



Committee Secretary
Senate Community Affairs References Committee
Department of the Senate
PO Box 6100
Parliament House
CANBERRA ACT 2600

6 July 2017

Dear Sir/Madam

Re: Value and affordability of private health insurance and out-of-pocket medical costs

This brief submission addresses one of the issues included in the inquiry terms of reference being "the effect of co-payments and medical gaps on financial and health outcomes".

Parkinson's Australia is the national peak body and not-for-profit organisation representing more than 70,000 Australians living with Parkinson's and 700,000 directly impacted by Parkinson's. More than 12,000 people are diagnosed every year.

Parkinson's is a progressive and substantially disabling neurodegenerative condition that impacts all body systems and can affect people from all walks of life. Parkinson's is the most common major movement disorder and the second most common neurological degenerative condition after dementia.

There are several advanced therapies that are available in Australia to treat people with Parkinson's. One of these therapies is Deep Brain Stimulation (DBS) which involves implantation of a neurostimulator (not unlike a cardiac pacemaker) into the chest wall and the insertion of electrodes deep into the brain through which a small electric current is passed to stimulate that part of the brain. DBS is not a cure for Parkinson's and does not slow the progression of the condition; however, it can provide very good symptom control often resulting in substantial reductions in medication requirements and in some cases going off medication altogether.

The NSW Agency for Clinical Innovation, in a 2012 Paper *Deep Brain Stimulation Models of Care*¹, found that “there is strong evidence that the provision of deep brain stimulation for people with Parkinson's disease is a cost-effective alternative to current sole therapeutic pharmacological regime.”

The availability of DBS in the public hospital system varies from State to State. In some States, almost all DBS surgery is done through the private hospital system with very few patients being able to access DBS in the public system. Many patients have little option but to go to the private hospital system for this life changing therapy.

In the great majority of cases patients will incur substantial out of pocket costs. Even for patients with the top level of health insurance these costs will usually be more than \$14,000 and can be as high as \$50,000+ depending on the level of private health insurance and the costs charged by the hospital and medical team. There will also be ongoing costs associated with replacement of devices, which requires further surgery, every 3-5 years for a neurostimulator with a non-rechargeable battery and 8-10 years for a device with a rechargeable battery.

The majority of people living with Parkinson's are over the age of 65 and many of them are living on fixed incomes or have very limited financial resources. Parkinson's Australia is aware of people who have had to mortgage their homes or have had to dip into their superannuation to finance their DBS treatment. There are also many who cannot afford this treatment at all even though it is appropriate for them and is considered cost effective.

Parkinson's Australia requests that during the inquiry that the committee look at options that will assist in reducing, what are unreasonable, out of pocket costs that people with Parkinson's have to fund for a cost-effective treatment that should be available to all in the community that require it.

Steve Sant

Chief Executive Officer
Parkinson's Australia

¹NSW Agency for Clinical Innovation, *Deep Brain Stimulation Model of Care*, accessed 5 July 2017, https://www.aci.health.nsw.gov.au/_data/assets/pdf_file/0003/163191/DBS-model-of-care.pdf.