Submission to the Royal Commission into Aged Care Quality and Safety

September 2019

Our Vision

A world without Parkinson's. Help for today. Hope for tomorrow.

Our Purpose

Parkinson's Australia works collaboratively at a national level with member organisations to advance the interests of people affected by Parkinson's, through developing national policies, promoting research and best practice in treatment and being the national voice of the Parkinson's community.

Our Goals

- To advocate for the interests of people affected by Parkinson's in Australia.
- To promote best practice models of service delivery so they are equally available for all people with Parkinson's nation-wide
- To increase awareness of Parkinson's.
- To increase support for and investment in research.

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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 (Royal Commission).

Parkinson's[1] is an incurable progressive neurodegenerative disorder with a complex and diverse range of motor and non-motor symptoms. People living with Parkinson's are likely, as their conditions progresses, to have at least some cognitive impairment, and many will progress to full dementia. For those who live with dementia this is further complicated by the other symptoms of Parkinson's. Unlike many chronic conditions it is impossible to predict exactly how Parkinson's will impact any individual.

Parkinson's Australia believes that older persons should have the right to access care and support 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 that they believe add meaning to their lives;
- maintain their dignity, identity, culture and values; and,
- be informed about care choices and be able to control care and their personal and social life.

People affected by a progressive neurological condition over the age of 65 are added to long waiting lists for aged care services or have been assigned lower level aged care packages that do not meet their needs. This lack of support for remaining in the home in the aged care system is causing people to be pushed into financial hardship or residential aged care earlier than they wish.

People with a disability should be able to access whichever Government support system best meets their needs, whether it be the National Disability Insurance Scheme (NDIS) or the aged care system. A person diagnosed under 65 years who obtains NDIS support will have access to supports that meet their individual needs and self-management as well as budgets held by a provider. However, a person diagnosed at age 65 and over must rely on the aged care system which, unlike the NDIS, is capped, means-tested and designed to address ageing, not disability. The supports provided under the two systems differ considerably.

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

Parkinson's Australia believes the long-term aim should be a transition to a single program for people with disabilities of all ages that allows people to gain the support they need, no matter where they are physically located.

In the short term, the priority should be to deal with the issues that require immediate attention in the aged care sector. People who become disabled after age 65 should be able to maintain their well-being and live a fulfilled life.

Maintaining quality of life will require adequate support for them to stay at home, engage in the community, and maintain a connection to the workforce for as long as possible. Aged care support would also benefit from a greater focus on community participation, which is a vital aspect of life for a person affected by a chronic, progressive neurological condition.

Summary of Recommendations

- To address the inequitable treatment of those under and over 65 years the Government should either transition to a single program for people of all ages or move to reduce the rationing of aged care. Meanwhile the cap on the number of home care packages should be removed.
- Once a person has been assessed as requiring care and support, they should be able to access a basic level of service immediately. Full support should be available within 28 days of the assessment date.
- People living in aged care facilities should be able to access their own GP. Where this is not practicable then they should be able to exercise choice of their GP.
- People living with Parkinson's in a RACF should have access to a Parkinson's Nurse Specialist and allied health services.
- People living with Parkinson's should receive specialist medical care in a RACF so that they can manage their Parkinson's and maintain the best quality of life possible.
- The Government should develop and implement innovative health care service delivery models for people receiving aged care services.
- The Government should develop and implement patient-to-staff ratios that provide the best mix of staff with respect to roles, scope of practice and numbers.
- Training should be provided for all personal care and health professionals working in RACF's on the management of Parkinson's disease. This should be provided by a Parkinson's Nurse Specialist.
- The Government should fund access to online training programs about caring for people with Parkinsons.

About Parkinson's

Parkinson's Disease is a neurodegenerative condition that has no cure. Parkinson's is the second most common neurodegenerative disease after Alzheimer's disease and has a higher prevalence than many cancers including breast and prostate cancer. The most recent research indicates that more than 210,000 people live with Parkinson's and that more than 1 million carers, family and friends are directly impacted (Ayton, et al. 2018). It has been estimated that the cost of Parkinson's to the community is in the order of $15b. The direct financial cost of Parkinson's to the Government is estimated at over $1b annually (Deloitte Access Economics 2015).

Age is the major risk factor for Parkinson's. As people age their risk of Parkinson's increases dramatically. Parkinson's affects 1% of the population over the age of 65 and increases to 5% over the age of 85 (Reeve 2014).

Australia's population is ageing. Currently around 15% of the population is over the age of 65, this is expected to increase to over 21% by 2066 (Australian Bureau of Statistics 2017). Unless a cure is found, the prevalence of Parkinson's will increase as the population ages.

