctuations. It improves strength and endurance, builds physical capacity while focusing on conditioning and adherence.

Physiotherapy is also essential in managing these complex symptoms and provides clinical risk management. It targets gait, balance, falls, freezing and functional independence while focusing on safety and technique. Early physiotherapy is proven to delay mobility decline.

Peer-reviewed studies confirm:

- Exercise is an essential part of Parkinson's symptom management. It is the only intervention currently shown to slow disease progression, improve motor and non-motor symptoms, and enhance neuroplasticity.
- Transfer and turning training reduces high-risk movements at home.
- Bed, chair, and bathroom transfers are common fall points. Physiotherapy improves technique and safety.
- Early intervention maintains independence and reduces downstream injury risk.
- High-intensity aerobic exercise slows clinical disease progression and decreases the worsening of motor symptoms.
- Exercise has neuroprotective outcomes, preserving dopamine-producing neurons.
- It also significantly improves posture, walking, muscle stiffness, sleep, and emotional wellbeing while reducing the risk of falls.

Nutrition

Nutrition plays a significant role in managing inflammation and gut-brain axis health in YOPD. An accredited practising dietitian is an integral part of the care team, not only for essential nutritional advice on stopping unintentional weight loss, unhealthy weight gain (particularly after DBS), swallowing issues needing food modification (as aspiration is the leading cause of PD-related death), but also in early intervention strategies around well-documented co-morbidities like diabetes (40% of PwP). Weight management reduces frailty and instability. PwP also require protein redistribution advice due to the complexities of managing polypharmacy and medication interactions. Dietitians recommend fibre, fluid, and meal timing strategies to help with dehydration, constipation and overall wellbeing.

- Strict adherence to anti-inflammatory diets is associated with a delayed onset of Parkinson's symptoms and may slow down overall disease progression.
- Diets rich in fresh vegetables, whole grains, nuts, and healthy fats (like olive oil) act as antioxidants that suppress neuroinflammatory cascades, leading to milder motor and non-motor symptoms.
- Dietary protein can competitively inhibit the absorption of levodopa, managing this interaction significantly improves daytime motor control and medication efficacy.
- Malnutrition and sarcopenia are common in Parkinson’s and are linked to reduced balance and increased falls. Dietitians assess intake and prescribe nutrition strategies to maintain muscle mass.
- Falls in Parkinson’s often result in fractures. Adequate vitamin D and calcium improve bone density and reduce injury severity.
- Dehydration contributes to low blood pressure on standing, increasing falls risk. Dietitians provide fluid plans and salt intake guidance where appropriate.
- Constipation is common in Parkinson’s and can lead to UTIs, poor medication up-take, straining-related dizziness or instability.
- Meal timing improves medication effectiveness and motor control.
- Protein can interfere with levodopa absorption. Dietitians structure protein intake to optimise medication response, supporting steadier movement and reduced falls risk.
- Unintentional weight loss is associated with poorer outcomes and increased falls. Dietitians monitor weight and adjust intake to maintain safe body mass.
- Dietitians work with speech pathologists to ensure nutritional adequacy when textures are modified to reduce choking risk.
- Deficiencies in nutrients such as B vitamins and iron can worsen fatigue and weakness, increasing falls risk. Dietetic assessment targets these deficits.

Speech pathology (speech & swallowing)

Speech and swallowing impairments in Parkinson's progress over time. Early intervention improves long-term safety outcomes. Speech pathologists teach communication, cognitive and dual-tasking strategies to reduce falls risk. Swallowing impairment (dysphagia) is common in Parkinson's and increases the risk of choking and aspiration pneumonia. Carer training improves safe communication and swallowing support. Improved swallowing safety reduces hospitalisation and mortality risk.

- Speech pathologists assess and manage swallowing safety, including texture modification and compensatory strategies.
- Evidence shows dysphagia management, including behavioural and dietary interventions, reduces complications linked to aspiration.
- Interventions such as Lee Silverman Voice Treatment (LSVT LOUD®) improve vocal intensity and respiratory control, which also supports cough strength and airway clearance.
- Speech pathologists teach strategies to reduce cognitive load during communication while moving, such as stopping before speaking or simplifying responses.
- Impairments in attention, executive function, and processing speed increase risk during complex tasks. Speech pathology targets these skills to support safer decision-making and sequencing.
- Speech pathologists provide practical guidance on posture, pacing, bite size, and supervision needs during meals. This directly addresses a high-risk daily activity.
- Education ensures carers recognise signs of aspiration, manage choking risk, and support safe eating and communication practices.
- Early assessment and treatment reduce downstream risks, including malnutrition, dehydration, and falls linked to weakness.
- Management of drooling that impacts dignity, skin integrity, and aspiration risk, through behavioural strategies and referral pathways.
- Speech pathologists support advance care planning for swallowing and nutrition decisions in later stages.
- Telehealth speech therapy shows comparable outcomes to in-person programs.

Occupational therapy

Occupational therapy improves functional independence, daily activity performance, and engagement. Not only do Occupational Therapists (OTs) prescribe appropriate assistive technology to improve independence and safety, but they also train care partners, do home modifications assessments and give strategies to cope with a wide range of symptoms. Strong evidence supports OT as part of standard Parkinson's rehabilitation.

- Randomised controlled trial demonstrated that home-based individualised occupational therapy improves performance in and satisfaction with meaningful daily activities, and these effects also last long term, 6 months after the end of OT intervention.
- Occupational therapists identify and modify environmental risks such as poor lighting, loose rugs, and unsafe bathroom layouts. Evidence shows that home modifications reduce falls, especially in neurologic conditions.
- Occupational therapists teach strategies such as cueing, pacing, and dual-task management to reduce freezing and instability during daily activities.
- Occupational therapy integrates cognitive strategies (e.g., attention, sequencing) to reduce risk during complex tasks such as cooking or transfers.
- Devices such as mobility aids, bed rails, and transfer equipment reduce physical strain and improve stability when used correctly. Occupational therapists assess and prescribe appropriate equipment.
- Training carers in safe transfer techniques and environmental setup reduces injury risk for both the person with Parkinson's and the carer.

