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parkinson's

AUSTRALIA

Submission to the Royal Commission into Aged Care Quality and Safety

July 2020

Our Vision

Promote the best possible quality of life for people with Parkinson's

Our Purpose

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.

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Executive summary

Parkinson's Australia welcomes the opportunity to make a submission to The Royal Commission into Aged Care Quality and Safety. This submission supplements our previous submission lodged in September 2019.

Parkinson's[1] is the second most common neurodegenerative disorder in Australia. It is an incurable, progressive and complex neurodegenerative condition caused by the degeneration of neurons controlling the motor function of the brain. People with Parkinson's can experience a range of clinical motor and non-motor symptoms which makes the management, care, and burden of the condition complex, and requires ongoing access to medications and precise timeliness of medicine administration. Parkinson's progresses and affects each individual differently, and, as a result, the person often does not receive correct or personalised Aged Care services in a timely manner.

Parkinson's Australia is aware of several instances where inadequate care provision in Aged Care settings was caused by a lack of understanding of the needs of people with Parkinson's. For example, the Royal Commission proceedings heard a recount of a residential Aged care provider telling a resident with Parkinson's:

"For goodness sake, stop this fidgeting" [2]

This example highlights the need for staff of Aged Care Services across Australia to receive Parkinson's-specific education.

Older Australians have the right to high quality and safe care. Parkinson's Australia believes high quality care for older Australians must be consumer directed, needs-based, and delivered in a timely manner to:

- Enable them to live independently in their communities;
- Maintain a quality of life that enables them to undertake the activities they believe add meaning to their lives;
- Maintain their dignity, identity, culture and values; and
- Be informed about care choices and their personal and social lives.

There are several challenges for people with Parkinson's in the Aged care setting. Firstly, older Australians living with Parkinson's can't access appropriate Aged Care Services in a timely manner due to extended waiting times. Secondly, there is limited access to multidisciplinary teams of health care experts and appropriately trained Aged care professionals in residential Aged care facilities (RACFs). Thirdly, older Australians

[1] In this submission, the term 'Parkinson's' refers to Parkinson's Disease and Atypical Parkinson's including Multiple System Atrophy, Progressive Supranuclear Palsy, Cortico Basal Degeneration and Lewy Body Dementia or Disease

[2] Royal Commission Proceedings into The Matter of Royal Commission into Aged Care Quality and Safety, Melbourne, Tuesday, 15 October 2019

with Parkinson's living in rural or remote Australia are unable to access much needed consumer directed, needs-based and integrated healthcare services.

Parkinson's Australia believes these challenges facing older Australians living with Parkinson's can be overcome by decreasing waiting times for home care packages (HCPs); implementing reliable, streamlined assessments with skilled assessors who are independent from care providers; implementing innovative models in delivering care and support to older Australian living in RACFs and rural areas, providing support for assistive technology; and training Aged care professionals to respond to the needs of consumers. Older Australians living with Parkinson's need to be able to access appropriate care and support customized to their needs and complexities in a timely manner. This will support older Australian's – their independence, quality of life, dignity, culture and values – throughout their lives.

Summary of Recommendations

- The number of HCPs must be increased to meet demand. Full support should be available within 60 days of the assessment date. The cap on HCPs should be removed.
- The Government should implement streamlined and reliable assessment processes with skilled, specialised and independent care provider assessors, to ensure proper assessment and allocation of appropriate care based on each individual's need. Assessment should be able to be completed by a team which includes GPs, specialists or Parkinson's Nurses who are familiar with the individual's needs.
- The Government should implement staffing ratios for registered nurse, enrolled nurse, nursing assistant and general or vocational carers and ensure this ratio is met.
- The Government should provide support for upskilling and training of the Aged care workforce at a national scale to improve quality.
- The Government should implement innovative models that support multidisciplinary care to enhance the management and wellbeing of people living with Parkinson's.
- The Government should provide support to increase access to GPs, specialists and allied health practitioners in RACFs as older Australians have the right to have control over and make choices about their care. Innovative and appropriate ways of implementing Telehealth in Aged Care Settings, should be explored and

implemented in RACFs to overcome the time and distance limitations that prevent healthcare provider visits to RACFs and people in regional, rural and remote areas.

