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National Advocacy • Connection • Awareness

SUBMISSION TO THE DEPARTMENT OF HEALTH AND AGED CARE CONSULTATION ON THE NEW AGED CARE ACT

FEBRUARY 2024

Executive Summary

Parkinson's Australia's concerns

Parkinson's Australia advocates for one of the most vulnerable groups within the aged care system – individuals grappling with a neurodegenerative, incurable condition characterised by debilitating motor and non-motor symptoms.

People with Parkinson's (PwP) experience extremely high levels of disease burden. Parkinson's in the initial stages is considered more burdensome than blindness and deafness; PwP in the intermediate stages is more burdensome than primary progressive multiple sclerosis and on-par with severe depression; and PwP in the final stages is more burdensome than living with disseminated colorectal cancer, and on par with terminal stage cancer or severe dementia (Deloitte, 2015).

RECOMMENDATIONS:

- That a rigorous ongoing monitoring process is adopted together with a 5-year Review.
- The public release of the findings and recommendations of the Aged Care Task Force be adopted into the exposure draft of the Act.
- The category of disability to access aged care supports should be recognised in the Act accordingly.
- Assessments are conducted in partnership with the older person and their representatives and do not take a one size fits all approach.
- Supports for people with disability aged over 65 years be made an explicit reason to access the aged care system in the Eligibility for Entry section of the Act.
- Supports for younger people with disabilities requiring support from residential aged care facilities be recognised.
- That Consumer Directed Care be reinstated into the Act along with the proposed "rights-based" approach.
- That the principles of consumer directed care are directly enforceable.
- That there is a requirement for co-planning not simply discussion.
- The new Act must clearly articulate those mechanisms that will ensure older people with disability will receive appropriate supports and services equivalent to the NDIS.
- The role of informal, unpaid carers and their importance to older people, as well as their needs, should be reflected in the relevant sections of the Act including equitable and timely access to respite and other available supports.



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About Us

There are up to 150,000 Australians living with Parkinson's.



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.

We advocate for the Parkinson's community on issues of national significance.

We work to reduce the impact of Parkinson's by promoting best practice care to ensure that people can maximise their opportunities to live well and maintain their independence.

About Parkinson's

Parkinson's Australia represents over a million people impacted by Parkinson's. Over 90% of Australians living with Parkinson's or an Atypical Parkinsonism are over the age of 65. This number is currently estimated to be increasing by 19,500 per year. (See Mellick, Ecosystem of Parkinson's in Australia, 2024).

Parkinson's is the second most common neurological condition worldwide and the fastest growing. It can affect anyone, male or female and at any age, although it is significantly more common in older age. It is more than a tremor - now recognised as a progressive, whole-body disorder affecting the gastrointestinal system, sleep, motivation, vision, cognitive function, mood, and movement resulting in significant disability.

The stereotypical Parkinson's is seen in people over the age of 65 with motor symptoms including stiffness, slowness of movements, tremor at rest, and a shuffling gait with balance issues. However, early on it is an invisible illness with some early and impactful non-motor symptoms present decades before motor symptoms. These include small handwriting, diminished or loss of sense of smell, excessive sweating, and sleep disorders like restless leg syndrome and REM sleep behaviour disorders. Unexplained fatigue, anxiety, depression, constipation, changes to the voice, and pain also may occur. There are now more than 50 symptoms reported to be associated with Parkinson's with the nature and severity of symptoms varying considerably from one individual to another.

The reported annual impact on the Australian economy in 2014 was over \$10 billion (See Deloitte, Living with Parkinson's Disease – An updated economic analysis 2014, Published 2015); based on Deloitte's growth forecast, ten years on it is estimated to be over \$16 billion.

Parkinson's Australia's concerns

The following are concerns Parkinson's Australia has about the draft exposure released for consultation.

The genesis of the draft has been long and complex based as it is on many reviews, the Royal Commission and consultations. It is not possible to know from a consumer viewpoint how the moving parts will come together in delivering and enforcing a rights-based approach and the implementation of consumer directed care.