THE STRATEGIC CASE FOR GOVERNMENT INVESTMENT IN EARLY INTERVENTION FOR YOUNG ONSET PARKINSON'S (YOP)

1. It drastically reduces long-term health system costs

The Government bore over $600 million (57%) of the financial costs associated with Parkinson's. Notably, only 64% of government costs are related to health system expenditure; the remainder primarily represents lost revenue, including lost taxes associated with reduced work by people with YOP and their carers, as well as welfare payments.

Parkinson's incidence rates are increasing at 4% per year, impacting the economy and healthcare systems at a cost of over $10 billion each year. This figure comes from Professor George Mellick's 2024 Ecosystem of Parkinson's in Australia report, commissioned by Parkinson's Australia.

The 2015 Deloitte Access Economics analysis, the most comprehensive Australian-specific economic modelling to date, provides the breakdown behind that number. That report estimated an economic burden totalling $9.9 billion, a 46% increase from 2005, with Australian health systems bearing the highest economic burden at an estimated $567 million in 2014, of which aged care was 48%, hospitals 23%, and pharmaceuticals 15%.

2. It preserves workforce participation and economic productivity

Given that over 150,000 Australians are living with Parkinson's, with 50 new diagnoses every day, the workforce and fiscal implications are substantial and growing.

The mean annual cost per person to the health care system was $32,556 AUD, with the broader burden to society an additional $45,000 per annum per person with Parkinson's. Hospitalisation made up 69% of total health system costs. Costs for people with moderate to severe disease were almost four times those with mild Parkinson's ($63,569 versus $17,537). That is why it is crucial to keep people with YOP well with early intervention.

The average annual financial cost per person living with Parkinson's in 2014 was around $15,400, a 61% increase since 2005. Health expenditure per person with Parkinson's per year is greater than for many other diseases, including prostate cancer and breast cancer. While the median number of years lived with Parkinson's is 12.4 years, many people with young onset live with the disease for well over 20 years. Given that costs escalate significantly with disease severity, the lifetime burden is substantial.

For younger people, the productivity losses are especially severe. European research found that in the 10 years after a Parkinson's diagnosis, average annual income reduced significantly, and lost employment potential was associated with an estimated 9.8 to 20.1 potential years of employment lost, depending on age at diagnosis. This directly impacts individual lifetime earnings with a consequential increase in societal costs.

People with Parkinson's exit the workforce an average of five years earlier than the general population due to motor, cognitive, and communicative symptoms:

- In Australia, premature workforce separation accounts for $114.4 million of the total $182.4 million in annual productivity losses associated with the disease
- Early intervention, including OT and vocational rehabilitation, can help people with YOP adapt their work environments and maintain employment longer
- Keeping these people and their carers in the workforce preserves vital tax revenue and reduces the reliance on government welfare, which currently costs the system $60.7 million annually in additional Disability Support Pensions
- Diabetes is a common co-morbidity with Parkinson's. Lost labour force participation due to diabetes resulted in a loss of $384 million in individual earnings, $56 million in lost taxation revenue, $4 million in additional welfare payments, and a $1.324 billion loss to GDP in 2010 alone.
- Mental health conditions are also very prevalent in Parkinson's. Early retirement due to depression and other mental health conditions cost the government $278 million in lost income tax, $407 million in additional transfer payments, and around $1.7 billion in GDP in 2009 alone. People who retire early due to depression have 73% lower income than their full-time employed counterparts.
- Parkinson's disease was responsible for 45,100 DALY, equivalent to 9.3% of the total disease burden attributed to neurological conditions and 0.8% of the total disease burden in Australia.

3. It sustains unpaid carers in the labour market, carer burden compounds the cost

Approximately 26% of Parkinson's caregivers had to reduce or give up work, and 30.4% reported that their finances worsened as a result of caregiving. An estimated 30 to 40% of total indirect costs associated with Parkinson's are attributable to lost earnings by caregivers and patients combined.

The progressive disability associated with Parkinson's requires increasing levels of informal care, heavily impacting the labour market. Unpaid carers (usually family members) lose an estimated $78.2 million annually in wage income because they are forced to reduce their work hours or quit entirely to provide support

By investing in early symptom management and therapies that prolong PwYOP's independence, the government can delay the need for intensive informal care, thereby keeping carers economically active and reducing their need for Carer Payments and Allowances.

4. It prevents costly medical emergencies and hospitalisations

Loss of balance, freezing of gait, and subsequent falls are major drivers of emergency medical costs. Treating accidental falls and related complications like pneumonia adds over $102.9 million to the annual health system costs of Parkinson's in Australia.

RECOMMENDATIONS

Parkinson's Australia calls on the Committee to recommend the following amendments:

EARLY INTERVENTION ACCESS PATHWAY

Early intervention through targeted physiotherapy and exercise physiology directly combats these risks. Evidence shows that specialised physical therapy networks can reduce hip fractures by up to 55%. Occupational therapy-led fall prevention, including home safety modifications, reduces hospital admissions and lowers health system costs. Furthermore, early access to specialised nursing has been proven to reduce unplanned hospital admissions by 10% to 67%, saving individual healthcare trusts hundreds of thousands of dollars annually in avoided emergency care and bed days.

Recommendation: The Commonwealth must retain the early intervention pathway for people with Young Onset Parkinson's who do not yet meet NDIS access criteria under the new Support Needs Assessment.

SUPPORT NEEDS ASSESSMENT

Schedule 4 clarifies assessment processes and limits assessor discretion regarding what information can be considered. While greater procedural consistency is in principle welcome, Parkinson's Australia is deeply concerned about whether assessors will have adequate specialist knowledge to assess people with Parkinson's accurately and fairly.

Parkinson's disease has a highly variable presentation. Two people with the same diagnosis and the same disease duration may have radically different functional profiles. Motor symptoms, non-motor symptoms (including cognitive impairment, psychosis, sleep disorders, autonomic dysfunction, and pain), medication effects, and on-off fluctuations all vary substantially between individuals and across time. An assessor without specific Parkinson's expertise will not be equipped to capture this complexity.

