



**parkinson's**  
**australia**

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# Consultation Aged Care Act Rules release 2a – Funding for Support at Home program



## Executive Summary

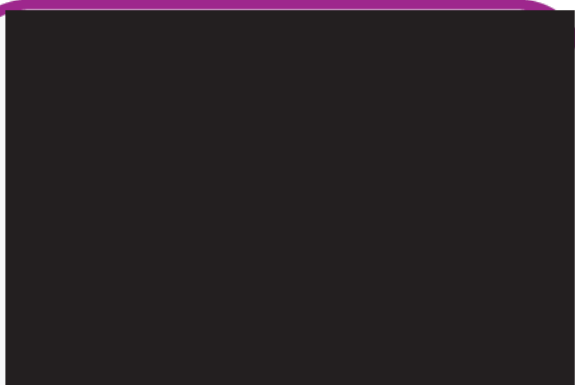
### Parkinson's Australia Submission to the ACA Rules - Support at Home

At Parkinson's Australia, we deeply understand the profound impact that dignified and compassionate care has on the lives of individuals living with Parkinson's disease.

The proposed changes to the Aged Care Act present a critical opportunity to enhance the quality of care for our ageing population, ensuring that their needs are met with respect, empathy, and integrity.

Our submission and supporting case study aim to highlight the necessity of these reforms in fostering an environment where every individual receives the care they deserve - care that upholds their dignity and acknowledges their unique challenges and contributions to our community.

We urge policymakers to embrace these recommendations, as they represent a pivotal step towards a more inclusive and humane aged care system.



#### Case Study Summary

*The system of diagnosing Parkinson's, as well as the support my husband needed upon his diagnosis whilst in residential aged care, failed him. The New Aged Care Act 2024, as it stands, will not improve outcomes for others like him with Parkinson's.*

**Recommendation 1:** The 'rules' need to define and include allowances and supplements to ensure that people managing a wide range of recognised disability and complex health conditions like Parkinson's can receive the essential support that they require.

**Recommendation 2:** The proposal to introduce individual contributions must be scrapped having acknowledged the financial hardship for people on low incomes. Parkinson's suggests that the existing income-tested fee criteria and assessment continues with the new support at home program.

**Recommendation 3:** The current basic daily fee needs to be removed from the home care packages and Support at Home programs to acknowledge that the majority of not-for-profit and community-based service providers do not collect the fee.

**Recommendation 4:** If individual contributions are not scrapped, the Aged Care Act and the 'rules' must support the recommendations of the Royal Commission and the Aged Care Task Force by:

- ensuring a strong safety net for low-means participants to meet aged care costs, and
- ensure that participants are left with disposable income needed to pay for essential services and out of scope supports that they need to sustain meaningful levels of independence in their own homes across their lifetime.

Parkinson's Australia is the national advocacy body for people living with Parkinson's, their families and carers, researchers and health professionals. We promote the best possible quality of life for people with Parkinson's.

Parkinson's Australia represents one of the most vulnerable groups in Aged Care – those with a neurodegenerative, incurable condition that has debilitating motor and non-motor symptoms.

There are in excess of 150,000 people living with Parkinson's in Australia.

**Parkinson's Australia is concerned that the 'Funding Rules' do not recognise nor accommodate the needs of a person managing complex conditions such as Parkinson's disease.**

## Introduction

To truly value your life as you age, it's essential to recognise that care and dignity go beyond physical tasks. You don't lose your identity when you care for others, nor should you feel diminished when others care for you.

Life encompasses more than just your physical being. It's about your role in society and the contributions you make to others. This doesn't change as you age or face disabilities.

In the current form, the Support at Home program [1] will not support our most vulnerable older persons with disability to have input into the supports to be received or over how those supports will be delivered to them.

Parkinson's Australia fears for our community who will be unable to maintain their independence and dignity in their own home and that they will be forced into residential aged care facilities.

## Understanding Parkinson's

Parkinson's disease is a whole-body, neurodegenerative, progressive condition that affects movement, mood, sleep, voice, vision and the gastrointestinal system.

The pathophysiology of Parkinson's is complex and involves multiple chemical messengers (neurotransmitters), resulting in many changes to a person's normal functioning and everyday life [2].

In Parkinson's disease, nerve cells in the brain called neurons slowly break down or die. Many Parkinson's symptoms are caused by the loss of neurons that produce chemical messengers in the brain. The main messenger involved is called dopamine, which regulates mood and movement.

