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VICTORIA

Royal Commission into Aged Care Quality and Safety - Parkinson's Victoria Submission

Contents

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About Parkinson's Victoria

Parkinson's Victoria is a not-for-profit, member based organisation raising awareness and funds for services and research that improves the quality of life for 27,000 people living with Parkinson's and Atypical Parkinson's conditions across the state.

Our multi-disciplinary health team provides specialist advice and support to people living with Parkinson's, their families, carers and health care professionals through:

- tailored health education programs and seminars
- a free and confidential health information service
- comprehensive web-based information
- an extensive Peer Support Group network

Parkinson's Victoria is committed to supporting vital research into effective treatments that improve the quality of life for people living with the condition, and for the pursuit of a cure.

Introduction

Parkinson's Victoria is the peak body representing an estimated 45,000 (Ayton et al 2019) people living with Parkinson's In Victoria, Parkinson's Victoria also supports people living with Atypical Parkinson's across Australia.

Parkinson's disease is the second most common neurological condition in Australia, growing at an exponential rate and has a higher prevalence in regional, rural and remote areas.
Research suggests that the prevalence of Parkinson's disease ranges from between 0.34% and 0.85% of the Australian population.

The exponential growth of Parkinson's disease is being considered a global pandemic (Doresy et al 2018) requiring new and innovative solutions to address the burdens it is placing on health systems and individuals.

Parkinson's is a complex, progressive neuro-degenerative condition. Symptoms are manageable in the early phases of the disease, but as the condition progresses symptoms become more unpredictable. People living with Parkinson's will experience physical disability, complex cognitive, non-motor symptoms and autonomic nervous system impairment. Symptom management is reliant upon complex medication regimes which are time critical in their delivery.

Family and Care Staff who are skilled in understanding and assessing symptoms and are able to ensure timely administration of medication therapies are essential in supporting quality of life in people living with Parkinson's and understand the often-complex motor and non-motor symptoms and strategies used to manage them. (Makoutonina and Iansek 2010)

- In 2014, it was estimated that there were approximately 8,500 PWP in residential aged care facilities, of which 201 were aged younger than 65 years (Deloitte Access Economics 2014)
- a residential aged care facility of 100 beds is likely to have 3 people with Parkinson's at any one time, compared to up to 40 people with Alzheimer's type dementia. Consequently, staff in the facility have much less experience managing the complexities of Parkinson's, which are quite different from the complexity of Alzheimer's type dementia.

This submission will present the key issues people living with Parkinsons, Atypical Parkinson's, their families and members of Parkinson's Victoria have raised with us regarding access and interactions with community and residential Aged Care. The observations and insights of the State-wide multi-disciplinary Health Information and Education team as they provide specialist education and consultancy within, he aged care sector have been considered when formulating this submission as has the information provided by colleagues within the Movement disorder sector.

Discussion

Access

Access to appropriate care in the Community

For most people, the capacity to remain at home and within their own community is important for wellbeing and remaining connected. For Individuals living with Parkinson's the complexity of the symptoms and management often result in these individuals needing a higher level of community support or requiring an aged care package to support needs. Limited numbers of aged care packages can result in admission to residential care as family carers are often also aged and may have their own health concerns. Carer burn out commonly precipitates admission to permanent care with death often occurring within 18 months. (Kempster et al. 2010)

Recommendations:

Improved access to community Aged Care Packages which are flexible to support changing needs as condition progresses

Investment in flexible respite options which are supported by staff who have a sound understanding of Parkinson's and Atypical Parkinson's

Acute care, Community and Aged care: System interfaces and communication

For people who are transitioning between acute care and aged care services, discharge summaries from acute care are not always fully comprehensive. Acute care discharge summaries often focus on the condition for which the person was admitted, so at times they will lack specific detail regarding management of the Parkinson's symptoms.

There are well documented challenges in people living with Parkinson's within the acute sector, with a common experience being not getting medication on time often leading to a worsening of symptoms which can impact upon discharge planning as symptoms may be exacerbated. If this has been the case the transition from acute care to home or residential aged care can be difficult.