The direct impairment link requirement, now applied to Support Needs Assessments under amended section 32L, creates a particularly acute problem for people with Parkinson's disease. Many of the most disabling features of the condition, such as depression, anxiety, orthostatic hypotension, and urinary dysfunction, are intrinsic to the Parkinson's disease process but may appear to assessors as separate comorbidities when they are in fact well-documented clinical symptoms of Parkinson’s disease. If the assessment framework treats these as secondary conditions that do not independently meet eligibility criteria, the support needs they generate will be excluded from funding despite being a direct consequence of Parkinson's disease.

Assessment must account for medication-related fluctuations. People with Parkinson's experience significant within-day variation in motor and cognitive function depending on whether they are in an 'on' state (dopaminergic medication is effective) or 'off' state (medication wearing off). An assessment conducted during an 'on' period will dramatically underestimate a person's support needs. Assessors must be trained to understand on-off fluctuations and to assess functional capacity across the medication cycle, not just at a single point in time.

Recommendation: Support needs assessors for people with Parkinson's disease must demonstrate specific competency in Parkinson's disease presentation, medication effects, and non-motor symptoms. The direct impairment link test must be interpreted to include all symptoms intrinsic to the Parkinson's disease process. Assessments must incorporate on-off medication fluctuations and be conducted across multiple time points or with explicit clinical evidence of fluctuation range.

FUNCTIONAL CAPACITY

The introduction of a strict definition of functional capacity under new section 9B assessed without assistance from other people, assistive technology, or modifications, and excluding personal and environmental circumstances as far as possible, is among the most consequential changes in the Bill for people with Parkinson's disease.

On-off fluctuations mean that a person with Parkinson's disease does not have a single, stable functional capacity. In an 'on' state, they may walk independently, dress themselves, and hold a conversation. In an 'off' state, which may occur unpredictably multiple times daily, the same person may be unable to walk, speak, swallow safely, or manage their own hygiene. A point-in-time assessment of unaided functional capacity will almost certainly be conducted during a relatively functional period and will fail to capture the true burden of the condition and the genuine level of support required.

Freezing of gait, one of the most disabling and dangerous features of advanced Parkinson's, is highly context-dependent and unpredictable. It is typically absent during a clinical assessment (when a person is walking in a structured, low-stress environment) and present in the real-world environments where it causes falls and injury. Especially around doorways, in crowded spaces, and while turning and dual-tasking. An assessment that excludes environmental circumstances will systematically miss this risk.

Dopaminergic medication itself is a form of treatment that partially masks the underlying impairment. A person with Parkinson's disease who is well-medicated may appear to have moderate functional capacity on assessment. The same person without medication, which is not a realistic, ethical or safe assessment scenario, would have severe impairment. The definition of functional capacity must clarify how medication effects are to be treated in the assessment and must not be interpreted in a way that leads assessors to underestimate the underlying severity of the condition.

Cognitive impairment is prevalent in Parkinson's disease. Parkinson's disease dementia affects approximately 80% of people with Parkinson's after 20 years, and mild cognitive impairment is common much earlier. It interacts with motor symptoms to compound functional disability in ways that are not captured by assessing motor capacity alone. A functional capacity framework that focuses predominantly on physical activity performance will miss the profound interaction between motor and cognitive impairment that is characteristic of advanced Parkinson's disease.

Recommendation: The functional capacity definition must require assessment across multiple time points and across the medication cycle for people with Parkinson's disease. Environmental context must be included in assessments of gait and falls risk. Clinical specialist reports must be accepted as determinative evidence of the functional capacity range, where a single assessment is insufficient to capture the condition's variability.

CHANGE OF CIRCUMSTANCE & PLAN REASSESSMENT

The restrictions on unscheduled plan reassessments introduced by amended sections 47A, 48, 48A, and 49 are particularly ill-suited to the natural history of Parkinson's disease, where functional decline is continuous but uneven, characterised by periods of relative stability punctuated by step-changes following falls, hospitalisations, medication changes, or the emergence of new symptom domains.

The requirement that a change be significant and ongoing before a reassessment can be requested creates a temporal trap for people with Parkinson's disease. A significant change, such as a fall resulting in hip fracture, the onset of dementia, or loss of independent swallowing, may be immediately and permanently disabling, but the NDIA's new framework requires the change to be confirmed as ongoing before a reassessment proceeds. In the meantime, the person is receiving support calibrated to their pre-event capacity.

The extension of the CEO's decision timeframe from 21 to 90 days is deeply problematic for people with Parkinson's disease in a period of significant change. A person who has just been hospitalised with a fall, discharged with new care needs, and returned home to an NDIS plan that no longer matches their requirements cannot wait three months for the NDIA to decide whether to reassess. The consequences, including inadequate personal care, falls risk, carer burnout, and avoidable re-hospitalisation, are foreseeable and serious.

The plan suspension provision under new section 40A allows the NDIA to suspend and ultimately revoke a participant's status if they are uncontactable for 90 days. People with Parkinson's disease experiencing acute episodes, including hospitalisation, delirium, post-operative recovery, or dementia-related confusion, may be genuinely unable to maintain contact with the NDIA for extended periods. Their nominees and carers may also be overwhelmed by the immediate care demands of the acute phase. The 90-day window, with no apparent mechanism to account for medical incapacity, creates a real risk that vulnerable participants lose their NDIS status at the most critical point in their disease course.

Support coordinators are banned from requesting reassessments on a participant's behalf under the new rules. For people with Parkinson's disease who have cognitive impairment, many of whom rely on their support coordinator to manage their NDIS plan and initiate changes on their behalf, this is a significant loss of practical advocacy capacity. The new rules assume a level of participant self-agency that is not realistic for people with advanced Parkinson's disease with dementia.

Recommendation: For people with Parkinson's, documented acute events including falls with injury, hospitalisation, new diagnosis of Parkinson's disease dementia, loss of independent swallowing, or significant medication change should constitute automatic grounds for reassessment without requiring confirmation of ongoing change. The 90-day decision window must not apply to incurable neurodegenerative conditions, and the 21-day period is maintained. Support coordinators and nominated representatives must retain the right to initiate reassessments on behalf of participants who lack the capacity to do so.