Nature of the condition and clinical features

Parkinson's is a chronic condition that varies in severity, disease course and the range of symptoms. Symptoms include motor symptoms such as tremor, muscle rigidity, slowness and postural instability as well as a range of non-motor symptoms such as depression, anxiety, hallucinations, cognitive impairment, dementia, gastrointestinal symptoms, sleep disturbance and sensory deficits.

Many people with Parkinson's will, over time, progress from a mild cognitive impairment to full dementia. Some studies have indicated that more than 83% of people living with Parkinson's progress to dementia (Hely MA 2008). Lewy Body Dementia alone accounts for 15% of dementia cases (National Institute for Clinical Excellence 2017) making Parkinson's the third most common cause of dementia.

Aged Care in Australia

The ageing of the Australian population will see a marked increase in the number of Australians likely to need aged care. The rapid expansion of the number of older people, particularly in the oldest age groups, will result in a marked increase in demand for aged care services. Around 1.3 per cent of 70-year-olds currently use home care or residential care; this compares to around 15 per cent of 85-year-olds and 50 per cent of 95-year-olds (Tune 2017).

Federal Government policy settings around the aged have effectively ensured that RACF's are a place of residence with a high need for health care. Older people in RACF's are the most vulnerable subsection of an age group that manifests the highest rates of disability in the Australian population. Annually, 30% of residents have one or more falls and 7% fracture a hip. The prevalence of chronic conditions among residents in high care is estimated to be 80% sensory loss, 60% dementia, 40–80% chronic pain, 50% urinary incontinence, 45% sleep disorder, and 30–40% depression (AIHW, Depression in Residential Aged Care 2008-12 2013) (AIHW 2016) (ACQSHC 2009).

People living with Parkinson's are overrepresented in RACF's with 8 per cent of all residents having Parkinson's compared to around 1 per cent of the general population aged over 65.

Funding

Aged care services are rationed by the current budget processes. This is unlike funding for health services, through Medicare, which are demand driven.

Like Medicare services provided through the Medical Benefits Schedule, aged care services are essential in ensuring that people are able to preserve their health and maintain the highest quality of life possible either in a RACF or in the community.

Aged care services should not be rationed but should be available based on need. Recipients of aged care services who are assessed as requiring essential supports and care should have access to these supports and care without having to wait extended periods of time. The community would not accept waiting 12 months for access to general health care.

Recommendation

To address the inequitable treatment of those under and over 65 years the Government should either transition to a single program for people of all ages or move to reduce the rationing of aged care. Meanwhile the cap on the number of home care packages should be removed.

Access to Aged Care Services

The issues relating to accessing aged care services are well documented. Older people express very strong preferences to remain in their own home as long as possible and preferably until death, and there is currently not enough care available in the community to allow those preferences to be met.

The Department of Health My Aged Care web site states that for someone needing a Level 1 home care package they can expect to wait between 3 and 6 months while for levels 2, 3 & 4 the wait is closer to 2 years (Dept of Health and Aging 2019).

The latest available Report on Government Services (Productivity Commission 2019) indicates that the time taken to access residential care continues to increase. The median wait time people entering residential aged increased to 121 days in 2017–18. Residential aged care waiting time increases are associated with a growth in the number of hospital bed days used by those eligible and waiting for residential aged care placement, reaching 353,695 hospital bed days in 2016–17 (Productivity Commission 2019).

Recommendation

Once a person has been assessed as requiring care and support, they should be able to access a basic level of service immediately. Full support should be available within 28 days of the assessment date.

Access to primary care, specialist and allied health services in RACF's

When people living with Parkinson's move into a RACF, the needs for particular care targeted to their condition remain. People in RACF's are 8 times more likely to have Parkinson's than the general population of people over the age of 65.

Primary Health Care

Access to good primary care through general practice is a cornerstone of a strong health care system. Aged care consumers usually have multiple, chronic and complex health care needs which are best addressed through access to comprehensive multidisciplinary primary care services. Most aged care consumers will have an established relationship with a GP, who has in most cases provided them with care for many years and has a good understanding of their medical history and care needs.

Good primary care services can improve people's health and wellbeing by supporting them to manage their complex and chronic conditions and, by doing so, reduce the need for specialist services and visits to emergency departments (Dept of Health and Ageing 2018). This is particularly pertinent

for people living with Parkinson's receiving aged care services. In fact, it is more critical as this group will usually have another chronic health condition and be at greater risk of injury, such as falls, or deterioration of their health if their primary health care needs are ignored.