- Innovative assistive technology that improves the wellbeing of people with Parkinson's should be supported through the Medicare Benefits Schedule, the Pharmaceutical Benefits Schedule or a payment through the RACF.

About Parkinson's

Parkinson's is a complex neurodegenerative condition that has no known cure. It is the second most common degenerative neurological disorder in Australia after Alzheimer's, with one in 340 people living with Parkinson's in Australia (Deloitte Access Economics, 2015). Moreover, the prevalence of Parkinson's is greater than some cancers including breast, prostate, ovarian, and liver cancers. The economic burden of the condition is equally great with an annual cost of $1b (2015) nationwide (Deloitte Access Economics, 2015). This equates to an individual's annual cost of living with Parkinson's of approximately $32,300, which can be as high as $63,600 depending on the stage of the condition (Bohingamu Mudiyanselage et al., 2017).

Research into modifiable risk factors and causes of Parkinson's is continuing, but age is the main factor (Hirsch et al., 2016). The Australian population is living longer and the average life expectancy has increased during the last 50 years (Australian Institute of Health and Welfare., 2019). This means that the prevalence and burden associated with Parkinson's is projected to increase in the future.

Hence, while finding a cure for Parkinson's is important, caring and supporting Australians currently living with the condition is vital.

Nature of the condition and clinical features

Parkinson's is a complex neurodegenerative disorder with symptomatic treatments and no cure. Parkinson's is caused by the degeneration of dopamine secreting neurons in the brain. This process results in a range of clinical features divided into motor and non-motor symptoms. The motor symptoms include bradykinesia, muscular rigidity, rest tremor and postural and gait impairment.

The control of motor symptoms in patients requires slow and careful titration of drugs, together with satisfactory adherence to daily medication regimen. Currently, the most effective treatment of Parkinson's is administration of dopamine through oral medications such as levodopa, dopamine agonists and MAO-B inhibitors. However, the

greatest challenge entails medication non-adherence amongst Parkinson's patients. Only 24.4% of the entire Parkinson's population adheres to their medications. Nonadherence worsens symptoms, life quality, health outcomes and heightens healthcare costs (Straka et.al, 2019; Tinelli, Kanavos & Grimaccia, 2016). Medication non-adherence is often a function of the mistiming of medication, which can result in "OFF" periods that makes activities more difficult. This can contribute to the progression of the condition as well as a reduction of quality of life, health outcomes and an individual's independency.

Parkinson's also presents with a range of non-motor symptoms that are not responsive to current dopamine treatment, making the management of the condition intricate. These non-motor symptoms can include depression, sleep disorders, constipation, pain, fatigue, olfactory dysfunction, cognitive impairment, and autonomic dysfunction which can result in unexpected falls and injuries. Further, there is a lack of awareness regarding the non-motor symptoms of Parkinson's; they often go underappreciated and unrecognised.

Parkinson's is often confused with Dementia in Aged Care settings as they have similar clinical presentations. This is concerning as the needs, treatment, care and management of each condition varies considerably. Firstly, Parkinson's and Dementia differ in their pathology. Parkinson's is caused by decreased dopamine secreting neurons while Alzheimer's (the most common type of Dementia) originates in the hippocampus. Secondly, there are important distinctions in the symptoms of the two conditions. Dementia primarily presents with cognitive, memory and behavioural symptoms (Ellison, 2017), while Parkinson's primary symptoms are motor related. As a result, the use of exercise in the management of the conditions is also different.

However, cognitive, memory and behavioural symptoms start to present as the Parkinson's progresses, increasing its similarity to Dementia. The clinical similarities can result in misdiagnoses, the dissemination of misinformation, and profound impacts upon people with Parkinson's.

In summary, it is vital that people caring for people with Parkinson's understand the importance of a treatment regime specific to this condition. Aged Care professionals need appropriate training, particularly on medication management and exercise in Parkinson's to provide need-based, consumer directed and quality care and support.