AUTOMATIC PLAN RENEWAL & LOSS OF CAPITAL FUNDING

New section 50A replaces scheduled plan reassessments with automatic 12-month renewals. When an old framework plan reaches its end date, it renews by operation of law, replicating core support funding but stripping out any one-off capital funding included in the previous plan. Unspent funds are not carried over. The renewal itself is not a reviewable decision.

For people with Parkinson's disease, one-off capital funding is not incidental to the plan; it is often among the most clinically significant components. Wheelchairs and mobility aids, home modifications including grab rails, ramps, and bathroom adaptations, assistive communication devices, and specialised beds or pressure care equipment are funded as one-off capital items. These supports are central to the daily safety, independence, and dignity of the person using them. Under section 50A, a person whose plan renews automatically will find that these items have been removed from their renewed plan. If they cannot meet the strict new criteria for an unscheduled reassessment, they may have no mechanism to reinstate the funding. Parkinson's is a progressive, degenerative condition – it won't get better, needs will only increase with each plan.

Recommendation: Where a plan renewed under section 50A previously included one-off capital funding, that funding must either be carried forward into the renewed plan or the participant must receive individual written notice of its removal with an automatic right to request reassessment for that item without being required to satisfy the significant-change threshold. Plan renewals that result in the removal of safety-critical equipment funding must be classified as reviewable decisions.

REASONABLE & NECESSARY SUPPORTS: LEASING & INFORMAL CARE PRESUMPTIONS

The Bill embeds two new presumptions directly into the reasonable and necessary test in section 34 that warrant specific attention for people with Parkinson's disease. The first is a presumption that leasing assistive technology or home modifications represents better value for money than purchasing, where a participant's circumstances may change in the short term. For people with Parkinson's, this presumption is clinically inappropriate. Parkinson's disease does not follow a short-term trajectory of change: it is a progressive, incurable, neurodegenerative condition. The supports a person requires, e.g., a motorised wheelchair, bathroom modifications, and a hospital-grade bed, all reflect a long-term, worsening need. Requiring people with a progressive condition to lease equipment they will need for the remainder of their lives, rather than own it, creates ongoing financial exposure, supply insecurity, and administrative burden with no clinical justification. The leasing presumption must not apply where the underlying condition is permanent, progressive and degenerative.

The second is a presumption that informal supports and care provided by family and community must be maintained rather than replaced by NDIS-funded supports, unless those networks are unsustainable or pose a risk of harm. As documented above, carers of people with Parkinson's disease already experience high rates of burnout, depression, and workforce exit. The point at which informal care becomes unsustainable is typically reached gradually and invisibly, and carers are often not well placed to identify that threshold themselves.

A framework that defaults to expecting informal care to continue and places the burden on the participant or carer to demonstrate unsustainability risks, systematically under-recognising carer capacity limits. The assessment of informal support sustainability must consider the full scope of the caring role, including overnight support, personal care, medication management, and behavioural support, not merely whether a carer is physically present.

Recommendation: The leasing presumption in the amended reasonable and necessary test must be disapplied for participants with permanent, progressive, and incurable conditions. Assistive technology and home modifications required for long-term needs must be assessed for purchase, not defaulted to lease. Assessments of informal support sustainability must consider the full scope and intensity of the caring role and must not assume sustainability based solely on the absence of a formal declaration of breakdown.

ALL POSSIBLE TREATMENTS EXPLORED (PERMANENCE)

New section 25A introduces a requirement that an impairment is not permanent unless the person has undertaken all appropriate treatment defined as evidence-based care, available in Australia, reliably expected to materially improve, reverse, or alleviate the impairment. The Bill includes a carve-out for degenerative conditions requiring ongoing maintenance treatment. Parkinson's Australia acknowledges this carve-out but has significant residual concerns about its application.

The permanence of Parkinson's disease as an underlying impairment should not be in doubt. Parkinson's disease is a progressive neurodegenerative condition with no curative treatment. The neurodegeneration underlying the condition is permanent and worsens over time. Dopaminergic therapy and other pharmacological treatments manage symptoms, but they do not reverse or halt the underlying pathology. The Bill's carve-out for ongoing maintenance treatment for degenerative conditions should apply clearly to Parkinson's disease.

However, the requirement risks being applied ambiguously at the level of individual symptoms and functional impairments. An NDIA assessor who is not an expert in Parkinson's disease may conflate symptom management with impairment alleviation and conclude that a person whose motor function is partially improved by levodopa has a condition that is not permanent, or that is adequately treated, in a way that affects eligibility or plan funding. This ambiguity must be resolved in guidance or in the legislation itself.

Deep brain stimulation (DBS), a surgical intervention that can provide significant motor symptom relief in carefully selected people with Parkinson's disease, may create specific problems under the permanence framework, and this doesn't even consider the fact that there aren't enough public listings to meet current demand. A person who has been declined DBS based on their individual circumstances, such as age, co-morbidities, or personal preference not to undergo brain surgery whilst awake, or neurological contraindication, may be required to justify this to NDIA assessors as a medical reason for not undertaking such dramatic and invasive treatment. This is an intrusive and inappropriate imposition on individual medical decision-making, limiting choice and control.

New and emerging therapies, including gene therapy trials and novel pharmacological approaches, exist for Parkinson's disease. People who have not participated in clinical trials or accessed experimental treatments should not be considered to have failed to exhaust appropriate treatment. The definition of appropriate treatment must be limited to evidence-based care in routine clinical use, not experimental interventions.

The burden of demonstrating that all appropriate treatments have been considered will fall on the participant. For people with Parkinson's disease who are already managing a complex medication regimen, multiple specialist appointments, allied health therapy, and increasing care needs, the administrative demand of compiling and presenting a treatment history to NDIA assessors is significant. This burden will deter access and delay planning for the people who most need it.

Recommendation: The legislation must explicitly state that symptomatic management, including dopaminergic therapy, does not constitute alleviation of the underlying impairment for the purposes of the permanence test. NDIA guidance must confirm that Parkinson's disease is a permanent impairment for NDIS purposes, regardless of treatment response. The definition of appropriate treatment must explicitly exclude experimental, investigational, and surgical interventions where individual clinical grounds exist for declining them.

