

**Submission
No 704**

**INQUIRY INTO HEALTH OUTCOMES AND ACCESS TO
HEALTH AND HOSPITAL SERVICES IN RURAL,
REGIONAL AND REMOTE NEW SOUTH WALES**

Organisation: Parkinson's NSW

Date Received: 15 March 2021



12 March 2021

The Hon. Greg Donnelly MLC
Chair
Portfolio Committee No.2 – Health
Parliament of New South Wales

Via email: portfoliocommittee2@parliament.nsw.gov.au

Dear Mr Donnelly,

Inquiry into health outcomes and access to health and hospital services in rural, regional, and remote New South Wales

Thank you for the opportunity to provide input for the Parliamentary inquiry into health outcomes and access to health and hospital services in rural, regional, and remote NSW.

Parkinson's NSW is a for-purpose organisation striving to improve the wellbeing and quality of life of people living with Parkinson's, their caregivers, families, and communities.

We provide essential services including an InfoLine staffed by Parkinson's Registered Nurses, community-based Parkinson's Specialist Nurses, Support Groups, counselling, education, and NDIS advocacy and Support Coordination.

We maintain a network of more than 90 Support Groups for people living with Parkinson's, and more than 70 percent of these are located in regional, rural, and remote areas of NSW.

This submission from Parkinson's NSW is relevant to the following Terms of Reference of the Inquiry:

- c) access to health and hospital services in rural, regional, and remote NSW including service availability, barriers to access and quality of services.
- d) patient experience, wait-times, and quality of care in rural, regional, and remote NSW and how it compares to metropolitan NSW.

Sincerely,

Jo-Anne Reeves
CEO

SUBMISSION

Inquiry into health outcomes and access to health and hospital services in rural, regional, and remote New South Wales

Parkinson's Disease

Parkinson's is a progressive, degenerative condition of the central nervous system. Nerve cell damage in the brain causes dopamine levels to drop, leading to the symptoms of Parkinson's.

Parkinson's symptoms can include tremors, slow movement, stiffness, and loss of balance – as well as fatigue, apathy, depression, disturbed sleep, loss of sense of smell, and issues with speech and swallowing.

Symptoms can be managed with medication, exercise and other forms of therapy and support. However, as yet there is no cure.

Parkinson's disease is the second most common age-related neurodegenerative disease after dementia with age being the greatest risk factor for developing itⁱ.

The average age of diagnosis is 60 and people may live with the disease for decades. Diagnosis itself can take years, meanwhile the disease progresses.

Parkinson's is more prevalent than many common cancers – including prostate, breast, colorectal, and lung cancers in Australians over the age of 50ⁱⁱ.

Despite cancers being declared a National Health Priority Area (NHPA) for Federal and State Governments, Parkinson's is not. Yet Parkinson's has a higher prevalence than cancers in the Australian and NSW populations.

The prevalence of Parkinson's increases by a factor of three after the age of 65 so the growth rate in the number of people living with this illness is expected to increase dramatically as the Australian population ages.

It is estimated that the average growth rate in Parkinson's will be 40 percentⁱⁱ over the next 20 years, compared with a general population growth rate of just over one percent.

Based on empirical research, estimates of the prevalence of Parkinson's in Australia range from 84,000ⁱⁱ to 212,000ⁱⁱⁱ and it is expected to grow by 79 percent from 2014 to 2034.

Based on this research, the number of people living with Parkinson's in NSW ranges from 24,000 to 63,750.

Health outcomes for people living with Parkinson's and caregivers are poorer in rural and remote areas.

Challenges of Parkinson's in rural and remote areas

1. More than 25 percent of the NSW population lives in rural or remote areas. For every working age adult in the state, there are:
 - 3 elderly (65 years plus) people living in cities
 - 6 elderly people living in rural and remote areas

Therefore, the demographics of rural and remote areas of NSW are skewed towards the age group most likely to be diagnosed with Parkinson's. Based on empirical research into the prevalence of Parkinson's in Australia we can project that the number of people currently living with Parkinson's in rural and remote NSW range from 24,000 to 63,750 people.

2. There is a shortage of neurologists serving the rural and regional Parkinson's community.

Of the 186 neurologists in NSW, 36 work outside metropolitan Sydney and less than ten movement disorder specialists – a sub-speciality required for the treatment of Parkinson's – are based or practice in rural and regional NSW.

This number includes neurologists who do fly-in fly-out clinics periodically in centres like Dubbo, Wagga Wagga, Port Macquarie, and Coffs Harbour.