Australians are living longer than before

The proportion of people over 65 in Australia is expected to increase from 15% to 23% by 2066 (Productivity Commission, 2020), which will only put more strain on our Aged Care services. This is concerning as Parkinson's is a leading condition in older cohorts, and research in the last 30 years has already documented an increase in the prevalence, burden and cost of Parkinson's (Savica et al., 2016). As Parkinson's is closely associated with ageing, we can only expect the prevalence of the disease to increase even further (Wanneveich et al., 2018). Moreover, as the severity of Parkinson's symptoms progress with age, the Aged Care sector is five times more likely to interact with consumers with Parkinson's compared with the general population (Deloitte Access Economics, 2015). Therefore, it is vital to pay special attention to the quality of care provided to older Australian's so we can overcome future challenges associated with the shift in demographics and an increased prevalence of Parkinson's.

Challenges facing People with Parkinsons in the Aged Care system

Unfortunately, older Australians with Parkinson's are often unable to access the care they require. Parkinson's Australia is aware of several challenges affecting the quality of Aged care in Australia. These challenges include:

- Long waiting times for Aged Care services;
- Complicated assessment processes conducted by people who do not understand the condition resulting in Home Care Packages that don't meet individual's needs;
- Insufficient access to primary health care providers in RACFs;
- Insufficient access to specialist and allied health care in RACFs;
- Shortages of skilled, specialised carers in both home care and residential care facilities;
- Scarcity of skilled, specialised and health care providers in rural or regional areas.

A long wait for the wrong service

The challenges of accessing Aged Care services is an ongoing issue. The interim report from the Royal commission into Aged Care Quality and Safety highlighted the need to make accessing Aged Care services easier, particularly the My Aged Care portal. However, accessing the system is only one part of the problem. Once assessed, the Government needs to provide ongoing support at a level that is needed. Greater

investment is necessary to reduce waitlist times and improve assessment procedures that will allow older Australians to remain in their own homes if they wish.

The Department of Health My Aged Care website states that someone needing a Level 1 HCP can expect to wait between 3 and 6 months, while for levels 2, 3 & 4 they wait more than 12 months (My Aged Care, 2020). Only 46.7% of older Australians requiring residential Aged Care were accepted within 3 months after an Aged Care Assessment Team (ACAT) assessment (Productivity Commission, 2020).

In a recent poll conducted by Parkinson's Australia with the Parkinson's community, more than half of the participants indicated that their current HCP is inappropriate for their needs. This reflects issues with incorrect assessments and a lack of appropriate HCP packages. The long period between receiving an assessment, receiving HCPs, or entering Residential Aged Care can contribute to incorrect supports being provided, as the condition may have changed since the time of assessment. The offering of home care packages at a level less than the assessment indicates is necessary guarantees incorrect support.

Assessments for support should be conducted by people who have a good understanding of the Aged Care system and Parkinson's. The current processes should be changed so that the initial assessment can be done by a team of people who understand the needs of the person. This team should include GPs, specialists and Parkinson's Nurses who are familiar with the person.

These people should be independent of the providers as there are obvious conflicts of interest between the providers need to turn a profit and the allocation of packages.

Recommendation 1

The number of HCPs must be increased to meet demand. Full support should be available within 60 days of the assessment date. The cap on HCPs should be removed.

Recommendation 2

The Government should implement streamlined and reliable assessment processes with skilled, specialised and independent care provider assessors, to ensure proper assessment and allocation of appropriate care based on each individual's need. Assessment should be able to be completed by a team which includes GPs, specialists or Parkinson's Nurses who are familiar with the individual's needs.

Improving the Quality Aged Care Services

The quality of care and services provided is directly linked to the availability of appropriately educated and specialised staff. RACFs with higher ratios of appropriately trained nursing staff provides better quality care (Schnelle et al., 2004). The most fundamental issues with current Aged Care quality are closely associated with inadequate staffing, training and low incentives.[3] Staffing shortages are further exacerbated by low wages and low paid staff working long hours at multiple facilities. The COVID-19 outbreak has only exacerbated staffing shortages, low wages, and lengthy work hours in multiple RACFs in Victoria.[4]

Furthermore, staff shortages have been highlighted in several recounts in Royal Commission hearings from both consumers, staffs and experts. In the investigation of an unfortunate accident involving a resident, the Coroner concluded:

> *" …the incident [has] highlighted a concerning norm in Aged Care. Staffing to patient ratios [is] administered at minimalistic levels which places the delivery of appropriate care at risk" [5]*

There is evidently a need to increase appropriately trained staffing levels at RACFs and implement standards for minimum staffing ratios of registered nurses, enrolled nurses and general or vocational carers.