Decreased dopamine leads to irregular brain activity. When 60% to 80% of these dopaminergic neurons are lost, this causes the hallmark movement symptoms of slowness, rigidity, and one-sided tremor.

People with Parkinson's also lose a chemical messenger called norepinephrine that controls many automatic body functions, such as blood pressure and temperature regulation [3].

Early signs of Parkinson's include a reduced or loss of sense of smell, depression and/or anxiety, sleep issues, constipation and handwriting changes.

## Supporting a person managing Parkinson's

In the current form the Support at Home is not a program that will support our most vulnerable elders to have input into the supports to be received or over how those supports will be delivered.

Parkinson's Australia fears for our community who will be unable to maintain their independence and dignity in their own home and will be forced into residential aged care facilities.

Inequity of support is a reality for people living with Parkinson's, and managing similar conditions. Due to a year difference in age, those aged 64 will receive many supports and services under NDIS that assist them to maximise wellbeing; while those over the age of 65 are left to finance the gaps in the systems and failure to recognise and support their individual need.

People with Parkinson's require regular medical review. There are a range of medications that have been demonstrated to be effective treatments for Parkinson's disease. Medications need to be administered at regular intervals with regular assessment for change. They are chemicals that pass into the brain to perform a similar function to dopamine.

Treatment is likely to include regular and ongoing aerobic exercise, physical therapy that focuses on balancing and stretching, and speech therapy. Parkinson's is a disease that can be managed in the home environment, as long as the people providing care are supported to be able to respond in a timely and appropriate manner.

Supporting people in their own homes has been shown to be the better environment to provide such specialist supports. The regime in residential care often fails to accommodate such specialist needs.

Proven services and activities to support people with Parkinson's include but are not limited to Exercise Physiology, Physiotherapy, Speech Pathology, Occupational Therapy, Dance and Art Therapies, Education Counselling and Social Support [4].

**Recommendation 1:** The 'rules' need to define and include allowances and supplements to ensure that people managing a wide range of recognised disability and complex health conditions like Parkinson's can receive the essential support that they require.

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## NDIS vs Aged Care Support for PD

Firstly, and most significantly, NDIS is not means-tested or subjected to services related to aging. Aged Care Funding is means-tested and if the current Aged Care Bill progresses through parliament, all people receiving aged care services will be subjected to individual contributions regardless of whether they are full pensioners or not.

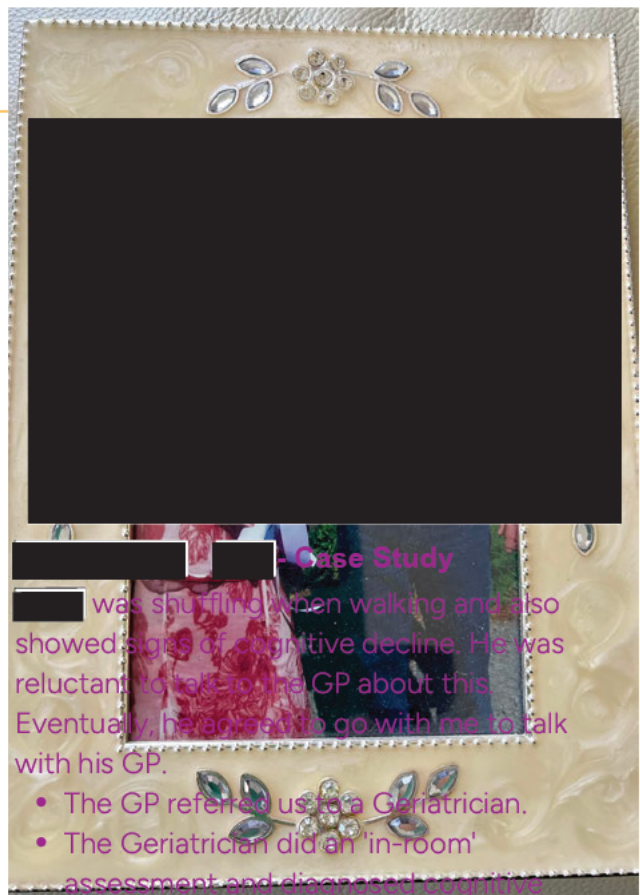
Aged Care: Support at Home will be income assessed and their Individual Contributions [5] for each and every service will range from:

- Zero, for services classified as clinical services
- 5% to 50% for services classified as independent living
- 17.5% to 80% for support classified as everyday living.

