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National Advocacy • Connection • Awareness

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Senate Standing Committees
on Community Affairs
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Dear Committee Secretary,

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

Parkinson's Australia submits this supplementary report to address the systemic dangers the National Disability Insurance Scheme Amendment (Securing the NDIS for Future Generations) Bill 2026 poses to Australians living with Parkinson's disease. Parkinson's is a progressive, incurable neurological condition. With over 150,000 Australians diagnosed, including 30,000 of working age, the proposed reforms represent a fundamental threat to the clinical safety and functional independence of this cohort. This Bill prioritises fiscal sustainability through rigid administrative pacing and algorithmic gatekeeping that fails to account for the fluctuating and degenerative progression of neurological conditions.

1. Prevalence & Clinical Reality

Parkinson's is the second-most common neurological condition globally, fastest growing, and imposes an economic burden exceeding $10 billion per annum on the Australian economy. One Australian is diagnosed every 27 minutes. The condition is progressive and remains incurable. The clinical complexity of Parkinson's requires highly specialised supports. A legislative framework that treats disability as a static or predictable state, as this Bill does, ignores the reality of millions of Australians living with chronic conditions and risks causing avoidable hospitalisations and health crises.

2. The 'Appropriate Treatment' Test & Permanence (Section 25A)

Parkinson's is a progressive neurodegenerative condition. Even where treatments improve a person living with Parkinson's (PwP) symptoms, they do not stop progression or cure the underlying neurodegeneration of the condition. The permanence of Parkinson's, or it's general worsening symptom trajectory, is not altered by:

- Medication
- Advanced therapies
- Surgical interventions
- Rehabilitation programs

A person's decision not to undertake an invasive treatment does not make their impairment any less permanent. The test should distinguish between treatment that may improve symptoms and treatment that fundamentally changes the long-term nature of an impairment. For Parkinson's, no currently available treatment slows or stops the condition from progressing over time.

The concept of "appropriate treatment" is also not fixed. What is clinically appropriate for one person with Parkinson's may be inappropriate, ineffective or unsafe for another, or as the condition progress things change with any combination of a constellation of nearly 50 motor and non-motor symptoms unique to each PwP.

Treatment decisions depend on:

- Age
- Symptom profile
- Cognitive status
- Mental health
- Co-existing health conditions
- Side-effects and medication interactions
- Personal circumstances
- Individual risk tolerance

Many evidence-based treatments have variable effectiveness and significant side effects. Public capacity is severely restricted, and out-of-pocket costs remain prohibitive for the majority of PwP. A person should not be required to undergo treatments that provide limited benefit or create unacceptable risks simply to satisfy an administrative eligibility test.

The proposed requirement for participants to exhaust all 'appropriate' evidence-based treatments to prove permanence (Section 25A) constitutes clinical coercion via administrative gatekeeping. This test mandates that the NDIA ignore the risks of invasive interventions and real-world barriers to specialist care.

Parkinson's Australia asks, what are considered 'appropriate' treatments?

- Medication, some come with unwanted side effects like Impulse Control Disorders or cannot be used because of co-morbidities
- Advanced therapies require long wait lists for the public system while PD progresses
- Invasive surgeries require a JPEG connection to the intestine or wires into the brain

For example, Section 25A could be utilised to mandate high-risk, invasive procedures such as Deep Brain Stimulation (DBS) as a prerequisite for NDIS eligibility. Australia, for example, performs nowhere near enough DBS public procedures per year for PwP with wait lists already 2-3 years long. It only treats a limited number of motor symptoms for a certain period of time. Clinical capacity and risks include: Public listing 1-3 years; assessment for DBS requires them to go off medications to test levodopa responsiveness; if deemed responsive, mentally fit and a suitable candidate they have to be willing to be awake for procedure; an invasive device is put in your body permanently; also get a battery implant in your chest to run the DBS. There is a suite of risks that come with the surgery including death. DBS does not stop the condition from progressing or symptoms from worsening.

3. The Danger of Rigid Funding Periods & "Budget Pacing"

The transition to the PACE computer system and the introduction of "budget pacing" (funding released in three-month blocks) is fundamentally incompatible with progressive neurological decline. While intended to prevent "overspending," this structure fails to accommodate the acute medical events common in Parkinson's.

Rigid funding periods prevent the immediate deployment of supports during rapid functional decline, inevitably leading to:

- Failure to onboard 24/7 care during acute phases.
- Inability to front-load allied health (high-intensity speech pathology or physiotherapy) required to slow functional loss.
- The transition of manageable clinical fluctuations into avoidable hospitalisation and family crisis.