PRIORITY ACCESS PATHWAY

The Priority Access Pathway, introduced in 2024, represented a significant improvement in how the NDIS responds to people with rapidly deteriorating conditions and life-limiting diagnoses. For people with Atypical Parkinsonism, such as Dementia with Lewy Bodies (DLB), Progressive Supranuclear Palsy (PSP), Multiple System Atrophy (MSA), Corticobasal Syndrome (CBS), and advanced Parkinson's, the pathway provides an eligibility decision within seven business days and a first plan within one month, timelines that are clinically meaningful for people whose condition does not wait for administrative convenience.

We strongly supported the introduction of this pathway and are concerned that the Bill does not guarantee its continuation. The Priority Access Pathway is not embedded in primary legislation. It exists as an administrative mechanism that can be altered, narrowed, or removed without legislative amendment or parliamentary scrutiny. The reforms introduced by this Bill represent exactly the kind of systemic reset that puts administrative pathways at risk of being overlooked or discontinued.

The new framework planning process and the tighter assessment criteria introduced by the Bill are not designed with urgency in mind. The 90-day decision window for reassessment requests is incompatible with the pace of decline in Atypical Parkinsonism and advanced Parkinson's. Without a guaranteed fast-track mechanism, people face a system that moves far more slowly than their disease.

Recommendation: The Priority Access Pathway should be enshrined in primary legislation, and its eligibility criteria should be defined by a documented functional decline trajectory rather than solely by proximity to death. People with Atypical Parkinsonism or Parkinson's disease in advanced stages must have guaranteed access to rapid assessment and planning.

MINISTERIAL POWER, CONTROL OVER PRICING & DETERMINATIONS

The Bill concentrates significant new power in the hands of the Minister, across pricing, support determinations, transitional rulemaking, and the formalisation of automated decision-making. Parkinson's Australia is concerned that this concentration of power lacks adequate participant safeguards and creates material risks for people with Parkinson's disease.

New section 34A introduces support determinations: legislative instruments that reduce funding for specified categories of support by a set percentage, applied automatically to existing plans without individual review. A person with Parkinson's disease could find that their plan funding for personal care, community participation, or support coordination is reduced mid-plan by ministerial instrument, with no right to contest the reduction on the basis of their individual circumstances. There is no requirement to individually notify affected participants in advance, no opportunity to make representations, and no right of merits review. This is a fundamental departure from the principles of administrative fairness and is particularly concerning for a cohort whose conditions make self-advocacy difficult.

The only safeguard in section 34A is that the Minister must 'have regard to' participant safety. This is not a prohibition on making determinations that harm participants; it is a procedural requirement that is extremely difficult to challenge in practice. For people with Parkinson's disease, many of whom rely on funded supports for basic daily safety, including falls prevention, medication management, and safe nutrition, a funding cut in a relevant support category is not an inconvenience; it is a safety risk.

Support coordination is particularly critical for people with Parkinson's disease who have cognitive impairment, who are navigating the NDIS for the first time in advanced disease, or who are managing a complex mix of health and disability supports. If support coordination is subject to a support determination reducing funding in this category, the capacity of participants with Parkinson's to navigate and use their plans effectively will be directly impaired, a downstream effect that ultimately increases cost to the scheme rather than reducing it.

Ministerial pricing instruments under new section 34B remove pricing decisions from the NDIA Board and place them in the hands of a political office, with an explicit statutory overlay requiring the Minister to prioritise scheme financial sustainability. Parkinson's specialist allied health services, including physiotherapy, speech pathology, and occupational therapy with neurological expertise, are already in short supply and operate on thin margins. These providers depend on stable, evidence-based pricing to sustain specialist workforces. Political pricing decisions introduce volatility that undermines the viability of specialist Parkinson's therapy services, and this risk is sharpest in regional and rural areas where the margin between viable and non-viable specialist service delivery is already thin. The NDIS has been critical in enabling people in these areas to access specialist therapy, often through telehealth or by including provider travel. Price cuts to therapy supports will disproportionately reduce access for participants in underserved areas where no alternative exists.

Recommendation: Support determinations under section 34A must include individual notification, a 28-day period for representations, an individual impact assessment for participants in affected categories, and a right of merits review before a determination takes effect. Pricing instruments must remain subject to Senate disallowance. Pricing decisions must be supported by transparent modelling of the impact on specialist service viability in underserved regions. An independent clinical advisory panel with neurological expertise must inform all pricing decisions affecting participants with complex neurological conditions.

NEW FRAMEWORK PLAN BUDGETS

The new framework planning provisions in Schedule 4 introduce a budget-setting method that allows funding amounts to be specified by levels of need, subject to maximum caps for particular supports or classes of supports.

Critically, the legislation explicitly provides that the funding amount determined by this method does not necessarily need to match the actual cost of providing or acquiring the support. For people with Parkinson's disease, this creates a concrete risk that falls below the threshold of a support determination but is equally serious in practice. A new framework plan budget that is algorithmically set at a level below the real-world cost of a participant's required supports is not an abstract financial shortfall: it means that the participant cannot purchase the volume or intensity of services their condition requires. The gap between the funded amount and the actual cost will be absorbed by the participant, their family, or left unmet.

Given that Parkinson's disease requires intensive, specialist, multidisciplinary allied health intervention, services that are already expensive and in short supply, even a modest systematic underestimation of real costs will translate to meaningful reductions in access to physiotherapy, speech pathology, and occupational therapy. The Bill provides no mechanism for an individual participant to challenge a budget that is below actual cost if it is technically within the rules; the legislative acknowledgement that underfunding is permissible removes the baseline from which a challenge could be mounted.

The formalisation of automated decision-making under Schedule 3 is concerning for a condition as complex as Parkinson's disease. Parkinson's involves a wide spectrum of motor and non-motor symptoms, including depression, anxiety, apathy, bradykinesia, freezing of gait, dysphagia, tremor, constipation, incontinence, psychosis, dementia, autonomic dysfunction, dyskinesia, and on-off fluctuations, all of which interact in highly individualised ways. Automated decision tools, however well-designed, cannot assess this complexity reliably. The aged care system provides a cautionary example of what happens when automated tools are applied to complex, heterogeneous populations: systematic underfunding that is difficult to identify and nearly impossible to reverse at the individual level.