The Aged Care workforce needs to be educated in the needs of the various populations they look after. People with Parkinson's have unique and complex care needs, such as the medication timing requirements discussed earlier. Timing of medication can have profound effect on health outcomes and life quality of people with Parkinson's.

In a poll conducted by Parkinson's Australia, 82% of participants stated that care providers and nurses fail to understand their needs. Medical adherence is greatly associated with health outcomes, with low medical adherence resulting in a worsening of motor and cognitive symptoms and decreased quality of life (Straka et al., 2019). However, only 24.4% of people with Parkinson's adhered to their prescribed medical

[3] Royal Commission Proceedings into The Matter of Royal Commission into Aged Care Quality and Safety, Adelaide, Friday 21, February 2020, Professor Harrington p7845.
[4] Grattan, Michelle. "View from The Hill: Aged Care Crisis Reflects Poor Preparation and a Broken System." The Conversation. Accessed July 29, 2020. http://theconversation.com/view-from-the-hill-aged-care-crisis-reflects-poor-preparation-and-a-broken-system-143556.
[5] Royal Commission Proceedings into The Matter of Royal Commission into Aged Care Quality and Safety, Adelaide, Friday 21, February 2020, p7867

regime (Straka et al., 2019). Therefore, there is urgent need to focus on education of staff at all levels of Aged Care Services, including RACFs.

Case study 1. My dad doesn't have a tremor, carers, nurses, and personal care assistants are grossly undereducated about both the motor and non-motor symptoms of all Parkinson's residents. They ASSUME they all have Alzheimer s or vascular dementia, know absolutely nothing about Lewy Body disease or Lewy body dementia associated with this disease… Ensuring meds are given at the correct times EVERY TIME to avoid variations of unnecessary " off " times…

Thus, in addition to ensuring adequate staffing levels, it is essential that people providing care at all levels of Aged Care Services have sound knowledge about Parkinson's and the differences between it and other neurodegenerative conditions to provide the best possible care.

Recommendation 3

The Government should implement staffing ratios for registered nurse, enrolled nurse, nursing assistant and general or vocational carers and ensure this ratio is met.

Recommendation 4

The Government should provide support for upskilling and training of the Aged care workforce at a national scale to improve quality.

Improving access to health care through innovative models

Federal Government policy settings concerning Aged care have effectively ensured that RACF's are a place of residence with a high level of need for health care. As of 2014 more than 8,000 people with Parkinson's were living in RACFs, which is projected to increase to 15,100 by 2034 (Deloitte Access Economics, 2015). Given the projected increase and complex care and management needs associated with Parkinson's, access to primary, specialist and allied health services are important to maintain quality of life, improve health outcomes and independence of residents with Parkinson's.

Increased access to multidisciplinary care enhances the management and wellbeing of people living with Parkinson's (Eggers et al., 2018, Scherbaum et al., 2020). However, people with Parkinson's living in RACFs are often unable to access the specialists, speech therapists, physiotherapists, exercise physiologists, nutritionists and palliative care providers that make up the multidisciplinary team.

General practitioners

General practitioners are usually the first point of contact in the health system, and most people have their own general practitioner who is familiar with their medical history. Being able to access your regular general practitioner when necessary is key part of a person's multidisciplinary team. Unfortunately, access to primary health care is decreasing as general practitioner visits to RACFs are restrained due to travel and financial factors (Australian Medical Association, 2019). The result is Australians in RACFs are not able to access their choice of primary health care provider when needed[6].

Specialist and allied health care

People living with Parkinson's need continued access to their specialist, ensuring that appropriate medication/therapy regimes are adjusted and adhered to as the condition changes. For the majority of people living with Parkinson's, care is best overseen by a neurologist and preferably a Movement Disorders Neurologist who specialises in conditions such as Parkinson's, or a gerontologist who has substantial experience in managing movement disorders. In most cases this requires a patient to travel to the specialist as it is unusual for most specialists to visit patients in the residential setting.

