



## Special Commission of Inquiry into Healthcare Funding

**Submission Number:** 63  
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**Parkinson's NSW Ltd Submission  
to  
Special Commission of Inquiry into Healthcare Funding**

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## **Parkinson's NSW Ltd Submission to Special Commission of Inquiry into Healthcare Funding**

### **Introduction**

Parkinson's NSW Ltd is a for-purpose organisation registered with the Australian Charities and Not-for-profits Commission.

It is the Peak Body for the Parkinson's community of New South Wales – which includes 70,000 people living with the disease, in addition to caregivers and family members.

Parkinson's NSW is the sole organisation in New South Wales dedicated to providing evidence-based information, education and healthcare services to people living with Parkinson's disease, their caregivers, families, and communities.

Other organisations contribute by fundraising to support research for a cure; however Parkinson's NSW is focused on support and service provision. Its goal is to keep people living with Parkinson's out of Emergency Rooms and avoiding hospital admissions for longer – and living well with appropriate supports as they remain connected with their communities.

### **Funding Model**

Less than 10 percent of the Parkinson's NSW operating budget is derived from Government funding. The organisation is heavily dependent on community fundraising and bequests to fund its specialised Parkinson's support services.

While NSW Health provides some movement disorder services, they do not meet the growing demand from, or specialised support required by, the NSW Parkinson's community. The global rate of Parkinson's disease is forecast to double by 2040.

Parkinson's NSW is respectfully submitting to the Special Commission of Inquiry recommendations on how support for the NSW Parkinson's community can be more equitably and efficiently funded.

**This can be achieved by investment in further developing Parkinson's NSW resources (without duplicating those of NSW Health), its sustainability, and its cost-efficient partnerships with NSW Health.**

## The power of partnerships

Proof of concept of the power of partnerships between Parkinson's NSW, the public sector and communities includes:

- Co-funded community-based Parkinson's Specialist Nurses in the Mid North Coast, Northern NSW, Southern NSW, and Northern Sydney Local Health Districts. These Nurses have more than 2,500 patients on their lists.
- Partnerships with St Vincent's Body Movement Clinic, Macquarie University Hospital, Integrated Neurology Clinic, John Hunter Hospital and Westmead Hospital to deliver Parkinson's telehealth consultations and fly-in-fly-out clinics to regional and remote areas.
- Joint research projects into regional and rural Parkinson's nursing models and Parkinson's Support Groups with Charles Sturt University School of Nursing, Paramedicine and Healthcare Sciences.
- A State-wide network of 63 face-to-face Parkinson's Support Groups and 13 specialised Caregiver Groups – in addition to another five Zoom teleconferencing-based Groups and four Facebook Groups. These are funded and administered by Parkinson's NSW in close cooperation with community leadership teams. Together, these Groups support more than 2,000 participants.
- Face-to-face education seminars on Parkinson's for General Practitioners, Aged Care support workers and nurses – as well as a series of grant-funded online education modules designed to up-skill Allied Health professionals seeking to develop greater understanding of how to effectively support Parkinson's patients.
- A 1800 Parkinson's HealthLine staffed by nurses with more than 30 years of experience, providing a single point of contact for people living with Parkinson's, caregivers and family members who require evidence-based advice, information, and connection with essential services. This service fields more than 3,200 calls per year and is funded by Parkinson's NSW.
- Parkinson's-experienced psychological counsellors who conduct more than 920 sessions per year delivered as individual and group sessions through Parkinson's NSW as well as War Memorial and Wolper Hospitals. Telephone and Zoom consultations are also offered.

## **Parkinson's NSW challenges to be addressed by selected Terms of Reference**

### **A. How funding of health services can most effectively support safe delivery of high quality, timely, equitable and accessible health services to the people of NSW.**

- Focus on community-based nurses with movement disorder experience – co-funded by Parkinson's NSW and NSW Health
- Capacity-building funding for the Parkinson's NSW HealthLine – Increase service hours and add telephone or video conference support and access to information on outside specialist appointments.
- Build a multi-disciplinary movement disorders team in every Local Health District with a Parkinson's nurse as facilitator and coordinator. (This approach is supported by research conducted in the U.S., Netherlands, and Israel – original papers available for sharing with the Commission)
  - Note: Similar programs existing in NSW Health using Allied Health coordinators have proved well-intentioned but ineffective due to lack of clinical skills and experience in liaising directly with neurologists.
- Also fund and add a local Parkinson Net service (also pioneered in the Netherlands) – a training and support program. See: <https://www.parkinsonnet.com/>
- With the advice and support of Parkinson's NSW, introduce increased graduate nursing education and in-service training on Parkinson's and related Movement Disorders.
  - Final year job nursing experience job placements with experienced Parkinson's NSW nurses in the field
  - Can be coordinated through existing relationship between Parkinson's NSW and Charles Sturt University School of Nursing, Paramedicine and Healthcare Sciences.
  - Funding by NSW Health

**B. The existing governance and accountability structure of NSW Health including:**

- **Balance between central oversight and locally devolved decision-making (by Local Health Districts)**
  - **Engagement and involvement of local communities in health service development and delivery**
  - **The impact of privatization and outsourcing on the delivery of health services and outcomes**
- Parkinson's NSW has existing cooperative/co-funded relationships with Local Health Districts.
    - These function well and successfully deliver joint services on the ground – assuming that Health NSW recognises the value of such relationships and provides top-down discretionary funding authority to Local Health Districts accordingly.
    - In terms of the proposed community-based movement disorder service proposed under Term of Reference A (above), it would require a top-down decision and funding.
    - Parkinson's NSW can present research by Charles Sturt University: *Evidence based models that support best practice nursing services for people with Parkinson's disease in regional NSW*
      - Note: This research was completed in 2018 but with additional funding can be updated within 2023-2024 fiscal year.
      - Further research into the impact of semi-outsourcing of the community-based Parkinson's nursing model can also be conducted through the Parkinson's NSW network of Support Groups.
    - The Parkinson's and Related Movement Disorders Service recently launched with Westmead Hospital in the Mid North Coast Local Health District would also be a useful source of data to evaluate the model in practice.