There are very few facilities which offer slow stream rehabilitation or maintenance rehabilitation programs. These programs which provide restorative care or assist in maintaining function may reduce need for services or prevent premature admission into residential aged care. Access to a level of maintenance care which helps address symptoms as disease progresses can be essential in promoting comfort, independence and quality of life within community and residential aged care settings.

Recommendation:

Strengthen communication systems within areas of Health Care, hospital Electronic Medical record management systems should be integrated with My Health Record and medical / health information systems within aged care

Develop system of alerts within EMS highlighting cautions and considerations when caring for a person with Parkinson's E.g. Time critical nature of Medication and drug interactions

Access to Movement Disorder / Parkinson's Skilled Health care Professionals

A Key area is access to skilled Neurologists and Allied health professionals who have a sound understanding of Parkinson's with in residential aged care. Neurologists are not able (or funded) to provide consultancy or visits to residential aged care, leaving the treating GP to manage often complex symptoms. Allied health Professionals while available within the aged care sector are often time limited or have funding restrictions on the range of services, they can offer.

Physiotherapists are employed in almost all residential aged care facilities, but the structure under which they are employed is very rigid (pain management and limited exercise programs) and allows for little specialist and specific intervention such as is required for people with Parkinson's. Many of the physiotherapists who work in the aged care sector do not have specialist neurological or movement disorders knowledge and experience.

In a similar manner, Speech pathology services are engaged to assess swallowing issues, but rarely to have input into communication. For people with Parkinson's, communication changes are very common and require expert intervention to maximize effective communication and decrease isolation. This also limits the independence of the person with Parkinson's and their capacity to have control over day to day activities.

Neuropsychologists, social workers, psychologists are rarely accessed in a residential aged care facility. People with Parkinson's who may experience complex cognitive changes benefit from comprehensive review of their cognitive and emotional status. Psychological support and education for the staff will provide staff with a greater understanding of the complex emotional and cognitive changes experienced by people with Parkinson's under their care, and will provide strategies to manage challenging behaviors and effectively assess when cognitive or neuro-psychiatric symptoms are becoming more evident, which can be a precursor to psychosis or inter- current illness.

People who have entered Residential aged care often are not able to access specialist movement disorder clinics or services as an outpatient once this admission has occurred, even when they may have been a patient at the service for many years. Limited capacity within specialist services and funding constraints frequently result in patients who are most in need not being able to access the specialist clinics, they may be familiar with and who have the capacity to support the most effective (and efficient) care and symptom management.

Recommendation:

Strengthen telehealth links between GP's in community and Aged Care facilities with treating neurologists to support ongoing expert management

Increase the rebate and scope of practice of Allied Health care professionals with in Aged Care- this may be through an enhanced and expanded Chronic Disease Management plan and Chronic disease management plan (Mental Health) which is able to be accessed in residential aged care providing a greater number of visits and expanding the services which can be provided.

Access to assistive Technology

There is often very limited access to assistive technology (E.g. Electronic Communication aids/ specialized powered wheelchairs) once someone has turned 65, with access further limited if the person lives in residential aged care. Currently much of the funding for assistive technology is focused on the disability sector and is means tested and subject to funding availability under My Aged Care.

If funding is identified individuals often encounter difficulties in accessing specialist health care professionals who have the skills to assess and prescribe this often highly personalized equipment, creating the potential for unsuitable and potentially dangerous equipment to be obtained.

The ability to access assistive technology is particularly felt in the community living with atypical Parkinson's conditions which are significantly more disabling and rapidly progressive in comparison to Parkinson's. As noted above the ability to access a health professional who can identify the most appropriate assistive technology to suit the individual need is also a significant impediment.

Recommendation:

Increase timely access to aids and equipment required to support independence, comfort and communication. This may be achieved by expanding the current SWEP program and provide a funding mechanism for clinicians to be able to effectively assess, prescribe and provide support to patients and aged care professionals when introducing assistive devises/ aids.