For example, a pensioner is estimated by the department to contribute \$95 from the \$1144 per fortnight pension. That is \$2,500 a year. It might not seem much to someone on the average Australian wage [6] of \$1,923.40 per week or \$100,016.80 per annum.

However, I can assure you that \$95 is a massive amount for people battling the raging costs of living from their annual pension of \$30,000.

Furthermore, we do appreciate the government for listening to feedback and lifting the cap on gardening and cleaning in Support at Home packages.



### Case Study

█ was shuffling when walking and also showed signs of cognitive decline. He was reluctant to talk to the GP about this. Eventually, he agreed to go with me to talk with his GP.

- The GP referred us to a Geriatrician.
- The Geriatrician did an 'in-room' assessment and diagnosed cognitive decline, but definitely no Parkinson's. Suggested MRI. But then... COVID.
- Approximately 9-12 months later MRI with the outcome, Vascular Dementia. Still no mention of Parkinson's.
- 1-2 years living at home. Then he entered Residential Aged Care (RAC).

█ lived in a dementia-specific facility, for three years in Tasmania. No Geriatricians were visiting RAC facilities at that time due to restrictions associated with COVID.

█ received some physiotherapy (PT) by a nearby Tasmanian multidisciplinary allied health organisation in RAC after COVID restrictions were eased. This was under a particular Government Scheme that had random 1:1 support around 2-3 times per week.

The Government changed the Allied Health Scheme in 2022 and put it out to tender. In the RAC facility (RACF) where █ lived the allied health contract was awarded to an inter-state company who contracted Physiotherapists locally. The system was piecemeal. We didn't know who or when they would come. They did some group sessions and occasionally 1:1 for approx. 15-20 minutes but there was no continuity.

## So, what do the changes mean for someone receiving aged care support?

In a nutshell, an enormous reduction in disposable income to pay for things out of scope in the programs such as recreational activities. Restricted opportunity to join family and friends at community events where there is a high admission cost and/or travelling /carer expense. School concerts are already beyond the means of many low-income grandparents, now this tax on their frailty and disability places them at a further disadvantage and second-tier citizenship.

But for many the biggest consequence of Aged Care vs NDIS is the lack of recognition and understanding of the impact upon them and their partners as a result of their disability. People with Parkinson's are likely to face confusion, erratic functional mobility, limb tremors and uncontrolled bowel movements. With great care and support many of these conditions can be managed and social outings planned around the support that is needed.

Sadly, much-needed support is unlikely to occur in residential care let alone in the home environment. Parkinson's like many conditions is expensive, not only on the individual but their entire family and support mechanisms .



## At the same time, I requested a review of [REDACTED] by a Geriatrician.

The original Geriatrician had no scope to attend RACF's. The visiting GP at RACF wished for Gene to be taken to the previous Geriatrician, an hour's return trip away. [REDACTED] and I did not want that, because he felt his visits to her prior to going into RAC were not very helpful. Also, [REDACTED] still had sufficient cognitive capacity to explain and see the value of being re-assessed by a new Geriatrician in situ, seeing him functioning around his environment.

After much advocacy with the RACF GP and the clinical staff, it was agreed that [REDACTED] could be referred to a Geriatrician who came on-site. During the consult with the new Geriatrician, he proposed that [REDACTED] may have Parkinson's and Dementia, Parkinson's as well as Parkinsonism. He suggested trying a small dose 50mg x3 of Parkinson's medication Levodopa. [REDACTED] was reluctant. After approximately two months he agreed.

He saw improvement within around two weeks. After another review with the geriatrician [REDACTED] agreed to regular increases in Levodopa as recommended to aid functioning. This was approximately 14 months before he died. Over that period Gene's levodopa increased to 400mg x 3 times per day.

## Support at home should be the subsidy

To suggest that ALL PEOPLE can afford to pay Individual Contributions is utter rubbish!

It is absolutely unbelievable to suggest that all people are able to pay for aged care support. The Aged Care Task Force report [7] recognised that 12% currently do contribute, that is 82% of current homecare package recipients have been income assessed by Services Australia under current guidelines that they are exempt from paying income-tested fees. Services Australia sets a high bar for people to receive a full pension and an extremely high bar for partially self-funded retirees to receive a pension let alone a health care card.