4. Plan Suspensions for 'Uncontactable' Participants (Section 40A)

Section 40A grants the Agency the power to suspend or revoke a plan if a participant is non-responsive within a 90-day window. Parkinson's Australia opposes this provision in the strongest possible terms. In advanced Parkinson's, being "uncontactable" is frequently a direct clinical symptom, not willful non-compliance. Symptoms including dementia, apathy, delirium, or emergency hospitalisation due to falls render participants unable to respond to Agency queries. Revoking essential supports in these circumstances constitutes a severe safety risk and a gross failure of the NDIA's duty of care.

5. Functional Capacity Assessments & On-Off Fluctuations (Section 9B)

The Section 9B definition of functional capacity, measuring "intrinsic ability" as a point-in-time snapshot, is technically flawed for fluctuating conditions. It prioritises the I-CAN v6 assessment tool over real-world clinical fluctuations. Parkinson's is characterised by "on-off" medication fluctuations of a unique suite of over 50 possible symptoms. A participant may appear functionally independent during peak medication efficacy ("on"), but become totally immobile, unable to speak, or incapable of swallowing minutes later as medication wears off ("off"). A snapshot assessment that ignores these fluctuations underestimates the level of support required for basic independece.

6. Restrictive Reassessments: 90-Day Window & 'Ongoing' Change

The Bill limits unscheduled plan reassessments to cases of "significant and ongoing change," introducing an administrative hurdle that is life-threatening for participants experiencing acute neurological events (e.g., falls with injury) requiring immediate intensive support to prevent permanent institutionalisation. Participants with sudden dysphagia (inability to swallow) also cannot wait 90 days for a decision before receiving life-saving therapy.

Exclusion of support coordinators from requesting reassessments removes the advocate most qualified to identify rapid clinical decline in PwP's cognitive impairment, dementia or apathy.

7. Ministerial Powers, Section 10 Support Lists & Automated Decisions

The expansion of Ministerial authority under Sections 34A and 34B represents an unfettered control over disability funding that bypasses individualised assessment.

- Section 34A/34B & Section 10 Lists: The Minister may arbitrarily exclude supports via the "Out" list or reduce funding categories (e.g., social participation) by a percentage across entire cohorts. This ignores the "reasonable and necessary" requirements foundational to the NDIS Act 2013.
- Schedule 3 (Automated Decisions): Algorithmic funding for fluctuating conditions risks embedding systemic bias against non-linear disability profiles.
- Human Rights Breaches: The NDIS Act 2013 was legislated specifically to give effect to Australia's obligations under the UN Convention on the Rights of Persons with Disabilities (UNCRPD). These new powers directly contravene Article 26 (Habilitation and rehabilitation) and Article 28 (Adequate standard of living).

8. Demand for a Priority Access Pathway

For those living with Atypical Parkinsonism, the standard 90-day administrative window is not merely a delay; it is a period during which they may permanently and irreversibly lose the ability to speak or swallow. Legislative Necessity: Parkinson's Australia demands a "Priority Access Pathway" enshrined in primary legislation. This must ensure supports are deployed within weeks of diagnosis for rapidly declining conditions like MSA, PSP and LBD to prevent irreversible functional loss. Internal policy guidelines are insufficient to protect this vulnerable cohort.

9. Early Intervention vs. Foundational Supports

The proposed "Foundational Supports" (general community support) are a clinically inadequate substitute for the NDIS-funded early intervention required by Young Onset Parkinson's participants.
1. Workforce Maintenance: Participants require intensive, targeted therapies to remain in employment. Generic community support lacks clinical specificity to maintain workforce participation.
2. Specialised Therapy: Foundational supports do not encompass the high-cost neurological physiotherapy and speech pathology required to delay functional decline.
3. Economic Insufficiency: Relying on general community services for complex neurological pathology will speed up the transition from independence to high-cost, total-care dependency.
10. Conclusion & Recommendations

The NDIS Amendment (Securing the NDIS for Future Generations) Bill 2026 prioritises fiscal sustainability over clinical safety. The move toward rigid pacing, Section 10 restricted lists, and snapshots of functional capacity will lead to systemic failure for the Parkinson's and Parkinson's Plus communities.

List of Recommendations

- Amend Section 25A: Remove the requirement to "exhaust all treatments" where treatments are invasive, high-risk, do not have enough places each year or geographically/financially inaccessible.
- Redefine Functional Capacity (Section 9B): Mandate that assessments account for "on-off" fluctuations and periods of medication non-efficacy.
- Legislative Priority Access: Enshrine a fast-track pathway for rapidly progressing neurological conditions in the primary Act.
- Limit Ministerial Power: Ensure any cohort-wide funding reductions are subject to independent clinical impact assessments and remain appealable.
- Protective Suspensions: Prohibit the suspension of plans for "uncontactable" participants where cognitive impairment, apathy, or hospitalisation is documented.
- Acute Event Exemption: Exempt progressive conditions from the 90-day administrative wait times for reassessments following acute health events.

Again, we offer that 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.

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Parkinson's Australia