Clinical Care

Medication management

Globally the most significant challenge for people living with Parkinson's in hospital and aged care is getting essential medication on time, and health care professionals responsible for medication administration not understanding the time critical nature of Parkinson's medication. When dopamine replacement therapy, the key drug therapy in Parkinson's is not delivered on time, the patient will experience a recurrence of both motor and non-motor symptoms causing significant discomfort and reducing the individuals motor functions and ability to be independent.

This limited understanding of the impact of medication on persons symptoms can cause patients/ residents to be considered as difficult or even depressed when they are unable to participate in tasks which they have previously been observed to be independent in.

Within the aged care sector, the limited understanding of the therapeutic benefit of medication by general practitioners and staff with medication administration responsibilities may lead to medication regimes not being reviewed when needed and treatable disease progression being untreated, increasing patient need, while reducing their quality of life. While seemingly minor the common practice within aged care of giving medication with a spoonful of Yoghurt to assist with swallow is impactful in Parkinson's as dietary protein will impact the absorption of Dopamine replacement therapy.

This limited understanding of medication and how to titrate drugs as the patient nears the end of life is significantly compounded as disability or residing with in an Aged care facility frequently causes the patient to lose contact with their treating neurologist. (Miyasaki 2016)

Recommendation:

Increase education opportunities for GP's and Aged care professionals to improve understanding of Parkinson's and Atypical Parkinson's and best practice treatments.

Increase education on medication management of Parkinson's in particular the need to get medication on time and medication interactions which can worsen the symptoms of Parkinson's or impact on medication absorption.

Symptom Support

Parkinson's and Atypical Parkinson's are complex conditions which frequently benefit from non-pharmaceutical management, with interventions to support symptom management often requiring multi-disciplinary input. Accessing an integrated multi-disciplinary approach can be difficult with in aged care and simple interventions such as rehabilitative cueing which would support independence may not be put in place. More technical strategies such as collaboration between Speech Pathology and occupational or Physiotherapy to identify the optimal seating position for safe swallow may not occur and increase the risk to the individual with the condition.

Recommendation:

Support aged care staff with funded access to skilled Allied health staff who can identify appropriate non pharmaceutical management and rehabilitative strategies.

Funding for multi-disciplinary professionals to collaborate, identify and introduce non-pharmaceutical interventions and strategies. This may be supported by an expansion of the Chronic Disease Management plan.

Medical Support in Aged Care

Within the aged care sector medical care is driven by General Practitioners. The experience of many people with Parkinson's and the much rarer Atypical Parkinson's conditions is the need to transfer their care to a GP who services the Aged Care Facility. Loss of continuity of medical care in a long-term chronic condition can be very disruptive and often comes at time when the challenges to keep appointment with specialist neurologists become insurmountable. GP knowledge of these conditions is often highly variable, with most GP's not having the skills or confidence to titrate medication to manage Parkinson's symptoms appropriately or to manage medication therapies as a person transitions into a palliative phase.

Recommendations:

Support General Practitioners with accessible education and information resources to support the most effective management.

Consider review of current telehealth programs and rebate mechanisms to support telehealth consultation and ongoing input from treating Neurologist.

Consider expansion of Medicare rebate to support case conferences between Neurologist, General Practitioner and Aged Care Professionals

Specialist Rehabilitation

Specialist centers of excellence in caring for people with Movement Disorders are a good source of consultancy services and support for staff working in more general settings, in either the acute or the aged care sector. Unfortunately, there are few of these centers, in Victoria, only one (Kingston Movement Disorders Program) receives limited funding to offer telephone and occasional telehealth consultancy services across the state. This significant capacity issues are often most impactful in regional and remote communities.

Other services exist but are only able to accept referrals from a strictly defined geographical area, in Victoria most of these services are in South East metropolitan Melbourne. There are numerous private programs, but these are not accessible to everyone and are again located unevenly across the state. Liaison between the private clinics and the aged care sector is minimal. Use of telehealth facilities to improve communication between specialist centers and residential aged care facilities is spasmodic.

