



Make Parkinson's a Priority: Action Framework

Parkinson's Australia 2015





About Parkinson's Australia

Parkinson's Australia is the national not-for-profit body working to support and advocate for all people affected by Parkinson's and atypical Parkinson's conditions such as Multiple System Atrophy, Progressive Supra Nuclear Palsy, Lewy Body Dementia and Cortico Basal Degeneration. Parkinson's Australia is supported by its members and through donations.



On the cover

The women pictured are Monica Hall, Donelle Bruin and Dee Reynolds all of whom have been diagnosed with Young Onset Parkinson's.

Parkinson's Australia mission

To create an environment that is responsive to the needs of all people affected by Parkinson's.

Our Business

- Advocate to raise awareness of the significant cost of Parkinson's in social and economic terms.
- Build partnerships with relevant bodies to enhance our effectiveness.
- Educate health professionals, politicians and the public about Parkinson's.
- Encourage research.

Members of Parkinson's Australia

- Parkinson's Australian Capital Territory
- Parkinson's New South Wales
- Parkinson's Queensland
- Parkinson's South Australia
- Parkinson's Tasmania
- Parkinson's Victoria
- Parkinson's Western Australia¹

The State Parkinson's members provide a variety of services to people living with Parkinson's, these include:

- Education for patients, clinicians and health care workers
- 290 support groups nationwide for people living with Parkinson's
- Support through the 1800 info line
- Counselling services for people living with Parkinson's and their carers
- Clinical support for people living with Parkinson's through specialist nurses and allied health professionals
- Support for research including scholarship programs

Parkinson's Australia works closely in partnership with the Shake It Up Australia Foundation² and maintains contact with other Parkinson's organisations around the world and is a World Parkinson's Coalition Partner³.

Parkinson's Australia acknowledges the extensive knowledge and experience of our member organisations, clinicians, supporters and people living with Parkinson's, who generously give their time and expertise to help ensure we produce the highest quality information and insight.

¹Parkinson's WA, supported by Parkinson's Australia, provide limited support services to Northern Territory

²Shake It Up Australia Foundation is a not-for-profit organisation established in 2011 to promote and fund Parkinson's disease research in Australia. <http://shakeitup.org.au/>

³The World Parkinson Coalition is a non-profit organization dedicated to providing an international forum to learn about the latest scientific discoveries, medical practices, caregiver initiatives and advocacy work related to Parkinson's disease.

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Introduction

Parkinson's is a neurodegenerative condition with no cure. The World Health Organisation observes that Neurological disorders, such as Parkinson's, are "one of the greatest threats to public health"⁴. Because of its chronic progressive nature, insidious onset, complicated and diverse motor and non-motor symptoms and limited management options Parkinson's is one of the most challenging diseases.

People diagnosed with Parkinson's have a complex range of movement related symptoms including tremor, muscle rigidity, poverty of movement and loss of normal posture with a tendency for falls. However, lesser known is the major impact on non-motor functions such as depression, anxiety, behavioural disturbances and cognitive impairment, sleep disorders, hallucinations, dementia, sensory deficits such as loss of smell and visual problems and impaired speech.

Parkinson's has a higher prevalence than a number of diseases considered to be National Health Priority Areas including some cancers, such as breast cancer, colorectal, stomach, liver and pancreatic cancer, lymphoma and leukaemia, kidney and bladder, uterine, cervical, and ovarian, and lung cancer. Conservative estimates indicate that one in every 340 people in Australia or around 70,000 people live with Parkinson's. Each year, over 11,500 new Parkinson's cases are diagnosed in Australia.

Parkinson's Australia estimates that up to 700,000 people, or 3% of the Australian population, are directly impacted by Parkinson's, they either have Parkinson's, provide care to someone with Parkinson's, have a family member or close friend affected by Parkinson's. Around 20% of people with Parkinson's are of working age often with young families.

There is a very substantial cost to the community of Parkinson's. The latest report⁵ commissioned by Parkinson's Australia notes that the total economic cost of Parkinson's to the community is approximately \$9.9b per annum.