Recommendation: New framework plan budgets set under Schedule 4 must be required to meet the actual cost of the funded supports for participants with complex neurological conditions. Where the budget-setting method produces an amount below the real-world cost of a participant's assessed and approved supports, the participant must have a right to seek individual review of the funding amount. The legislative acknowledgement that plan funding may fall below actual cost must not be used to insulate systematically inadequate budgets from challenge.

CONCLUSION

Parkinson's disease is a condition that does not plateau. It progresses.

The proposed support needs assessment tool is designed to measure current functional deficit. For people with young onset Parkinson's disease, this creates a structural problem: at the point of diagnosis and in the early years of the condition, many people are still working, managing their own households, and presenting with relatively mild motor symptoms. Under an assessment framework anchored to present-day support needs in daily living, they will not meet the threshold for funded support.
This does not reflect clinical reality. The evidence base for early intervention in Parkinson's disease is compelling. Intensive, neurologically targeted exercise commenced early in the disease course has been shown to slow motor progression, preserve cognitive function, reduce falls risk, and delay the onset of significant disability. Commencing these supports early, when the nervous system retains greater plasticity, and the person has the physical and cognitive capacity to engage fully, produces materially better long-term outcomes than waiting until functional decline is significant enough to trigger NDIS access.

The cost consequences of this design flaw extend beyond the individual. A person with young onset Parkinson's disease who accesses evidence-based allied health intervention early is more likely to remain in the workforce longer, require less intensive personal care supports later, avoid costly hospitalisations from falls, and draw on the NDIS at a higher level of need for a shorter period. The assessment tool, as proposed, optimises for present need at the direct expense of future cost to the NDIS, the health system, and the broader economy.

An assessment framework fit for purpose for young onset Parkinson's disease must be capable of recognising trajectory, not only current status. Diagnosis by a specialist neurologist, combined with evidence of a condition with a known progressive course, should be sufficient to establish eligibility for early intervention supports without requiring the person to first demonstrate significant functional loss in daily living.

The NDIS has offered these Australians something that no other system has been able to provide - individualised, flexible, responsive support that can move with them as their condition changes. The Bill, as currently drafted, risks dismantling the features of the scheme that make it work for people with Parkinson's disease, including:

- clinically informed assessment
- responsive reassessment
- protection from arbitrary funding reductions
- support for the evidence-based allied health interventions that slow progression and maintain quality of life.

FINAL RECOMMENDATIONS

We call on the Committee to recommend the following amendments:

- **The Commonwealth must retain the early intervention pathway for people with Young Onset Parkinson's who do not yet meet NDIS access criteria under the new Support Needs Assessment.**

- **Support needs assessors for people with Parkinson's disease must demonstrate specific competency in Parkinson's disease presentation, medication effects, and non-motor symptoms. The direct impairment link test must be interpreted to include all symptoms intrinsic to the Parkinson's disease process. Assessments must incorporate on-off medication fluctuations and be conducted across multiple time points or with explicit clinical evidence of fluctuation range.**

- **The functional capacity definition must require assessment across multiple time points and across the medication cycle for people with Parkinson's disease. Environmental context must be included in assessments of gait and falls risk. Clinical specialist reports must be accepted as determinative evidence of functional capacity range where a single assessment is insufficient to capture the condition's variability.**

- **For people with Parkinson's disease, documented acute events including falls with injury, hospitalisation, new diagnosis of Parkinson's disease dementia, loss of independent swallowing, or significant medication change should constitute automatic grounds for reassessment without requiring confirmation of ongoing change. The 90-day decision window must not apply to incurable neurodegenerative conditions, and the 21-day period should be maintained. Support coordinators and nominated representatives must retain the right to initiate reassessments on behalf of participants who lack the capacity to do so.**

- **The Priority Access Pathway should be enshrined in primary legislation, and its eligibility criteria should be defined by documented functional decline trajectory rather than solely by proximity to death. People with Atypical Parkinsonism or Parkinson's disease in advanced stages must have guaranteed access to rapid assessment and planning.**

- **Where a plan renewed under section 50A previously included one-off capital funding, that funding must either be carried forward into the renewed plan or the participant must receive individual written notice of its removal with an automatic right to request reassessment for that item without being required to satisfy the significant-change threshold. Plan renewals that result in the removal of safety-critical equipment funding must be classified as reviewable decisions.**

- **The leasing presumption in the amended reasonable and necessary test must be disapplied for participants with permanent, progressive, and incurable conditions. Assistive technology and home modifications required for long-term needs must be assessed for purchase, not defaulted to lease. Assessments of informal support sustainability must consider the full scope and intensity of the caring role and must not assume sustainability based solely on the absence of a formal declaration of breakdown.**

- **Support determinations under section 34A must include individual notification, an individual impact assessment for participants in affected categories, and a right of merits review. Pricing instruments must remain subject to Senate disallowance. An independent clinical advisory panel must inform all pricing decisions affecting neurological condition participants.**

- **New framework plan budgets set under Schedule 4 must be required to meet the actual cost of the funded supports for participants with complex neurological conditions. Where the budget-setting method produces an amount below the real-world cost of a participant's assessed and approved supports, the participant must have a right to seek individual review of the funding amount. The legislative acknowledgement that plan funding may fall below actual cost must not be used to insulate systematically inadequate budgets from challenge.**

Parkinson's Australia is available to provide oral evidence to the Committee and to meet with Senators and officials to discuss these concerns in further detail. We welcome the opportunity to work constructively with government to ensure that people with Parkinson's disease are not left behind by this reform.