Speech therapists, physiotherapists, exercise physiologists, nutritionists and palliative care providers provide vital support for a person living with Parkinson's and help them maintain the highest level of independence possible.

Improving rural, regional and remote Aged Care Services

Many older Australian's live in rural and remote areas of Australia and their access to quality health and aged care services is limited by this rurality. There are fewer RACFs available in remote and very remote areas, with 75% of facilities having fewer than 20 places (Australian Institute of Health and Welfare, 2018).

Older people living in rural or remote areas rely on home-based Aged Care Services. However, current HCP funding for the providers does not reflect the additional costs associated with providing services to rural areas. This funding limits care providers and the model needs to be changed to ensure the correct incentives are provided for HCP providers to service regional, rural and remote Australians.

[6] Charter of Aged Care Rights 2019, Aged Care Quality and Safety Commission, Australian Department of Health, Australian Government

Additionally, people living in remote areas have difficulties accessing needs-based, consumer directed Aged Care services such as general practitioners, specialist and other allied health care, which makes treatment and management of chronic conditions such as Parkinson's challenging. The implementation of innovative models of care would be beneficial to these populations who have remained at home. One such example could be the integration of Telehealth services combined with pop-up shop style drop-in centres into traditional models of health services.

All of the above issues can be overcome by implementing innovative health service delivery approaches in RACFs. One such approach is Telehealth consultations and follow-ups with GPs, specialists, nurse practitioners, physiotherapist and other allied health professionals. These approaches have been proven to improve the efficacy of health care in chronic disease (Hersh et al., 2001). Usage of Telehealth during the COVID-19 pandemic has been largely appreciated. In a recent survey conducted by the Consumer Health Forum of Australia, 82% of participants reported the Telehealth service to be excellent, and 68% considered the service as good or better than face-to-face consultations (Consumer Health Forum of Australia, 2020). The recent poll conducted by Parkinson's Australia with the Parkinson's saw 86% of participants state they wished to continue the usage of Telehealth after COVID-19.

All these healthcare practitioners are important members of the team that cares for a person with Parkinson's. Improving access will improve outcomes and wellbeing.

Recommendation 5

The Government should implement innovative models that support multidisciplinary care to enhance the management and wellbeing of people living with Parkinson's.

Recommendation 6

Access to GPs, specialists and allied health practitioners of choice should be increased in RACFs as older Australians have the right to have control over and make choices about their care. Innovative and appropriate ways of implementing Telehealth in Aged Care Settings, should be explored and implemented in RACFs to overcome the time and distance limitations that prevent healthcare provider visits to RACFs and people in regional, rural and remote areas.

Improve access to assistive technologies

There are many assistive technologies available to improve the wellbeing and independence of people with Parkinson's. Supporting the use of assistive monitoring technologies, such as wearable devices that continuously measure gait, tremor, postural instability, falls, freezing, medication timing and sleep in a home or residential care setting could be a pathway towards personalising and increasing accessibility of medical treatments and care (Morgan et al., 2020). There are also many apps, wearable devices and tools that can help a person with Parkinson's maintain a greater level of independence either at home or in a RACF. Examples include stabilising tools, devices to overcome gait issues/freezing of gait, and monitoring systems.

Wearable smart devices can facilitate long-term medication management, symptoms assessment, education, training and symptoms progression thus improving quality of care and life (Channa et al., 2020).

Support for these innovative assistive technologies would allow a person affected by Parkinson's to:

- Decrease the workload of Aged care workforce.
- Increase their quality of care, management and remote monitoring of Parkinson's outcomes.
- Reduce the burden of their condition related to poor management and care, such as non-adherence to medication and progression of clinical symptoms.
- Increase their quality of life and independency older Australians through provision of consumer directed and needs-based care in both home-based and RACFs settings.

Recommendation 7

Innovative assistive technology that improves the wellbeing of people with Parkinson's should be supported through the Medicare Benefits Schedule, the Pharmaceutical Benefits Schedule or a payment through the RACF.