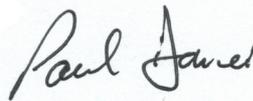
Parkinson's Australia believes that there are many opportunities open to the Commonwealth and States/Territories to both improve the quality of lives of people living with Parkinson's and to achieve the efficiencies that will reduce the cost of Parkinson's to the community.

For the first time Parkinson's should be made a focus of national action through the Commonwealth and States by:

- **Recognition of Parkinson's as a National Health Priority Area;**
- **Investment in better care and support for people living with Parkinson's through access to Parkinson's Nurse Specialists and equitable access to medications and therapies;**
- **Investment and capacity building in Parkinson's research; and,**
- **Investment in upskilling the workforce to enable timely diagnosis, better care and support of people living with Parkinson's.**

Without action Parkinson's remains a burden on society, on individuals and on carers.

Parkinson's Australia is seeking a commitment from the Commonwealth and States to a best practice, evidence based and nationally consistent approach to supporting people living with Parkinson's and for investment in research to find better treatments and ultimately a cure for Parkinson's.



Paul Davies
President, Parkinson's Australia

⁴ World Health Organization (2006) Neurological disorders: public health challenges. www.who.int/mental_health/publications/neurological_disorders_ph_challenges/en/

⁵ Deloitte Access Economics, Living with Parkinson's Disease: An updated economic analysis 2014, August 2015.

Immediate Priorities

For the first time Parkinson's should be made a focus of national action through the Commonwealth and States by:

- **Recognition of Parkinson's as a National Health Priority Area;**
- **Investment in better care and support for people living with Parkinson's through access to Parkinson's Nurse Specialists and equitable access to medications and therapies;**
- **Investment and capacity building in Parkinson's research; and,**
- **Investment in upskilling the workforce to enable timely diagnosis, better care and support of people living with Parkinson's.**

These four immediate priorities are supported by the best economic and clinical evidence available including the 2015 Deloitte Access Economics report "*Living with Parkinson's Disease: An updated economic analysis 2014*" and have been developed after extensive consultation with the Parkinson's Community including people living with Parkinson's, carers and clinicians.

In a climate of tight fiscal constraints, Parkinson's Australia believes that it is responsible to invest in better care as this has been proven, not only to improve the care of people living with Parkinson's, but to achieve overall net savings in the direct cost of Parkinson's to our community.

Recognition of Parkinson's as a National Health Priority Area

The National Health Priority Areas (NHPAs) are diseases and conditions that Australian governments have chosen for focused attention

because they contribute significantly to the burden of illness and injury in the Australian community. Australia has nine National Health Priority Areas, these are: cardiovascular health, cancer control, injury prevention and control, and mental health (1996); diabetes (1997); Asthma (1999); arthritis and musculoskeletal conditions (2002); obesity (2008); and, dementia (2012).

There is an increasing Burden of Disease⁶ in the community associated with Parkinson's. In their 2007 report on the Burden of Disease⁷ the Australian Institute of Health and Welfare (AIHW) noted that as a result of population aging there "will be the steady growth in the burden from diseases associated with old age such as dementia, Parkinson's disease, hearing and vision loss, and osteoarthritis", they went on to note "current prevention and (with the exception of osteoarthritis and cataract) treatment strategies are largely ineffectual." The latest Deloitte Access Economics report estimates that the net value of the burden of disease associated with Parkinson's at \$8.9b in 2014, a 42% rise since 2005⁸. The average lifetime cost of Parkinson's is estimated to be \$161,300 which is similar to the lifetime cost of cancer (\$144,000)⁹.

It is clear that Parkinson's:

- Contributes very significantly to the burden of disease in the community and that the burden of disease will increase at a substantially higher rate than is explained by population growth alone;
- There is a great potential to improve the health outcomes and reduce the overall burden of disease associated with Parkinson's; and,
- That the costs, burden of disease and health inequalities associated with Parkinson's is greater than, or similar to, those associated with other National Health Priority Areas.

Recognition of Parkinson's as the tenth National Health Priority Area will help focus attention and effort on Parkinson's and drive collaboration in development of strategies and policy directions, research priorities, education, services and community awareness to better support people living with Parkinson's.