It is frequently reported to Parkinson's Australia that residents in RACF's find it increasingly difficult to access the services of general practice. This observation is supported by the 2017 AMA Aged Care Survey Report which found that more than a third of doctors who currently undertake RACF visits intend to either visit current patients but not visit new patients, decrease the number of visits, or stop visiting RACFs altogether (Australian Medical Assosciation 2017).

The value a GP brings to a RACF should be recognised by the government. General practitioners should be encouraged to visit RACF's and additional incentives, on top of those already announced, may be necessary.

Recommendation

People living in aged care facilities should be able to access their own GP. Where this is not practicable then they should be able to exercise choice of their GP.

Specialist Medical Services

People living with Parkinson's have complex care needs including very complicated medication/therapy regimes that require constant monitoring and regular adjustment as the condition progresses. These regimes differ from those needed for people living with Alzheimer's and Dementia.

For the great majority of people living with Parkinson's their 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 rooms as, with the exception of gerontologists, it unusual for most specialists to visit patients in the residential setting.

The result is that the person living with Parkinson's does not get the care they need whilst living at the RACF.

Recommendation

People living with Parkinson's should receive specialist medical care in a RACF so that they can manage their Parkinson's and maintain the best quality of life possible.

Parkinson's Nurse Specialists

Parkinson's Nurse Specialists play a crucial role in supporting people living with Parkinson's. These nurses work with patients, carers and care providers to provide advanced clinical leadership and support, advice and education. Research on the use of Parkinson's Nurse Specialists has demonstrated that they:

- Improve the management of symptoms and improve the quality of life of people living with Parkinson's
- Reduce hospital admissions and length of stay
- Delay entry into residential care
- Reduce the need for medical consultations.

Given the very limited access that people in RACF's have to medical specialists the Parkinson's Nurse Specialists provide a vital role in ensuring that patients have access to advanced clinical support and care. The nurse is also the entry point for the patient to multidisciplinary care and often undertakes the role of care coordinator. Parkinson's Nurse Specialists are able to work with consumers and aged care service providers to ensure that care plans are patient-centred to meet the needs of people living with Parkinson's and to train staff how best to manage clients living with Parkinson's.

People living with Parkinson's often have unique needs, compared with other residents. For example, a delay of even five minutes in taking medication at a specified time can lead to 'freezing', where the patient suddenly loses the ability to move, walk, and speak (Buetow, et al. 2010). Understanding these needs is vitally important to providing care. Education and training for personnel on the needs of this group will help the residents and provide the carers with options that will make caring easier. A UK study concluded that Parkinson's Nurse Specialists could be an effective way to help train staff in facilities (Walker, et al. 2013).

Given the high proportion of people in RACF's who are living with Parkinson's, support via a Parkinson's Nurse Specialist will ensure that they receive the appropriate care.

Allied Health Services

People living in RACF's generally have limited access to allied health services.

There is increasing evidence that best practice management of Parkinson's is facilitated where the person living with Parkinson's has access to multidisciplinary care. 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 and enable a good quality of life.

Recommendation

People living with Parkinson's in a RACF should have access to a Parkinson's Nurse Specialist and allied health services.

Access in rural and remote Australia.

Whilst many of our aged live in a rural or remote area, there is not a corresponding amount of health practitioners to support them. Access to general practitioners, allied health, specialist and Parkinson's nurses is negatively impacted upon by rurality.

People living in rural and remote areas are often more reliant on home-based care due to their distance from service providers (AIHW 2008). Home-based aged care services need to be appropriately funded to reflect the costs of providing care to users. Being responsive to the geographical location of service users will require funding to adequately reflect any additional costs of travel, particularly where people live in rural and remote locations and service providers need to travel to provide care.

Home care packages currently do not reflect the additional costs associated with travelling long distances to provide care. This allocated funding for care must allow for the travel of care providers, with this particularly impacting on rural and remote Australians requiring care.

People requiring care in rural and remote areas could benefit from innovative modalities of care provision. The current fee-for-service payment model restricts the use of flexible and potentially more efficient methods of providing primary and specialised care services, e.g. follow up telephone conversations or video consultations. While it is recognised that the Medicare Benefits Schedule Review Taskforce have provided recommendations for reforms in this area—to date these recommendations have been limited to care provided by general practitioners and nurse practitioners. Additional consideration needs to be given to support models of care that require input from specialists such as Parkinson's nurses or neurologists.

Better access to responsive, appropriate, high-quality and safe healthcare services and specialist neurological services is needed for many people receiving aged care services. A robust evaluation of the true cost and effectiveness of different service models for providing appropriate and high-quality primary care to people living in residential aged care, and people with home-based packages is needed to inform changes to care funding and service delivery.