Recommendation:

Strengthen pathways for people living with Parkinson's and Atypical Parkinson's to continue to access services they are familiar with once they have transitioned into Aged Care. Increasing funding to specialized serviced to increase capacity is also a necessary consideration.

Provide education to Increase skills in best practice Movement disorder rehabilitation within existing community-based rehabilitation teams to support people to access skilled and knowledgeable care proximal to them.

Commensurately fund expanded access to specialist consultancy services who can support problem solving and care planning for people with complex neurological conditions.

Advance Care Planning

Current inconsistencies in staff skills in developing Advance Care Plans and limited resources in the community to assist with developing Advance care plans are a key challenge to address. Increasing skills for staff within the Aged care and Community sectors to sensitively support a patient and their family to develop an advanced care plan and working with these professionals to increase knowledge of Parkinson's and Atypical Parkinson's will support developing an Advance Care Plan appropriate to condition and reflecting individuals wishes.

Developing a robust Advance Care Plan is particularly important in Advanced Parkinson's and atypical Parkinson's as end of life in is caused by an inter-current or treatable illness (such as Pneumonia). A well-developed ACP which is communicated clearly amongst staff will support the provision of appropriate palliative measures and prevent unnecessary transfer to acute care.

Recommendation:
Provide Aged care professionals and General practitioners with the education and support enabling them to better understand the conditions and support people living with them and their families to develop informed advance care plans.

Increase awareness of Advance Care planning with in community and primary care to support patients and families to better understand processes and consider future medical treatments and make choices.

Palliative and End of life care
Within the community and residential aged care sectors there are challenges in delivering high quality and appropriate end of life care. There is limited evidence on identifying the palliative phase of Parkinson's, and Atypical Parkinson's. The most appropriate assessment of this comes from skilled neurologists and multidisciplinary teams who are not available in residential aged care.

The palliative phase may be several months in duration and may be shaped by the wishes within the individuals advance care plan. Most people with Parkinson's will die from Pneumonia when End of life linked to decisions not to treat this. (Miyasaki 2016, Chaudhri 2018)Existing Palliative care services in community and residential aged care are frequently focused on cancer diagnoses and often only are accessed once it is clear the person living with a movement disorder has an irreversible inter-current illness, although they may benefit from this approach many months before this occurs.

Recommendation:

Comprehensive education on identifying and managing the complex symptoms seen in advanced Parkinson's and Atypical Parkinson's for General Practice, Aged care and Palliative care staff.

Pathways supporting early and appropriate referral and timely referral to Palliative care

Consider a model of Palliative care which will comprehensively meet the needs or someone living with Parkinson's and atypical Parkinson's such as a Neuro-rehabilitative model (concise guideline to clinical practice No. 10)

Education and understanding

Aged Care Professional- understanding of Parkinson's and Atypical Parkinson's
The main challenge for most staff in the aged care system relates to a minimal knowledge of Parkinson's and the care needs that someone living with Parkinson's is likely to have. Parkinson's as a condition also gives rise to some challenges as each person will experience symptoms uniquely and will require individualized treatment regimes. People with Parkinson's who are living in residential aged care facilities often demonstrate a wide range of symptoms involving all physiological systems – motor, non-motor, neuro-psychiatric – as well as a range of co-morbidities normal for their age.

Community and residential aged care are unlikely to understand the complex symptoms and management needs of a person living with Parkinson's. Education of the care of a person with Parkinson's is not part of core education and or ongoing education for the Certificate in Aged Care which personal care assistants, the bulk of the workforce in the aged care are required to hold.

The limited opportunities to develop knowledge and an understanding of Parkinson's and Atypical Parkinson's significantly impacts upon the Aged Care Professionals ability to accurately assess symptom management and be able to delineate changes related to progression or those caused by reversable illness. For example, Motor Deterioration, cognitive decline or neuro-psychiatric symptoms may precede or be related to an inter-current illness.