⁶ Burden of Disease is the impact of a health problem as measured by financial cost, mortality, morbidity, or other indicators. [www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/1370.0~2010~Chapter~Burden%20of%20disease%20\(4.1.6.4\)](http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/1370.0~2010~Chapter~Burden%20of%20disease%20(4.1.6.4)).

⁷ Begg S, Vos T, Barker B, Stevenson C, Stanley L, Lopez AD, 2007. The burden of disease and injury in Australia 2003. PHE 82. Canberra: AIHW.

⁸ Deloitte Access Economics, Living with Parkinson's Disease: An updated economic analysis 2014, August 2015, pp. 79

⁹ Deloitte Access Economics, Living with Parkinson's Disease: An updated economic analysis 2014, August 2015, pp. 101



**Parkinson's Australia
is seeking a commitment
from the Commonwealth
and States that Parkinson's
be recognised as a National
Health Priority Area.**

Investment in better care and support for people living with Parkinson's through access to Parkinson's Nurse Specialists and equitable access to medications and therapies

As there is no cure for Parkinson's, and most people live for many years with this progressive condition, the primary focus of treatment is on the control and management of symptoms and reduction in complications associated with Parkinson's. The management of Parkinson's is very complex with very detailed medication and therapy regimes which require continual monitoring and adjustment.

Key to achieving effective management of Parkinson's is having access to multidisciplinary care and clinical support which is both coordinated

and planned. This care is best facilitated for people living with Parkinson's through access to Parkinson's Nurse Specialists¹⁰.

In the UK, Parkinson's Nurse Specialists have been providing effective care in the community for more than 20 years. Parkinson's Nurse Specialists are also widely used in many European countries, the USA and Canada. The UK Parkinson's Disease Society Competency Framework¹¹ recommends that Parkinson's Nurse Specialists have the following competencies:

- Communication
- Patient and carer assessment
- Symptom management
- Medicines management
- Providing ongoing support and advice
- Referral to other therapists
- Education.

In Australia, Parkinson's Nurse Specialists provide advanced clinical leadership, advice and support to patients and carers to promote effective condition and symptom management in the community. Parkinson's Nurse Specialists have an important role in assisting to manage the very wide, complex and idiosyncratic medication regimes of individuals which is essential, as access to a neurologist is usually, at best, only 6 monthly and in the country regions may be non-existent. They also deliver education to both patients and other health professionals, provide advanced clinical support and care coordination to patients with more complex needs and provide expert advice and support to hospital staff for patients who are hospitalised.

The provision of best practice nursing care by Parkinson's Nurse Specialists has been demonstrated in Australia¹², and internationally¹³, to

- Improve the management of symptoms and quality of life of people living with Parkinson's;
- Reduce hospital admissions and length of stay for necessary admissions;
- Delay entry into residential care; and,
- Reduce the need for costly medical consultations and interventions.

¹⁰Clinical Nurse Consultants or Nurse Practitioners.

¹¹National Institute for Health and Care Excellence. Parkinson's Disease: National clinical guideline for diagnosis and management in primary and secondary care. 2006 and Parkinson's Disease Society. Competencies: an integrated career and competency framework for nurses working in PD management. London: Parkinson's Disease Society; 2005

¹²Pereira, M.M., Lewis, S.J.G., Naismith, S.L., Dixon, M.; Neurological nurse educator Shoalhaven project - Nursing in the community [abstract]. Movement Disorders 2013;28 Suppl 1 :268

For the 8,500 people with Parkinson's that live in Residential Aged Care Facilities (RACFs), Parkinson's Nurse Specialists not only provide direct clinical support but undertake the vital role of educating the aged care workers most of whom have little or no understanding of Parkinson's. RACF residents with Parkinson's are often frail, physically disabled with associated high fall rates and many are cognitively impaired with dementia and consequently have a poor quality of life. Parkinson's Nurse Specialists can reduce these poorer outcomes avoiding significant costs being incurred in the acute care setting as a result of falls and other avoidable complications associated with Parkinson's.

The Parkinson's Nurse Specialist model of care can be easily adapted utilizing a number of different service delivery models to take account of local health care delivery arrangements and environments. All of the models work towards the same goals, are tailored to the local community requirements and are based on coordinated multi-skilled multidisciplinary teams which focus on patient centred self-management, education, information, research, referral and clinical support.