Recommendation

The Government should develop, monitor and ensure innovative health care service delivery models for people living in rural and remote areas receiving aged care services to improve access to health care providers that specialise in Parkinson's.

Quality

Staff

There is no doubt that the quality of care provided through aged care programs is directly linked to the availability of appropriately trained and skilled staff. This is particularly true in residential aged care where the residents are usually totally or largely dependent on the support of staff to undertake their activities of daily living and to maintain a good quality of life.

People living with Parkinson's have specialised care needs, such as medication management, which are often not met within the current aged care arrangements. It is regularly reported to Parkinson's Australia that people living with Parkinson's do not receive their medication on time or that essential mediations are not provided. Because of their motor and cognitive symptoms, it is essential that staff looking after people living with Parkinson's have a good knowledge of the condition and requirements for best practice management of Parkinson's.

It is of concern that it is frequently reported to Parkinson's Australia that the care provided in Aged Care facilities is inadequate. A study undertaken between 2012 and 2015 found that missed care[2] occurred on all shifts and that staffing levels, resident acuity and skill were identified for as the reason for the missed care (Henderson, et al. 2017). A 2016 survey found that only 8.2% of 3,200 registered and enrolled nurses and personal care workers, covering all States and Territories, believed that staffing was always adequate (Willis, et al. 2016).

Recognising the diverse mix of skills needed to deliver comprehensive care, including direct care and care coordination, it is necessary to ensure that the staffing mix provided at any time is appropriate. There is an absence of strong evidence-based tools for effectively and efficiently specifying the appropriate patient-to-staff ratio that is required to provide appropriate, comprehensive and high-quality care to match the care and health needs of residents or aged care service users.

Recommendation

The Government should develop and implement patient-to-staff ratios that provide the best mix of staff with respect to roles, scope of practice and numbers.

[2] Missed care refers to the care including hygiene, ambulation, delayed or missed feeding, missed drug interactions, missed medications and other care and support that would normally be given to a resident.

Training and Education

A report commissioned by Parkinson's Australia has shown that "residential Aged Care workers have insufficient knowledge about how to provide best practice care for consumers with Parkinson's" (Howard and Barnett 2016).

It is commonly reported to Parkinson's Australia that many staff delivering aged care services have little or no understanding of Parkinson's or the best ways to deliver care to people living with Parkinson's.

In most cases, very small care changes can have a huge impact on the quality of life for someone living with Parkinson's. Examples of these changes include ensuring that they get their essential medications on time, every time; time activities such as meals and hygiene to ensure that the person is in an 'on state'[3]. Improving the quality of care for people living Parkinson's requires knowledge that can be gained within a short period of training.

Training for most health professionals and personal care attendants does not include appropriate training in the management of Parkinson's and particularly the management of Parkinson's in the aged care setting. The following real-life cases demonstrate how, with a small amount of training, the experience of both the person receiving the care and the person providing the care can be improved.

> *Case One: A resident in an aged care facility was unable to get up for breakfast or even feed himself as he did not receive his medication until sometime after the morning shift commenced. Parkinson's medications can take a long time to be absorbed because of changes in the gastrointestinal system and as a result the person is effectively like a car that has no fuel until the medications kick in, which can take an hour or more. Changes were made to ensure that the resident received his required medication before night duty staff finished which ensured that the medications were working before the resident had breakfast. This enabled the resident to feed himself and gain function in time for breakfast.*
>
> *Case Two: A resident with significant motor symptoms experienced freezing of gait particularly when coming to a doorway. The local Parkinson's nurse delivered a short training course into the facility and one of the carers mentioned the freezing issue. The nurse was able to work with the carers and the resident to put in place a piece tape across the doorway, which tricked the resident's brain enabling them to step over it like going up a step.*

[3] In an 'on state' a person with Parkinson's will usually feel more energetic and be able to move around and function more easily. In an 'off state' a person may become very stiff, slow, and may even be unable to move at all and may also have difficulty communicating.

Parkinson's Australia was funded in 2015 by the Department of Health and Ageing to develop a training package for aged care providers. Whilst developed, implementation of the package was not funded for RACF's. As a result, it has only been delivered to a very small number of aged care providers. An online module was also produced and requires Government funding for its implementation.

Recommendations

That training is provided for all personal care and health professionals working in RACF's on the management of Parkinson's disease. This should be provided by a Parkinson's Nurse Specialist.

The Government should fund access to online training programs about caring for people with Parkinsons.

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