References

Australian Institute of Health and Welfare. 2018. *Older Australia at a glance* [Online]. Available: https://www.aihw.gov.au/reports/older-people/older-australia-at-a-glance [Accessed 09 July 2020].

Australian Institute of Health and Welfare. 2019. Deaths in Australia. .

Australian Medical Association 2019. AMA Submission to the Royal Commission into Aged Care Quality and Safety.

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. *Parkinsons Dis,* 2017**,** 5932675.

Channa, A., Popescu, N. & Ciobanu, V. 2020. Wearable Solutions for Patients with Parkinson's Disease and Neurocognitive Disorder: A Systematic Review. . *Sensors (Basel).* 20**,** 2713

Consumer Health Forum of Australia. 2020. *What Australia's Health Panel said about Telehealth - March/April 2020* [Online]. Consumer Health Forum of Australia. . Available: https://chf.org.au/ahptelehealth [Accessed 16 July 2020].

Deloitte Access Economics 2015. *Living with Parkinsons's Disease: An updated economic analysis.* .

Eggers, C., Dano, R., Schill, J., Fink, G. R., Hellmich, M., Timmermann, L. & Group, C. P. N. S. 2018. Patient-centered integrated healthcare improves quality of life in Parkinson's disease patients: a randomized controlled trial. *J Neurol,* 265**,** 764-773.

Ellison, J. M. 2017. *Alzheimer's and Parkinson's Disease: Similarities and Differences* [Online]. Available: https://www.brightfocus.org/alzheimers-disease/article/alzheimers-and-parkinsons-disease-similarities-and-differences [Accessed 16 July 2020].

Hersh, W. R., Helfand, M., Wallace, J., Kraemer, D., Patterson, P., Shapiro, S. & Greenlick, M. 2001. Clinical outcomes resulting from telemedicine interventions: a systematic review. *BMC Med Inform Decis Mak,* 1**,** 5.

Hirsch, L., Jette, N., Frolkis, A., Steeves, T. & Pringsheim, T. 2016. The Incidence of Parkinson's Disease: A Systematic Review and Meta-Analysis. *Neuroepidemiology,* 46**,** 292-300.

Morgan, C., Rolinski, M., Mcnaney, R., Jones, B., Rochester, L., Maetzler, W., Craddock, I. & Whone, A. L. 2020. Systematic Review Looking at the Use of Technology to Measure Free-Living Symptom and Activity Outcomes in Parkinson's Disease in the Home or a Home-like Environment. *J Parkinsons Dis,* 10**,** 429-454.

My Aged Care. 2020. *Home Care Packages* [Online]. Available: https://www.myagedcare.gov.au/help-at-home/home-care-packages [Accessed 07 July 2020].

Productivity Commission 2020. Report on Government Services 2020, PART F, SECTION 14, Aged Care Services.

Savica, R., Grossardt, B. R., Bower, J. H., Ahlskog, J. E. & Rocca, W. A. 2016. Time Trends in the Incidence of Parkinson Disease. *JAMA Neurol,* 73**,** 981-9.
Scherbaum, R., Hartelt, E., Kinkel, M., Gold, R., Muhlack, S. & Tonges, L. 2020. Parkinson's Disease Multimodal Complex Treatment improves motor symptoms, depression and quality of life. *J Neurol,* 267**,** 954-965.
Schnelle, J. F., Simmons, S. F., Harrington, C., Cadogan, M., Garcia, E. & M Bates-Jensen, B. 2004. Relationship of nursing home staffing to quality of care. *Health services research,* 39**,** 225-250.
Straka, I., Minar, M., Skorvanek, M., Grofik, M., Danterova, K., Benetin, J., Kurca, E., Gazova, A., Bolekova, V., Wyman-Chick, K. A., Kyselovic, J. & Valkovic, P. 2019. Adherence to Pharmacotherapy in Patients With Parkinson's Disease Taking Three and More Daily Doses of Medication. *Front Neurol,* 10**,** 799.
Wanneveich, M., Moisan, F., Jacqmin-Gadda, H., Elbaz, A. & Joly, P. 2018. Projections of prevalence, lifetime risk, and life expectancy of Parkinson's disease (2010-2030) in France. *Mov Disord,* 33**,** 1449-1455.