Olivia Nassaris
Chief Executive Officer
Parkinson's Australia
May 2026

EVIDENCE-BASE

Care team

- Rafferty, M. R., Foster, E. R., Roberts, A. C., Smaller, K. A., Johnson, L. L., & Lawson, R. A. (2024). Stemming the Tide: The Proactive Role of Allied Health Therapy in Parkinson's Disease. Journal of Parkinson's disease, 14(s1), S7–S19. https://doi.org/10.3233/JPD-230267
- ABS Statistics (2022) Access to care and support services. Equitable access to quality health and care services.
- Waller, Sophie, et al. "The initial diagnosis and management of Parkinson's disease." Australian journal of general practice 50.11 (2021): 793-890.

Mental health & maintaining independence

- Aarsland, D., Påhlhagen, S., Ballard, C. G., Ehrt, U., & Svenningsson, P. (2011). Depression in Parkinson's: Epidemiology, mechanisms and management. Nature Reviews Neurology, 8(1), 35–47. https://doi.org/10.1038/nrneurol.2011.189
- Bloem, B. R., Okun, M. S., & Klein, C. (2020). Parkinson's. The Lancet, 397(10291), 2284–2303. https://doi.org/10.1016/S0140-6736(21)00218-X
- Dobkin, R. D., Menza, M., Allen, L. A., et al. (2011). Cognitive behavioral therapy for depression in Parkinson's: A randomized controlled trial. American Journal of Psychiatry, 168(10), 1066–1074. https://doi.org/10.1176/appi.ajp.2011.10111669
- Lord, S., Galna, B., & Rochester, L. (2014). Moving forward on gait measurement in Parkinson's: Toward a more refined approach. Movement Disorders, 28(11), 1534–1543. https://doi.org/10.1002/mds.25545
- McNamara, P., Durso, R., & Harris, E. (2008). Life goals of people with Parkinson's: Implications for rehabilitation. NeuroRehabilitation, 23(5), 447–454.
- Seppi, K., Ray Chaudhuri, K., Coelho, M., et al. (2019). Update on treatments for non-motor symptoms in Parkinson's. Movement Disorders, 34(2), 180–198. https://doi.org/10.1002/mds.27602
- Simpson, J., Lekwuwa, G., & Crawford, T. (2014). Predictors of quality of life in Parkinson's. Journal of Neurology, 261(4), 728–735. https://doi.org/10.1007/s00415-014-7267-6
- van der Feltz-Cornelis, C. M., et al. (2014). Workplace interventions for chronic conditions: A systematic review. Occupational Medicine, 64(6), 405–412. https://doi.org/10.1093/occmed/kqu084

Exercise physiology & physiotherapy

- Tomlinson, C. L., Patel, S., Meek, C., et al. (2013). Physiotherapy intervention in Parkinson's disease: Systematic review and meta-analysis. BMJ, 345, e5004. https://doi.org/10.1136/bmj.e5004
- Allen, N. E., Sherrington, C., Suriyarachchi, G. D., Paul, S. S., & Canning, C. G. (2010). Balance and falls in Parkinson's disease: A meta-analysis of the effect of exercise and motor training. Movement Disorders, 25(15), 2510–2519. https://doi.org/10.1002/mds.23272
- Goodwin, V. A., Richards, S. H., Taylor, R. S., Taylor, A. H., & Campbell, J. L. (2008). The effectiveness of exercise interventions for people with Parkinson's disease: A systematic review and meta-analysis. Movement Disorders, 23(5), 631–640. https://doi.org/10.1002/mds.21922
- Bloem, B. R., Grimbergen, Y. A., Cramer, M., Willemsen, M., & Zwinderman, A. H. (2001). Prospective assessment of falls in Parkinson's disease. Journal of neurology, 248, 950-958.
- Langeskov-Christensen M, Franzén E, Grøndahl Hvid L, et al. (2024). Exercise as medicine in Parkinson's disease. Journal of Neurology, Neurosurgery & Psychiatry; 95:1077-1088.
- Giardini, M., Nardone, A., Godi, M., Guglielmetti, S., Arcolin, I., Pisano, F., & Schieppati, M. (2018). Instrumental or Physical-Exercise Rehabilitation of Balance Improves Both Balance and Gait in Parkinson's Disease. Neural plasticity, 2018(1), 5614242.

Evidence-base

Exercise physiology & physiotherapy continued

- Shen, X., Wong-Yu, I. S., & Mak, M. K. (2016). Effects of exercise on falls, balance, and gait ability in Parkinson's disease: a meta-analysis. Neurorehabilitation and neural repair, 30(6), 512-527.
- Xu, X., Fu, Z., & Le, W. (2019). Exercise and Parkinson's disease. International review of neurobiology, 147, 45-74.
- PARKINSON'S DISEASE & EXERCISE PROFESSIONAL EIM Factsheet (2020). Exercise is medicine.
- Keus, S. H. J., Munneke, M., Graziano, M., et al. (2014). European physiotherapy guideline for Parkinson's. KNGF/ParkinsonNet.

Dietitian

- Barichella, M., Cereda, E., & Pezzoli, G. (2019). Major nutritional issues in the management of Parkinson's. Movement Disorders, 34(12), 1881–1892. https://doi.org/10.1002/mds.27895
- Barichella, M., & Cereda, E. (2019). Dietary protein and levodopa interaction in Parkinson's. Nutrients, 11(9), 2158. https://doi.org/10.3390/nu11092158
- Cichero, J. A. Y., Lam, P., Steele, C. M., et al. (2017). Development of international terminology and definitions for texture-modified foods and fluids (IDDSI). Dysphagia, 32(2), 293–314. https://doi.org/10.1007/s00455-016-9758-y
- Fasano, A., Visanji, N. P., Liu, L. W. C., Lang, A. E., & Pfeiffer, R. F. (2015). Gastrointestinal dysfunction in Parkinson's. The Lancet Neurology, 14(6), 625–639. https://doi.org/10.1016/S1474-4422(15)00007-1
- Mischley, L. K., Lau, R. C., & Bennett, R. D. (2017). Role of diet and nutritional supplements in Parkinson's. Parkinsonism & Related Disorders, 22(Suppl 1), S90–S94. https://doi.org/10.1016/j.parkreldis.2015.09.041
- Sheard, J. M., Ash, S., Silburn, P. A., & Kerr, G. K. (2011). Prevalence of malnutrition in Parkinson's. Movement Disorders, 26(7), 1251–1257. https://doi.org/10.1002/mds.23611
- van den Bos, F., Speelman, A. D., Samson, M., & Munneke, M. (2013). Parkinson's and osteoporosis. Age and Ageing, 42(2), 156–162. https://doi.org/10.1093/ageing/afs161
- van der Marck, M. A., Dicke, H. C., Uc, E. Y., et al. (2012). Body mass index in Parkinson's and clinical outcomes. Parkinsonism & Related Disorders, 18(3), 263–267. https://doi.org/10.1016/j.parkreldis.2011.10.016