**D. Strategies available to address escalating costs, limit wastage, minimize overservicing and identify gaps or areas of improvement**

- See also suggestions in B. above about research into optimal community nursing models for people living with Parkinson's, and co-funding of community nurse placement which avoids duplication by tapping the existing knowledge and resources of Parkinson's NSW

**F. The current capacity and capability of the NSW Health workforce to meet the current needs of patients and staff, and its sustainability to meet future demands.**

- **The role of multi-disciplinary community health services in meeting current and future demand and reducing pressure on the hospital system**
- See also comments under A. above relating to building a multi-disciplinary movement disorders team in every Local Health District with a Parkinson's nurse as facilitator and coordinator

**H. New models of care and technical and clinical innovations to improve health outcomes for the people of NSW**

- Expand on existing joint telehealth/fly-in fly-out movement disorder clinic models involving St Vincent's Body Movement Clinic, Macquarie University Hospital, Integrated Neurology Clinic, John Hunter Hospital, and Westmead Hospital.

**Footnote: History of Parkinson's NSW Ltd**

*Parkinson's NSW had its beginnings in 1979 when a Sydney man was diagnosed with Parkinson's. He and his wife found there were no sources of information about the disease except from his treating doctor. There was also no support or advice available from others in the same situation.*

*The couple recognised the need for a mutual self-help society and sought out like-minded people. This led them to establish The Parkinson's Syndrome Society of Australia.*

*In 1983 the Society commenced the formation of local area Support Groups.*

*Parkinson's NSW was built on the principles of The Parkinson's Syndrome Society and launched in 1979. Today it maintains a network of Parkinson's Support Groups in addition to the extensive list of services noted above.*

## **In Their Own Words**

### **Feedback from Clients of Parkinson's NSW**

#### **Parkinson's NSW HealthLine**

"Thank you so much for your assistance today. I feel so much better after talking to someone about it and it's great to know there is a lot of support out there for us."

*Person living with Parkinson's*

"Thank you for listening to me pour my heart out, it was nice just to debrief! I love Mum more than anything, and if I can keep her as safe and well as possible it will ease my mind a bit. She really has been the best Mum."

*Caregiver of person living with Parkinson's*

"I thank you ever so much for talking to me yesterday and helping me out. For once I really feel I am not alone in this hardship and feel such a relief how people really understand things. You are a gem!"

*Person living with Parkinson's*

"I wouldn't wish Parkinson's on my worst enemy and hearing from you has given me a glimmer of light. I now have an appointment to see a Parkinson's Nurse at my home."

*Person living with Parkinson's in Western Australia*

#### **Community-based Parkinson's Specialist Nurses**

"Thank you for our session with you yesterday. It helped us a great deal to remain positive and to take the doctor's comments in balance with our own feelings about how I am going."

"I must admit that before you took up this role, I wondered how a Parkinson's nurse would be helpful. After we had the session with you yesterday, I now realise how important it is to have a professional at hand to deal with problems as they arise and thus stop them from escalating."

*Person living with Parkinson's*

"Life is nearly normal, we never thought we would ever experience normal again. We are very grateful to have your friendship and expertise on the journey."

*Family member of a Deep Brain Stimulation patient*

"I just wanted to acknowledge and thank you again for your wonderful work in the development of the partnership with Western Sydney Local Health District – and Westmead Hospital – in particular, regarding the Movement Disorders Service that was launched in Coffs Harbour last week."

"The benefits for our community are significant, and I am aware that you and your colleagues have been a driving force to see this partnership formalised – well done and congratulations."



“The Launch itself was so thoughtfully considered and was a celebration of the sometimes-small things that can make such a difference to our Parkinson’s patients and their families.”

*Lydia Dennett, Acting Chief Executive  
Mid-North Coast Local Health District*

You are definitely making a difference to us all. You are so bright, bubbly and encouraging to everybody and your ability to take on knowledge about Parkinson’s has been phenomenal. Keep up the great work!

*Person living with Parkinson’s*

“Can’t fault the service. The nurse is terrific and follows everything up and is very helpful.”

*Person living with Parkinson’s*

“It is an excellent service. My husband who has Parkinson’s very much appreciated the contact with the nurse.”

*Partner of person living with Parkinson’s*

“Jody has been wonderful explaining and discussing information on Parkinson’s and has helped me understand my condition much more in only the first visit.”

*Person living with Parkinson’s*

“Whenever I have asked for help or advice concerning my husband’s Parkinson’s and his worsening symptoms, the local Parkinson’s Nurse has visited and made recommendations that he has passed on to my husband’s GP, Nursing Home, and Geriatrician. This has all been very useful and has led to various changes in medication and treatment.”

*Partner of person living with Parkinson’s*

## **Parkinson’s NSW Support Groups**

“My husband was diagnosed in 2020 and we joined the Support Group for him to communicate with like-minded people. During that time the information and support we received has been exceptional.

“I volunteered to take on the Leadership role in March 2021. I personally gain self-satisfaction from helping members and making sure that they all feel supported.”

*Rural Support Group Leader*

“My satisfaction in the leadership role comes from the joy of having a social and happy environment for people living with Parkinson’s and their carers. New friendships are formed and everyone is there for each other.”

*Metropolitan Support Group Leader*