

Parliamentary Inquiry into Accommodation and Intensive Family Support Funding for People with Disabilities

This submission represents people with Young Onset Parkinson's Disease (YOPD).

Overview of Parkinson's Disease

Parkinson's disease is the second most common neurological condition in Australia. It is a relentless, life-long, incurable disease with a gradual onset and slow progression over many years. Current medications do not cure or halt progression of the disease and cause significant side-effects that over time, with increasing dosages, inevitably become just as debilitating as the disease itself.

The Deloitte Access Economics Report: Living with Parkinson's Disease (October 2011) highlights the following:

- There are currently 80,000 people in Australia living with Parkinson's disease (Pd)
- 30 people are newly-diagnosed with Parkinson's disease everyday
- 20% are still of working age, and 1 in 10 are under the age of 50
- In 2011 there were over 2,000 people with Parkinson's disease aged in their 30s and 40s
- More than 12,000 Australians aged 25-64 are estimated to be living with Parkinson's disease
- 80% of this group with Young Onset Parkinson's Disease are in stages 1-3 and will reach stage 4 (advanced stage of disease) over the coming 5-10 years. At this advanced stage care is required outside of what families and carers are able to provide.

Addressing the Terms of Reference:

1. *The adequacy of current processes for determining funding support for people with disabilities who live with their families:*

There is a lack of awareness in the general healthcare system of the full impact and complex nature of the disease and the daily challenges faced by those suffering its debilitating physical, cognitive and emotional effects.

Parkinson's disease is uniformly treated as a condition of the elderly with most services geared towards that belief; however there are many with Young Onset Parkinson's Disease (YOPD) hidden in the community coping as best they can until a crisis situation occurs. It has been the experience of those with YOPD that when crisis care is required it has not been available, resulting in long hospital stays with nowhere else to go as their families/carers are no longer able to cope.

2. *The Level of Unmet Need:*

When the person with YOPD reaches the advanced stages of the disease (stage 4) they will require ongoing 24-hour assistance with the activities of daily living: overseeing medication schedules that can range from every 1-3 hours, dressing, toileting and eating. Of particular

concern at present is obtaining urgent access to disability support services, respite care and long-term supported accommodation outside the aged care system.

The biggest fear amongst those with YOPD is the progression to a total loss of independence and being placed in an aged-care facility. In 2011 there were already 188 people with YOPD residing in aged-care facilities in Australia (Access Economics Report 2011).

Current options in aged-care do not meet the needs of the person with YOPD, particularly their very individual medication regimes and timing of meals around medication schedules. Medications must be taken on time every time, at schedules anywhere between 1-4 hours, and at least 30 minutes before meals or 1 hour after. Meals need to be of very low protein content and often vegan in nature as protein competes with the uptake of the medication (protein eaten can block uptake by 80%). Therefore meals need to be taken around the person's particular medication regime which varies greatly. As the current aged-care system is already over-burdened, these regimes are usually not followed thus greatly affecting the person's mobility and functioning. The YOPD person will experience the more debilitating later stages (Hoehn and Yahr scale stages 4-5) before many are 65 years of age. Being placed in an aged-care facility will often trigger the young onset person into rapid deterioration.

There is a chronic lack of understanding of the needs of the YOPD group for disability and community support, respite care and long-term supported accommodation, and a distinct lack of a concerted advocacy strategy to identify the needs of this group. In particular people aged 50-65 years are in a policy vacuum. Aged-care services are inappropriate and limited in focus. This requires urgent priority as it is this age group range (50-65) when the YOPD group are most likely to require higher levels of disability support and accommodation within the next 5-10 years.

3. The nature and extent of planning required to meet increasing demand for these support services in Western Australia in the future.

The YOPD community report they are unable to obtain information on what services are available to them and the need to develop information pathways that will assist them to make informed decisions about their future care whilst they are still in the middle stages of Parkinson's disease (7-14 years post diagnosis).

Critical areas of support include:

- A transition plan to avoid a crisis situation to enable the YOPD person to have a sense of control about their future
- Establish access to suitable assisted living centres for the YOPD group who are no longer able to live independently, or with their families, and require long-term supported accommodation that caters for those under 65 years of age.
- The facility should offer care by staff trained in the management of Parkinson's disease and include an allied health component.

(Such centres are currently available for sufferers of Multiple Sclerosis).