There is even a higher bar for people to receive aged care support via a home care package. The reality is that people on pensions and low incomes are being doubly disadvantaged. They can no longer do such things as shower, clean, prepare meals safely, all things they could once do for themselves. People with Parkinson's and other significant disability have the added challenge of managing chronic and progressive disease and debilitating conditions.

Not ALL people can pay and nor should they be expected to. People on low incomes should not be subjugated to a system that will prevent them from living in a community.

This Act and the funding rules will create greater division in the community between those who can afford services and those who cannot.



## demise and death on 30 June 2024.

In early June 2024, unit of eight people where he lived had a case of COVID. The person was confined to their room. At the same time as this single-person outbreak, all external doors were locked. Residents were locked into the unit.

I emailed management on 5th June 2024. See below my questions in an email to management, and their reply in *red italics*:

1. Can be allowed to move for a part of the day outside of the house to enjoy some fresh air, and exercise whilst he is a close contact. And if so, under what conditions? *I agree that fresh air would be beneficial however we can't allow to walk around the village whilst xxxxxx is on lockdown. We don't have any other area where he could either. You are welcome to take out as often as you wish though.*
2. That he be given some physio attention or exercise in his room to assist in his mental and physical health. His mobility due to Parkinson's has declined recently. He cannot afford to have no exercise for an undetermined time. *Again, I totally understand. I can ask physio to work with staff on some exercises that could do in his room or around the house.*

Due to the above response, I requested help from Advocacy Tasmania (OPAN). I waited a few days for someone to get back to me as they were inundated with requests for help.



The one-size-fits-all model of assessment and service provision cannot address the needs of people living with a disability. Parkinson's is a complex condition with many motor and non-motor symptoms that are chronically progressive and degenerative. The Support at Home program has an over-emphasis of supporting services only where it can be demonstrated that they are needed due to age-related decline, not disability, injury or chronic conditions.

In-home care and services are essential, and Support at Home must not become a glib statement.

Parkinson's Australia is extremely concerned that people on low incomes will not be able to fund the services they need to remain in the community and in their own homes. The alternative is fraught with risk and systemic failure. Far too many residential care providers have not been able to demonstrate that people with Parkinson's will receive their medication and allied health supports in a timely way so as to prevent sudden and permanent decline in their health.

**Recommendation 4:** If Individual contributions are not scrapped, the Aged Care Act and the 'rules' must support the recommendations of the Royal Commission and the Aged Care Task Force by:

- ensuring a strong safety net for low-means participants to meet aged care costs, and
- ensure that participants are left with disposable income needed to pay for essential services and out of scope supports that they need to sustain meaningful levels of independence in their own homes across their lifetime.

### This is what the Advocate wrote to the facility management...

I am a client-directed advocate working with █████ and his wife █████ has informed me of the recent lockdowns in xxxxxx due to positive cases of Covid-19 of residents, which has meant that █████ and the other residents have been restricted from leaving the house to access other areas, irrespective of whether they have been returned positive tests for Covid-19.

█████ has also informed me of your agreement to her being able to take █████ off the premises. However, the point I wish to raise is the denial of █████ accessing the outside areas of xxxxxx and having freedom of movement.

As I write █████ has spent upwards of two weeks in xxxxxx with the exception of one outing supported by █████. With three other residents returning positive tests in the past couple of days, it is apparent that the lockdown of all residents of xxxxxx will possibly go on for several weeks irrespective of whether or not they have Covid-19.

█████ has expressed this week that his mental health has declined significantly. He has spent a significant period of time sitting in his chair inactive and experienced several falls in the past 5 days. He has been very unhappy in isolation, with no definite end date in sight.

It is undeniable that residents who are positive for Covid-19 need to be properly isolated according to appropriate guidelines and policies to minimise the risk of infection to other residents, family members and staff.



## The Aged Care Bill 2024 proposes a Tax on frailty and disability

Royal Commission into Aged Care Quality and Safety; both commissioners were quite clear in their summary and recommendations that a hypothecated tax or levy should be introduced to pay for Aged Care Services.

