

## **Demanding a better deal for Parkinson's disease in Queensland**

We represent more than 17,000 people living with Parkinson's, their carers, families and healthcare professionals who support them.

- We demand a better deal for people living with Parkinson's and their carers.
- We need funding to employ neurological nurses in urban, rural and remote locations in Queensland trained and supported through the peak body representing people living with Parkinson's disease in Queensland – Parkinson's Queensland. This model of care is based on sound evidence in the UK and in WA where the outcomes of a speciality nurse service ensured
  - People with Parkinson's disease felt supported to take control of their condition
  - Improved access to care close to client's homes, support to the carer and client
  - Reduction in the need for admission to hospital and reduction in the number of clients requiring premature transition to nursing home care, and
  - Improved quality of life.

### **Our Growing Challenge**

Parkinson's is a chronic, progressive, complex, disabling neurological condition which currently has no known cure. The four key symptoms are tremor, rigidity, slow or impaired muscle movement and postural instability, with literally dozens of complex, secondary and non-motor symptoms.

Typically the disease manifests in patients aged around 60 years; however, 10% of those diagnosed will be under the age of 40 and 20% under the age of 50.

- Parkinson's is more prevalent than prostate, ovarian and cervical cancer or leukaemia
- One in five people with Parkinson's is of working age (15-64)
- Of particular concern to policy makers is the sobering fact that Parkinson's prevalence is increasing at around 2-3% per year.

### **Key Facts**

- About 17,000 of your fellow Queenslanders (80,000 Australians) have a diagnosis of Parkinson's
- More than 30 people are diagnosed with Parkinson's every day (that's more than one Australian per hour)
- The estimated total economic burden of Parkinson's is more than \$8 billion a year from diagnosis
- Over a lifetime, people with Parkinson's experience significant disability and require increasing levels of care
- Parkinson's imposes a debilitating array of symptoms, including depression and anxiety and that, together with decreasing mobility, leads to social isolation

- Younger people with Parkinson's have to face the loss of earning ability, at a time when they are trying to raise a family and to provide for the future
- Despite its increasing prevalence and high cost to the community, Parkinson's is still not recognised as a priority under Australia's Chronic Disease Strategy.

**Background:**

In 2014/15, Parkinson's Queensland will receive \$41,030.00 from the Queensland Government, to deliver a variety of strategies for people aged under the age of 65 years. These strategies include:

- a State-wide information, advice, support and referral service
- provision of strategic advice to community educators and training providers
- the development of resources, and
- Community awareness campaigns.

However, this small amount of funding ceases on 30 June 2015. Parkinson's Queensland also delivers other strategies which are funded through fundraising and other support activities of the association including:

- 49 support groups across the State managed by carers or people with Parkinson's
- professional forum's for nursing staff, neurologists and General Practitioners
- a health promotion and early intervention service, and
- Parkinson's Plus – a service for clients with Idiopathic Parkinson's diseases including Dystonic Tremor, Progressive Supranuclear Palsy, Restless Legs Syndrome and Corticobasal Degeneration.

**The evidence:**

- In 2011, the cost to the Queensland community from Parkinson's disease was \$155.1m (Access Economics – 2011). Of this cost, \$100.5m were health system costs with \$12.87m due to inpatient/outpatient care and \$13.0m due to pharmaceuticals. Health system costs for people with Parkinson's disease are rising by 6% per annum (AIHW, 2011).
- The average lifetime cost of someone living with Parkinson's disease is \$144,000, second only to cancer at \$165,000 (Access Economics, 2011).
- Parkinson's disease, which is Australia's 2<sup>nd</sup> most common neurological condition, is increasing in incidence at approximately 4% per annum (AIHW, 2011).
- There are approximately 17,000 Queenslanders living with Parkinson's disease. While the majority of these people are aged over 65 years of age, 20.5% are of working age and 5% are aged under the age of 30 years. The costs due to lost productivity, which was \$25.7m in 2011 are also rising at 5% per annum.

[www.parkinsonsqld.org.au](http://www.parkinsonsqld.org.au)

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