Access to Parkinson's services is particularly problematic in regional and rural areas, in these areas the model can be modified so that neurological or movement disorder nurses provide services to people with Parkinson's along with patients with other neurological conditions. The provision of specialist nurse services substantially reduces the disadvantage that people living with Parkinson's in rural communities' experience.

International evidence¹⁴ indicates there should be one specialist Parkinson's nurse for every 300 to 450 Parkinson's patients, which equates to a need for around 155-200 nurses in Australia. Parkinson's Australia considers that 51 specialist Parkinson's Nurse Specialist phased in over 4 years would provide initial, essential support for those with the most complex care needs and demonstrate the value of this service. The cost in year one of direct funding of Parkinson's Nurses Specialists would be \$2.1m rising to \$7.8m in year four. Total cost over the 4 year Forward Estimates period¹⁵ would be \$19.6m¹⁶.

Based on the United Kingdom experience, where a similar model of community based specialist Parkinson's Nurses exists, net savings would accrue and even using the lower estimates of savings from the UK it could be expected that each nurse would generate net savings to the system. Evidence from the UK¹⁷ indicates that a single Parkinson's Nurse Specialist can save:

- between £17,331 and £114,912 in avoided consultant appointments each year;
- between £80,000 and £81,522 in reducing unplanned hospital admissions per year; and,
- between £77,448 and £190,218 in reducing the number of days spent in hospital each year.

Parkinson's Nurse Specialists are an essential element of effective care for people with Parkinson's and their families; however, this support is available now only to a very few with many still struggling to manage their condition. Parkinson's Nurse Specialists are a cost effective intervention that can:

- reduce the overall burden of disease;
- help people living with Parkinson's remain active and independent; and
- reduce health care costs through avoidance of unnecessary hospital and aged care admissions and reduced length of stay and medical specialist consultations.



**Parkinson's
Australia is seeking
a commitment from the
Commonwealth and States to
fund 51 Specialist Parkinson's
Nurses to provide essential care
to people living with Parkinson's
at a cost of \$19.6m over
the 4 year Forward
Estimates period.**

¹³Deloitte Access Economics, Living with Parkinson's Disease: An updated economic analysis 2014, August 2015, pp. 109-114

¹⁴National Institute for Health and Clinical Excellence (2006). Clinical Guideline 35. National cost impact report to accompany 'Parkinson's disease: diagnosis and management in primary and secondary care'

¹⁵Budget year next 3 years

¹⁶Phased in over 4 years Yr 1 12.75 FTE, Yr2 25.5FTE, Yr3 38.25FTE, Yr4 51FTE

People living with Parkinson's have a reasonable expectation that they will have equitable access to therapies that will assist in the management of their condition and this is currently not the case.

Access to medications that are not covered by PBS or are 'off label', advanced therapies¹⁸ for Parkinson's such as neurosurgical procedures including Deep Brain Stimulation and access to specialist services provided by allied health professions, are not available to all people living with Parkinson's that require them.

Access to these medications, therapies and services can cause very significant additional costs for the people impacted by Parkinson's. In some cases, people living with Parkinson's in one State have had to fund out of pocket expenses of more than \$50,000 to access a treatment that is available free to patients in another State. The majority of people living with Parkinson's are over the age of 65 and usually have limited, if any, financial capacity to fund medications or other treatments.



Investment and capacity building in Parkinson's research

While an estimated 123,000 people will be living with Parkinson's by 2034¹⁹, there are no treatments to prevent, slow, halt, reverse or cure the condition. Treatments available today can, at best, only assist in controlling the symptoms, have very significant side effect profiles and over time they become much less effective.

To address the growing prevalence of Parkinson's and its ever-increasing total economic cost to the Australian community – estimated at \$9.9 billion²⁰ - Parkinson's Australia believes that a significant increase in funding for medical research is essential.