This limited knowledge extends to knowledge of the medication management of Parkinson's, particularly the time critical nature of the medication. Limited numbers of staff who can administer medication can exacerbate difficulties in getting medication on time.

Within residential aged care there are very limited opportunities for the patient to retain independence over medication management, very few facilities have self-administration protocols or capacity to support self-administration of medication. This also impacts on the individual's ability to remain independent during respite stays, or the health care staffs ability to assess concordance and put appropriate supports, such as medication timer devices in place should the individual be observed to be struggling with self-administration.

The complex motor and non-motor symptoms that the individual experiences are often exacerbated if the patient becomes constipated or during an intercurrent illness. Clinical and Personal care staff need to have the skills to identify signs and symptoms of evolving intercurrent illness and act quickly to address the symptoms.

Increasing knowledge of Parkinson's, its presentation and management can be identified as improving outcomes and quality of life (Makoutounina, Iansek, 2010). This is an important considering people living with Parkinson's and atypical Parkinson's will experience complex motor, non-motor and autonomic symptoms and understanding the symptoms will better equip aged and community staff to understand symptoms and identify when condition is worsening.

Recommendation:

Include information on Parkinson's and its management as part of the basic training for aged care workers.

Improve access to ongoing training opportunities both online and face to face to increase knowledge of best practice ways of managing Parkinson's and supporting the range of complex symptoms which may be difficult to manage with in community and residential aged care settings.

Provide opportunities to access real time support and education on the Atypical Parkinson's conditions, which are rarer and people living with them often have highly specific care needs

Provide comprehensive education and support materials increasing awareness of medication management of Parkinson's for GP's. Community Pharmacists and Nurses and Aged Care Professionals responsible for medication administration.

Develop medication administration Key Performance indicators including on time delivery and awareness of medication interactions

Support aged care facilities to develop sensible self-administration guidelines to promote independence and enable patient concordance to be assessed for appropriate clients.

Education and Support for General Practice

There are limited opportunities for General practitioners to increase knowledge and skills in Parkinson's and Atypical Parkinson's. There is an absence of online learning opportunities which are readily available and current, and opportunities to seek real time guidance and support from specialist medical colleagues are absent. Telehealth support within aged care is largely unavailable, and while skype or facetime consultations occasionally occur, they are usually initiated and supported by family members and frequently do not include the GP.

Recommendations:

Better support treating General Practitioners working in community and in Aged Care with online and face to face educational opportunities on the fundamentals of Parkinson's. Additional support with specialized modules providing opportunities to increase knowledge and capacity to manage the complex needs such as Palliative care, Neuro-psychiatric symptoms or those experienced by people living with Atypical Parkinson's which are accessible as required.

Conclusion

Access, Education and Clinical care are the key challenges to delivery of high quality residential and community based aged care for people living with Parkinsons and Atypical Parkinson's.

While Access issues are a common issue within the aged care sector and will need investment in to the future. For people living with Parkinson's and Atypical Parkinson's the poor understanding of condition, symptoms and symptom management, the need to get medication on time stand out in community feedback and are a well-documented challenge globally.

Comprehensive education to support General Practitioners and Aged care professionals better understand the complex symptoms and best practice ways of manging Parkinson's will, in part help address challenges in getting medication on time. Education will also support a better understanding of the symptoms experienced by people with the condition which are frequently misunderstood, and miss interpreted which is another key challenge identified by community.

It must be acknowledged that most aged care professionals are doing their best and many of the difficulties that people living with Parkinson's and Atypical Parkinson's encounter relate to knowledge and resource limitations. An ongoing investment in the professional development and knowledge of workers within community and residential aged care sectors would address may of the current challenged and causes for concern with in the residential and community aged care sectors.

A key investment to improve the lives of people living with these conditions is to increase the access and scope of practice which Multi-disciplinary professionals can offer with in the aged care sector. This investment is likely to improve the lives of people with Parkinson's, make delivering care easier and in many instances stop unrequired transfers to acute care. The multi-disciplinary approach is also likely to support better identification of palliative symptoms and articulation into palliative care.

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