*A philosophical shift is required that places the people receiving care at the centre of quality and safety regulation. This means a new system empowering them and respecting their rights. An independent Aged Care Commission with guaranteed funding through a hypothecated Aged Care Levy will, in my view, create the substrate upon which this change in philosophy can flourish.[8]*

**Recommendation 144: Introduce a new earmarked aged care improvement levy**

1. By 1 July 2022, the Australian Government should introduce legislation to Parliament to establish an aged care improvement levy of a flat rate of 1% of taxable personal income. The levy imposed should be levied, and paid, for the financial year commencing on 1 July 2023 and for all subsequent financial years until the Parliament otherwise provides.
2. The legislation introducing the levy should be based on the Medicare Levy Act 1986 (Cth).[9]



However, whilst policies or isolation in the current fashion may have been appropriate and lawful during the height of the Covid-19 pandemic, isolating entire houses irrespective of diagnosis is no longer appropriate in the absence of a Public Health Order; particularly where it significantly impacts the rights, health and wellbeing of residents.

On behalf of [G] I wish to request that freedom of movement be restored to [ ] and other residents who have not tested positive for Covid-19, and to lodge a complaint regarding the practices being undertaken. To support this request, I point to the following:

- There are no current Public Health Orders in place regarding Covid-19.
- Residents who are Covid-19 positive are able to be effectively isolated in their rooms, which is currently occurring in addition to xxxxxx being on lockdown as a whole.
- According to the Aged Care Quality and Safety Commission: "Environmental restraint is a practice or intervention that restricts, or involves restricting, a care recipient's free access to all parts of their environment (including items and activities) for the primary purpose of influencing their behaviour. The care recipient's environment is taken to include the care recipient's:
  - room,
  - any common areas within the facility,
  - the common grounds outside of the facility.

## Rules: Chapter 10 Means testing Part 2 Means testing in a home or community setting Division 1 Section 314AA

It is very clear, by the intent that all people will be subject to individual contributions, and what's more this principle not only ignores the recommendations of the Royal Commission but also of The Aged Care Task Force which stated in their report [10].

*Recommendation 3: It is appropriate older people make a fair co-contribution to the cost of their aged care based on their means.*

*Recommendation 4: Ensure a strong safety net for low-means participants to meet aged care costs.*

Sadly, I cannot find that assurance for safety nets in the aged care Funding Rules nor in the associated Social Security legislation that will provide meaningful support to people on low incomes managing complex conditions such as Parkinson's disease.

Whilst it is not suggested that the restriction from the common grounds is for the purpose of influencing behaviour, it is important to point to the practice of environmental restraint being a last resort and needing to be the least restrictive possibility.

- According to the Communicable Diseases Network Australia's National Guidelines for the Prevention, Control and Public Health Management of Outbreaks of Acute Respiratory Infection (including COVID-19 and influenza) in Residential Care Facilities (the Guidelines), 'The risk of transmission should be managed whilst balancing the risk related to social isolation and deconditioning through application of the least restrictive controls appropriate'. [REDACTED] has expressed that he is experiencing severe impacts to his mental health, and that the lockdown is undoubtedly having a negative compounding effect on his physical wellbeing. It is insufficient to propose the solution of a staff member coming to inform [REDACTED] of some more physical activities he can do in his room after requests have been made for a physical therapist to attend to his physical decline twice a week as usual to assist with his physical care of Parkinson's symptoms. The positive impact of walking and fresh air cannot be overstated.
- [REDACTED] and [REDACTED] do not suggest that [REDACTED] and other exposed residents be able to access all areas, just that they be able to access an outside area to be able to walk, breathe fresh air, have some sun exposure or sit, utilising a N95 as required.

Would you kindly advise why this has not been facilitated? The Guidelines are clear that exposed residents should not socialise with positive cases or residents from unaffected areas. Freedom of movement in appropriate areas and the ability to exercise does not amount to socialisation if supported and facilitated effectively.

## Hardship Provision: 'The Rules' How to Access department guidelines

*Aged Care Claim for financial hardship assistance form (SA462) [11].*

*To fill in this form digitally you will need a computer and Adobe Acrobat Reader, or a similar program. You can download Adobe Acrobat Reader for free. If you can't complete the form digitally, you can print it, complete it by hand and return it to us following the instructions on the form.*

*If you have a disability or impairment and use assistive technology, you may not be able to access our forms. If you can't, please use self-service, request someone to deal with us on your behalf, or contact us. We can help you access, complete and submit them.*

There is no provision within the Aged Care Act, rules or the Social Security Act that includes the cost of managing disability in the Meaning of essential expenses for a recipient of home care [12]. This definition is used to access essential expenses when making decisions and fee reduction and/or exemption. Anyone living with a disability will inform you very quickly that yes disability supports are essential.