Research priorities should be directed towards²¹:

- understanding the biomedical causes of Parkinson's such as genetic links in Parkinson's, and include epidemiological (population-based) medical risk factors and public health research (including accurate estimation of the prevalence of Parkinson's in Australia);
- development of a definitive test for Parkinson's and effective models (best clinical practice) of diagnosis and care for people with Parkinson's;
- development of allied health and alternative therapies to improve motor and non-motor aspects of Parkinson's and slow disease progression (e.g. exercise therapy);
- best treatment models of Parkinson's involving primary care and allied health services; and
- measures that prevent or postpone the onset of Parkinson's, or that slow or reverse disease progression such as nerve growth factors and neuro-protective drugs, and further development of non-invasive neuro-stimulation options and deep brain stimulation which have been shown to be effective in reducing symptoms of Parkinson's.

¹⁷Deloitte Access Economics, Living with Parkinson's Disease: An updated economic analysis 2014, August 2015, pp. 114

¹⁸Examples of medication and therapies is contained in Appendix 1 at page 13

¹⁹Deloitte Access Economics, Living with Parkinson's Disease: An updated economic analysis 2014, August 2015, pp. 30.

²⁰Ibid. pp. 86

²¹Ibid. pp. 113

Australian medical research can contribute globally, at the highest international levels, towards better understanding the cause, the development of Parkinson's treatments, and the pursuit for a cure. Parkinson's research can provide large returns on investment, with estimates as high as 2.4 to 1 in terms of the value of gains in healthy life²², and has the potential to drastically improve the lives of people with Parkinson's.

In 2014, the National Health and Medical Research Council (NHMRC) invested \$10 million in Parkinson's research, providing a foundation for future growth. However, to maintain and strengthen the Parkinson's research agenda, build the capacity of researchers in this field, and ultimately improve the quality of life for people with Parkinson's, a significant and ongoing increase in investment is urgently needed.

Both Parkinson's Australia, state organisational members and Shake It Up Australia continue to make significant contributions to support Australia's Parkinson's research; however, an increase in government support to \$20m per annum, at an additional cost of \$29m²³ over the Forward Estimates period, will provide significant support for research into Parkinson's that will contribute to the worldwide search for innovation in the potential prevention, diagnosis, treatment and management of Parkinson's.

There is a strong, but small, Parkinson's research community in Australia that is contributing valuable research to the world wide Parkinson's knowledge pool; however, there is a need to support further development of research capacity by supporting and encouraging early career researchers to remain in Australia and undertake research to relevant to Parkinson's.



**Parkinson's
Australia is seeking
a commitment from the
Commonwealth and States to an
increased investment of \$32.54m
over the Forward Estimates
period for increasing Parkinson's
research to \$20m per annum
and provision of early career
researcher scholarships/
fellowships.**

²²Deloitte Access Economics, Living with Parkinson's Disease: An updated economic analysis 2014, August 2015, pp. 113.

²³Phased in over 4 years

Investment in upskilling the workforce to enable timely diagnosis, better care and support of people living with Parkinson's

There are at least 70,000 living with Parkinson's and 11,500 new cases every year; however, knowledge about Parkinson's in the health and ageing workforce is generally very low. Whilst access to Neurologists, with expertise in Parkinson's, and Parkinson's Nurse Specialists can provide much needed care and support to people living with Parkinson's there is still a need to ensure that the generalist health and aged workforce have a working knowledge about Parkinson's, as in most cases they deliver the majority of the care to people living with Parkinson's.

Parkinson's Australia and its members are committed to supporting workforce capacity to provide high quality care to people living with Parkinson's and have:

- developed a National Training Package²⁴ for Residential Aged Care workers aimed at improving the quality of life for people with Parkinson's disease who are in residential care, by developing a national training package in the care and medical management of residents with Parkinson's disease as part of the Aged Care System Improvements and Healthy Ageing Grants initiative;
- funded the Australian College of Remote and Rural Medicine to provide access to a 6-hour online education module for general practitioners; and,
- provided seminar and education programs in all States for health and aged care workers.

Parkinson's Australia and its member organisations currently provide a limited number of education sessions to the health and aged care workforce; however, the ability to undertake this important role with no dedicated government funding for specialised Parkinson's educators is extremely limited. Whilst excellent feedback has been

received about these education activities, they are currently only reaching a very small proportion of the workforce.