Speech pathology

- Kalf, J. G., de Swart, B. J. M., Bloem, B. R., & Munneke, M. (2012). Prevalence of oropharyngeal dysphagia in Parkinson's: A meta-analysis. Parkinsonism & Related Disorders, 18(4), 311–315. https://doi.org/10.1016/j.parkreldis.2011.11.006
- Manor, Y., Mootanah, R., Freud, D., Giladi, N., & Cohen, J. T. (2013). Video-assisted swallowing therapy for patients with Parkinson's. Parkinsonism & Related Disorders, 19(2), 207–211. https://doi.org/10.1016/j.parkreldis.2012.10.010
- Miller, N., Noble, E., Jones, D., & Burn, D. (2006). Life with communication changes in Parkinson's. Age and Ageing, 35(3), 235–239. https://doi.org/10.1093/ageing/afj054
- Murray, L. L. (2012). Cognitive-linguistic therapy for Parkinson's. American Journal of Speech-Language Pathology, 21(4), 351–364. https://doi.org/10.1044/1058-0360(2012/11-0082)
- Ramig, L. O., Sapir, S., Fox, C., & Countryman, S. (2001). Speech treatment for Parkinson's: Randomized controlled trial of LSVT. Neurology, 57(3), 492–498. https://doi.org/10.1212/WNL.57.3.492
- Troche, M. S., Okun, M. S., Rosenbek, J. C., et al. (2010). Aspiration and swallowing in Parkinson's. Movement Disorders, 25(10), 1572–1579. https://doi.org/10.1002/mds.23151
- Marks, L., Turner, K., O'Sullivan, J., Deighton, B., & Lees, A. (2001). Drooling in Parkinson's disease: a novel speech and language therapy intervention. International journal of language & communication disorders, 36 Suppl, 282–287. https://doi.org/10.3109/13682820109177898

Occupational Therapy

- Clemson, L., Mackenzie, L., Ballinger, C., Close, J., & Cumming, R. G. (2008). Environmental interventions to prevent falls in community-dwelling older people: A meta-analysis of randomized trials. Journal of Aging and Health, 20(8), 954–971. https://doi.org/10.1177/0898264308324672
- Foster, E. R. (2014). Instrumental activities of daily living performance among people with Parkinson's: A review. Physical & Occupational Therapy in Geriatrics, 32(1), 39–52. https://doi.org/10.3109/02703181.2013.875081
- Gillespie, L. D., Robertson, M. C., Gillespie, W. J., et al. (2012). Interventions for preventing falls in older people living in the community. Cochrane Database of Systematic Reviews, (9), CD007146. https://doi.org/10.1002/14651858.CD007146.pub3
- Gitlin, L. N., Winter, L., Dennis, M. P., Corcoran, M., Schinfeld, S., & Hauck, W. W. (2006). A randomized trial of a multicomponent home intervention to reduce functional difficulties. Journal of the American Geriatrics Society, 54(5), 809–816. https://doi.org/10.1111/j.1532-5415.2006.00703.x
- Nieuwboer, A., Rochester, L., Müncks, L., & Swinnen, S. P. (2009). Motor learning in Parkinson's: Limitations and potential for rehabilitation. Parkinsonism & Related Disorders, 15(Suppl 3), S53–S58. https://doi.org/10.1016/S1353-8020(09)70781-3
- Sturkenboom, I. H. W. M., Thijssen, M. C. E., Gons-van Elsacker, J. J., et al. (2014). Effectiveness of occupational therapy in Parkinson's (OTiP trial): A randomised controlled trial. The Lancet Neurology, 13(6), 557–566. https://doi.org/10.1016/S1474-4422(14)70055-9
- van der Marck, M. A., Klok, M. P. C., Okun, M. S., et al. (2014). Consensus-based clinical practice recommendations for falls in Parkinson's. Parkinsonism & Related Disorders, 20(4), 360–369. https://doi.org/10.1016/j.parkreldis.2013.12.030

Costs of Parkinson's

- WHO technical brief, Parkinson disease: a public health approach (WHO, 2022)
- Participants with a neurodegenerative condition in the NDIS (NDIS, 2021)
- Deloitte Access Economics: Living with Parkinson's Disease An updated economic analysis 2014 Parkinson's Australia Inc.; cited 11 Nov 2024
- Bohingamu Mudiyanselage, S., Watts, J. J., Abimanyi-Ochom, J., Lane, L., Murphy, A. T., Morris, M. E., & Iansek, R. (2017). Cost of Living with Parkinson's Disease over 12 Months in Australia: A Prospective Cohort Study. Parkinson's disease, 2017, 5932675. https://doi.org/10.1155/2017/5932675
- Ecosystem of Parkinson's in Australia Parts 1, 2, & 3 (Mellick, 2024)
- Bramble, M., Wong, A., Carroll, V., Schwebel, D., & Rossiter, R. (2021). Using an economic evaluation approach to support specialist nursing services for people with Parkinson's in a regional community. Journal of advanced nursing, 77(12), 4722–4732. https://doi.org/10.1111/jan.14920
- Chaudhuri, K. R., Azulay, J. P., Odin, P., Lindvall, S., Domingos, J., Alobaidi, A., Kandukuri, P. L., Chaudhari, V. S., Parra, J. C., Yamazaki, T., Oddsdottir, J., Wright, J., & Martinez-Martin, P. (2024). Economic Burden of Parkinson's Disease: A Multinational, Real-World, Cost-of-Illness Study. Drugs - real world outcomes, 11(1), 1–11. https://doi.org/10.1007/s40801-023-00410-1