*The system of diagnosing Parkinson's, as well as the support my husband needed upon his diagnosis whilst in residential aged care, failed him. The New Aged Care Act 2024, as it stands, will not improve outcomes for others like him with Parkinson's.*

- The lockdown of the entire house is not the least restrictive option, as there are alternative options for isolating symptomatic Covid-19 patients within the area without restricting the reasonable freedom of non-symptomatic residents.
- It is imperative that ████████ and other residents' rights under the Charter of Aged Care Rights are not restricted. In particular the right to independence, and the right to have control over, and make decisions about, the personal aspects of daily life.
- Under the Aged Care Quality Standards, notably standard 4 requirements 3(a), 3(b) and 3(c), each resident should be supported in their activities of daily living and engagement in a manner that promotes residents' emotional, psychological and physical health.

We request that given the above justification, ████████ right to movement be upheld and xxxxxx provides the means, for example, a cordoned-off outside area staff to accompany or support him with the option to leave xxxxxxxx house to safely access outdoor areas, with no need for isolation in the absence of a Covid-19 diagnosis.



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## Section 197A 24 Care Rules 2024

### Part 5—Secondary person-centred supplements for home support, assistive technology and home modifications

This part of the rules only considers general expenses and does not consider the extra expense that a person with Parkinson's and/or other disability and/or complex health conditions need to pay. There are a wide range of activities that people with Parkinson's can no longer perform for themselves, that are not included in the Support at Home Program. This includes but is not exclusive to essential home maintenance, fixing leaking taps, non-PBS medication and extra costs of maintaining contact with family and community.

### Subdivision E—Primary person-centred supplements

There are extra supplements and or considerations for Providers supporting people requiring oxygen, feeding needs, management for dementia, veteran's mental health and for people living in rural and remote communities but not for people requiring specialist services and support to address complex and progressive conditions such as Parkinson's.

### Section 205B Care management supplement—applicability

There are case management supplements for people who have experiences of homelessness, institutionalised care, abuse etc., but not for specific disability needs.

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## Division 2—Available assistive technology account balance

### Section 211B Account period for classification type short-term

(b) if subsection (2) applies to the individual:

- (i) the period of 24 months beginning on the entry day for the individual; or
- (ii) if the System Governor determines a longer period for the individual under subsection (6)—that longer period.

(2) This subsection applies to an individual if a medical practitioner has certified, in writing, that the individual has been diagnosed with any of the following conditions—

- (a) cerebral palsy;
- (b) epilepsy;
- (c) Huntington's disease;
- (d) motor neurone disease;
- (e) multiple sclerosis;
- (f) Parkinson's disease;
- (g) polio;
- (h) spinal cord injury;
- (i) spinal muscular atrophy;
- (j) stroke;
- (k) other acquired brain injury;
- (l) muscular dystrophy or muscular atrophy.

Given that a number of complex disability and health conditions are recognised with regard to supply of assistive technology, why has this recognition not also been extended to specialist need in care and service provision in the Support at Home program?

Though there are 8 classifications of Support at Home services, options and supplements are all defined by the same rules within the Act.

## Section 234 Part 8—Subsidy for certain specialist aged care programs [to be drafted]

## Section 273B Division 3—Fees and contributions for specialist aged care programs [to be drafted]

Question: what are the [to be drafted] certain specialist aged care programs? Whatever they are, they must include provisions in both residential and home care settings.

### FINAL SUMMARY: Parkinson's Australia Submission to the ACA Rules - Support at Home

We want to iterate that we understand the profound impact that dignified and compassionate care has on the lives of individuals living with Parkinson's disease.

The proposed changes to the Aged Care Act present a critical opportunity to enhance the quality of care for our ageing population, ensuring that their needs are met with respect, empathy, and integrity.

Our submission and supporting case study highlight the necessity of these reforms in fostering an environment where every individual receives the care they deserve - care that upholds their dignity and acknowledges their unique challenges and contributions to our community.

We urge policymakers to embrace the following recommendations, as they represent pivotal steps towards a more inclusive and humane aged care system. We can significantly improve the quality of life for those affected by Parkinson's and create a more compassionate and effective aged care system.

**Recommendation 1:** The 'rules' need to define and include allowances and supplements to ensure that people managing a wide range of recognised disability and complex health conditions like Parkinson's can receive the essential support that they require.

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