Funding is now sought to

- Further develop the National Training Package for Residential Aged Care workers so that it can be used in education programs in both the acute and primary health care settings. This package also has potential to be used for the provision of training to undergraduate medical, nursing and allied health students²⁵.
- Deliver the National Training Package for Residential Aged Care workers across Australia and to deliver training to the primary and acute care workforce.
- Review and update the general practitioner online training module and make it available through additional online education channels.

It is expected that significant savings would accrue as a result of better care arrangements e.g. reduced admissions to hospitals for avoidable complications, reduced need for rural patients to travel to see specialists in the city.

The annual cost of improving the skills and capacity of the health and aging workforce would be \$2.638m²⁶ in a full year totalling \$10.55m over the Forward Estimates period.



²⁴Supported through the 2013 Commonwealth Aged Care Service Improvement and Healthy Ageing Grants Fund

²⁵Supported through the 2013 Commonwealth Aged Care Service Improvement and Healthy Ageing Grants Fund

²⁶Based on 14.24 Full Time Equivalent staff

Appendix 1: Summary of costings

Initiative	Forward Estimates cost ²⁷	Notes
Recognition of Parkinson's as a National Health Priority Area	N/A	
<p>Investment in better care and support for people living with Parkinson's through access to Parkinson's Nurse Specialists and equitable access to medications and therapies:</p> <ul style="list-style-type: none"> 51 Specialist Parkinson's Nurses to provide essential care to people living with Parkinson's equitable access to medications, advanced therapies and services for the treatment of Parkinson's 	<p>\$19.6m</p> <p>N/A</p>	<p>Phased over 4 years: Year 1 - 12.75 FTE Year 2 - 25.5 FTE Year 3 - 38.25 FTE Year 4 - 51 FTE plus 1 FTE program support</p> <p>Funded within current National Health Reform Agreement, Medical Benefits Schedule and Pharmaceutical Benefits Scheme funding</p>
<p>Investment and capacity building in Parkinson's research;</p> <ul style="list-style-type: none"> increased investment to \$20m per annum for Parkinson's research Full and partial scholarships for early career Parkinson's researchers 	<p>\$29.0m</p> <p>\$3.54m</p>	<p>Phased over 4 years: Year 1 - \$2.5m Year 2 - \$7.5m Year 3 - \$9m Year 4 - \$10m</p> <p>4 full scholarships p.a. of \$60,000 - cost of \$2.69m over 4 years. 10 top up scholarships per annum of \$7500 – cost of \$0.85m over 4 years</p>
Investment in upskilling the workforce to enable timely diagnosis, better care and support of people living with Parkinson's	\$10.55m	14.25 FTE plus admin support
Total	\$62.69m	

²⁷ 3 year plus Budget year costs

Appendix 2: The facts about Parkinson's

Parkinson's is a progressive and substantially disabling neurodegenerative condition that affects people from all walks of life. Parkinson's is the most common major movement disorder and the 2nd most common neurological degenerative condition after dementia. It is conservatively estimated that 70,000 Australians are living with Parkinson's with approximately 32 new cases of Parkinson's diagnosed every day. Approximately 1,740 people die from Parkinson's every year.

Whilst 'typical' or idiopathic Parkinson's constitute the vast majority of our community there are a number of 'atypical' Parkinson's conditions including Multiple System Atrophy, Progressive Supra Nuclear Palsy, Lewy Body Dementia and Cortico Basal Degeneration which have signs and symptoms similar to Parkinson's. People diagnosed with an atypical Parkinson's condition generally have a poorer prognosis than those with Parkinson's.

The average age of diagnosis is 65 years and 82% of people living with Parkinson's are over the age of 65. However, people as young as 20 years can be diagnosed with Parkinson's and this is referred to as Young Onset Parkinson's.

According to ABS data in 2012 there were 3,061 deaths where Parkinson's was an associated cause, of these 46% Parkinson's was the underlying cause.

It is not easy to diagnose Parkinson's. There are no laboratory tests (such as a blood test or brain scan). The diagnosis is made on the basis of the clinical presentation and history of the patient so it is important that the diagnosis is made by a specialist, such as a neurologist.

Parkinson's sign and symptoms

Parkinson's is characterised by a wide variety of signs and symptoms that affect both motor and non-motor areas of the brain. Parkinson's

symptoms are mostly attributed to the reduction in a key neurotransmitter production (dopamine) in the brain. The reduction in dopamine causes difficulties in the coordination of muscle movements and contributes to mood and cognitive disturbances in the later stages of the condition.