It is of great concern that the average of practicing neurologists in NSW is 51, with 24 percent aged over 60 and a total of 58 percent planning retirement within the next three to five years^v.

Meanwhile, a 2016 survey of neurology trainees by The Australian and New Zealand Association of Neurologists Regional Committee identified "...negative perceptions of the impact of regional training on future metropolitan training and employment prospects that contribute to a culture of pessimism towards regional training..."^{vi}

In addition to the potential impact on rural and remote regions from the high turnover in neurologists due to retirement, there are likely to be issues in attracting new practitioners to these areas.

3. There are waiting lists of up to a year to see a Movement Disorder Neurologist (required for the treatment of Parkinson's). Also, due to the neurodegenerative nature of Parkinson's, patients often need to surrender their driver licenses – and therefore lose the mobility and independence required to travel long distances to the nearest regional town or city for specialist appointments.
4. General Practitioners lack the training or experience required to make medication changes or support advanced Parkinson's treatments such as the adjustment of stimulators for Deep Brain Stimulation or stoma care for patients fitted with a Duodopa pump.

This represents a significant gap in the continuity of care for people living with Parkinson's in rural and remote areas.

Parkinson's Specialist Nurses: Enabling continuity of care to maximise health and wellbeing outcomes

Community-based Parkinson's Specialist Nurses enable early intervention and self-management strategies for people living with Parkinson's and their caregivers living in rural and remote areas of NSW.

Proof of concept is provided by two Parkinson's Specialist Nurse positions in the Mid North Coast Local Health District and one in the Tweed region of the Northern NSW Local Health District – all co-funded by Parkinson's NSW.

This nurse model is further supported by the conclusions and measurable outcomes noted in a research project^{vii} commissioned by Parkinson's NSW and undertaken by the Charles Sturt University School of Nursing, Midwifery, and Indigenous Health.

The community-based nurse model illustrates how care for people living with Parkinson's can be seamlessly delivered across a variety of settings – clinics, hospitals, homes, and aged care facilities – to maximise health and wellbeing outcomes for Parkinson's patients and caregivers.

Parkinson's Specialist Nurses are highly trained and experienced. Among other qualifications they are required to:

- Be a Clinical Nurse Consultant – Level 2
- Provide expert Parkinson's clinical consultancy and services
- Provide complex client-centred consultancy within multidisciplinary teams and across multiple services and settings including hospitals, the community, Parkinson's and speciality nurse clinics, aged care, dementia care, psychiatry, medicine, surgery, mental health, and continence.
- Provide leadership in the ongoing review of clinical practice for the complex service of Parkinson's disease
- Adapt and apply scientific research to the clinical speciality of Parkinson's
- Conduct ongoing analyses of current practices and the impact of new directions on the clinical speciality service
- Manage complex projects related to significant practice changes e.g., Apomorphine and Duodopa.

Parkinson's NSW is advocating for the placement and funding of Parkinson's Specialist Nurses in every Local Health District covering rural and remote areas of NSW.

In those settings, Parkinson's Specialist Nurses function as the 'glue' which holds together multidisciplinary teams that include the neurologist, GPs, other nursing and Aged Care support staff, and Allied Health practitioners – and the patient's caregivers and family members.

These Nurses are also critical to the success of the trend towards using Telehealth services to rural and remote communities. There are now 11 city-based neurologists depending on community-based Parkinson's specialist nurses to facilitate and provide patient care via telehealth consultations.

References

ⁱ Reeve, A., Simcox E., and Turnbull D. (2014). Ageing and Parkinson's Disease: Why is advancing age the biggest risk factor? Ageing Research Reviews, 2014 Mar.

ⁱⁱ Deloitte Access Economics. (2015). Living with Parkinson's Disease: An updated economic analysis 2014, 2015 Aug.

ⁱⁱⁱ Ayton, D., Ayton, S., Barker, AL., Bush AL., and Warren, N. (2018) Parkinson's disease prevalence and the association with rurality and agricultural determinants. Parkinsonism & Related Disorders, 2018 Oct.

^{iv} Australian Bureau of Statistics

^v Medical Workforce in NSW, NSW Ministry of Health 2018

^{vi} The Australian and New Zealand Regional Neurology Training Survey, Neurology. 2016 Apr.

^{vii} <https://science.csu.edu.au/schools/nurse/research/research-projects/snmih-researcher-parkinsons-disease>