We need to ensure that at last delivery of aged care services puts decision-making and planning into the hands of consumers, albeit in partnership with health and care staff. This is particularly in respect of planning which is so important for people living with Parkinson's.

RECOMMENDATION:

That a rigorous ongoing monitoring process is adopted together with a 5-year Review.

Inadequate Support at Home

Unfortunately, we feel the current iteration of the Support at Home program fails to adequately address the needs of our most vulnerable older people, lacking mechanisms for them to provide input on the support they receive or how it is delivered.

RECOMMENDATIONS:

- **The public release of the findings and recommendations of the Aged Care Task Force be adopted into the exposure draft of the Act.**
- **The category of disability to access aged care supports should be recognised in the Act accordingly.**

Enforceability of Consumer Directed Care

Consumer Directed Care (CDC) is a crucial concept in the field of aged care. It emphasises flexibility, choice, co-planning and individual control for older people who receive care and services. While the foundational principles are embedded in the draft there is a need for the consumer to be able to directly enforce consumer directed care in the areas of assessment, co-planning and service delivery.

CDC was a 2016 amendment to the current 1997 Aged Care Act; it is missing from the proposed bill. Parkinson's Australia fears for our community who will be unable to maintain their independence and dignity in their own home and be forced into Residential Aged Care Facilities (RACFs).

RECOMMENDATION:

- **That Consumer Directed Care be reinstated into the Act along with the proposed “rights-based” approach.**
- **That the principles of consumer directed care are directly enforceable.**
- **That there is a requirement for co-planning not simply discussion.**



No recognition of disability, in addition to ageing and fragility

Parkinson's Australia believes a one-size fits all model of assessment does not address people living with Parkinson's which is a complex condition with many motor and non motor symptoms that are chronically progressive and degenerative. There has been an over emphasis on only supporting services where it can be demonstrated that they are needed due to age-related decline, not disability, injury or chronic conditions.

The assessment process for a service plan does not sufficiently ensure an individual's needs are taken fully into account in the assessment outcomes. Parkinson's is an individualised condition which affects every person differently, symptoms are highly variable and fluctuate from day to day and is degenerative and progressive. While a discussion with the older person seeking to receive aged care services is required under the exposure draft, no mention is made of the required service plan, nor a requirement to work together so that service plan can accommodate chronic and progressive disabilities like Parkinson's.

Furthermore, many people in the early stages of Parkinson's disease do not meet the eligibility criteria for the NDIS but would benefit from access to community-based cognitive rehabilitation and other supports, including carer supports that may prevent or delay their entry to residential aged care. We also note that the disability service system is currently not always able to meet the needs of people living with younger onset Parkinson's, and that they should not be refused access to funded aged care supports if required.

RECOMMENDATIONS:

- **Assessments are conducted in partnership with the older person and their representatives and do not take a one-size fits all approach.**
- **Supports for people with disability aged over 65 years be made an explicit reason to access the aged care system in the Eligibility for Entry section of the Act.**
- **Supports for younger people with disabilities requiring support from residential aged care facilities be recognised.**

Vast funding inequities between My Aged Care and the NDIS

We have people living with Parkinson's, suffering from the same condition but due to one year difference in age, have significant inequities in support and service funding. 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 waiting for packages, can't find the supports they need on Commonwealth Home Support Programme (CHSP) or don't qualify for other assistance such as short-term restorative care.

At the moment, with our current aged care services versus those on NDIS it's a case of the haves and the have-nots. Currently, all people who acquire a disability on or after the age of 65 years must obtain support for their disability from the aged care system. Accordingly, the Act should recognise the reasons why older people with a disability are seeking services from aged care to improve or maintain their functions. improve their quality of life and maintain their independence.

Currently aged care packages are grossly inadequate for older people with disabilities such as those resulting from the conditions represented by the NAA. An older person with disability may only get a package to a maximum of \$60,000, which means extremely limited supports. The cost of individual NDIS packages for participants with neurological conditions is comparatively high. The average payment for participants with 'other neurological' primary disability type is \$125,000, a 19% increase on the previous year (Participants with a neurodegenerative condition, NDIS Report, 31 March 2021).

RECOMMENDATION:

- **The new Act must clearly articulate those mechanisms that will ensure older people with disability will receive appropriate supports and services equivalent to the NDIS.**

PLEASE SEE CASE STUDY NEXT PAGE

ATYPICAL PARKINSONISM CASE STUDY: M. Rocliffe and wife, Mags, who is living with an Atypical Parkinsonism, Multiple System Atrophy

“I’m just seeing our savings haemorrhaging away as we try our best to maintain a normal home and work balance, whilst watching my wife Mags die a slow and degrading death from Multiple System Atrophy”. M Rocliffe

Support p/a	Actual care needs
HCP Level 4 \$53,000	Personal means test -\$12,000
PEG & Dementia supports \$15,000	“Let’s Get Care” Fees (HCP) -14%
BALANCE \$48,160 equates to approx. 23hrs care/week	COST OF SHORTFALL -\$40,310 need 40 hrs care/week -17hrs care/week shortfall

“On top of these costs we are having to pay for Medications, Nappies and PEG feed. The supplements for the latter two and the PBS Safety Net help, but we still pay out over \$5k per year.

If I work away from home overnight, the approximate cost for carers is another \$350-400 per night including evening and early morning. I’m averaging 1-2 nights per week now. So, equates to a personal out of pocket cost of another \$15-20k per year.

I’m only 61 and may need to retire early to care for my wife. Ironically If I retire, the government will immediately lose nearly \$100k in taxes that I currently pay plus taxes on my savings and investment property.

We will almost certainly have to sell our investment property (which was supposedly to be our retirement plan) to fund carers and/or a place in a residential Care Home.

I’ve been back on forth with Centrelink, My Aged Care, Aged Advocacy Network, Wesley Mission. Trying to discover untapped sources of funding. I even spent \$1,800 with financial expert who specialises in funding Care Home places and pensions. No luck though.

One Centrelink “expert” on Aged Care funding told me in front of social worker that “your problem is, as far as the system is concerned, you earn too much”.

The social worker said “Mr Rocliffe’s problem is he has a terminally ill wife and needs help!”.

Even the PEG and Dementia supplement payments through the HCP took weeks and weeks of work and multiple visits to GP!

Whilst plenty of folk are far worse off than me, believe me when I say that I’m not rich and have a modest lifestyle.”

The importance of informal and unpaid carers

Whilst the role of informal carers is recognised in the new Act, the role and needs of carers in supporting older people who receive aged care services, as envisaged by the Aged Care Royal Commission recommendations, must be responded to or addressed. The role of informal, unpaid carers and their importance to older people, as well as their needs, should be reflected in the relevant sections of the Act including equitable and timely access to respite and other.

Parkinson's is a complex condition with a significant list of motor and non-motor symptoms such as Tremors, Rigidity, Bradykinesia Vocal Softness, Postural Instability, Walking or Gait Difficulties, Cognitive Changes, Depression and Anxiety, Loss of Smell, Eye and Vision Issues, Fatigue, Constipation, Lightheadedness, Pain, Personality Changes, Psychosis, Sexual Concerns, Sleep Problems, Sweating, Urinary Issues, and Weight Loss amongst others.

The management of many of these symptoms relies on the support of informal and unpaid carers. For example, someone in the household ensuring that meals are prepared with natural fibre to avoid constipation, a partner having to rise at night for urinary urgency and to clean up after an incontinence episode, a friend or family member transporting someone living with Parkinson's to an exercise class to maintain balance and participate in social interaction.

RECOMMENDATION:

- **The role of informal, unpaid carers and their importance to older people, as well as their needs, should be reflected in the relevant sections of the Act including equitable and timely access to respite and other necessary supports.**



Parkinson's Facts

Parkinson's is the second-most common neurological condition in the world, but remains one of the least understood.



**52% are
male**



**48% are
female**



**Cost to economy
>\$10 billion p/a**





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