Typically, the signs and symptoms include:

- Bradykinesia and Akinesia (slowness and absence of movement)
- Muscle Rigidity
- Tremor
- Postural Instability
- Fatigue
- Speech changes
- Mood changes including anxiety and depression
- Sleep disturbances/changes
- Gastrointestinal symptoms including slowed gastric emptying and constipation
- Sensory changes including loss of smell and inability to distinguish colour shade variation
- Significant cognitive changes including hallucinations, memory loss and dementia, particularly in the later stages of the condition

Parkinson's is a progressive condition but with significant variation between individuals. Each person living with Parkinson's will experience a different journey and may not experience all symptoms.

What causes Parkinson's?

Through research, our understanding of the possible causes of Parkinson's is increasing; however, currently there is no known cause or understanding of why a person develops Parkinson's. There are many theories as to the causes and it is generally thought that multiple factors are responsible.

Treatments for Parkinson's

There is currently no cure for Parkinson's so treatments are aimed at controlling of symptoms to improve activities of daily life and independence. The most common treatments focus on replacing the neurotransmitter dopamine which is reduced in Parkinson's.

There are also a number of advanced Parkinson's therapies that provide more effective control of Parkinson's symptoms for more complex patients through innovative delivery mechanisms including continuous sub-cutaneous infusion or an ambulatory pump device direct through the abdominal wall into the small intestine (jejunum).

Some patients also gain significant benefit from a neurosurgical procedure, Deep Brain Stimulation, which assists in controlling tremor and twitching.

For most people living with Parkinson's, symptoms can be controlled but as the disease progresses treatments become less effective. Almost all medications used in the management of Parkinson's have significant side effects such as involuntary movements, wearing off, impulsive and compulsive behaviours, hallucinations and delusions. These side effects can be reduced and managed where Parkinson's Nurse Specialists provide expert advice and support.

The cost of Parkinson's to our community

In 2007 Parkinson's Australia commissioned Access Economics to produce an economic report 'Living with Parkinson's disease: Challenges and positive steps for the future' which was updated in 2011 and reviewed and updated in 2015. The reports highlight the significant growth in both the number of people living with Parkinson's disease and health system costs and productivity and other losses.

The key finds of the report include:

- Conservative estimates indicate there are just under 70,000 people living with Parkinson's in Australia making it the second highest prevalence neurodegenerative conditions with only dementia exceeding it in the number of deaths. One in every 340 people in Australia lives with Parkinson's.

- Of the 70,000 people living with Parkinson's around 18% or just over 12,000 people are of working age.
- As Parkinson's prevalence increases threefold after the age of 65, the growth rate in number of people living with Parkinson's is expected to increase dramatically as the Australian population ages. It is estimated that the growth rate will average 4% over the next 20 years compared to a general population growth rate of just over 1%. Over 11,500 new cases are diagnosed every year.
- In 2014 the prevalence of Parkinson's was higher than many cancers including breast cancer, colorectal, stomach, liver and pancreatic cancer, lymphoma and leukaemia, kidney and bladder, uterine, cervical, and ovarian, and lung cancer.
- The average time from onset to death is 12.4 years although many people who are diagnosed early in life will live with Parkinson's for many more years than this.
- People living with Parkinson's are more than 5 times more likely to be in residential aged care facilities than the general population.
- The average direct cost per person living with Parkinson's is \$14,500 per annum and the total financial cost of Parkinson's was almost \$1.1b per annum. Health expenditure costs per year were relatively higher in comparison to many other diseases that have high profiles in the community including breast and prostate cancer.
- The burden of care borne by carers has increased over 14 times the value in 2005.
- In addition to the direct financial costs, the burden of disease costs amounted to a net value of \$8.9b in 2014.
- Overall the direct financial cost of Parkinson's has increase by 103% since 2005 and the burden of disease cost has increased by 42% in the same period.
- There are cost effective interventions that can assist in allowing people living with Parkinson's to achieve a higher quality of life whilst at the same time reducing the cost to the community of this condition.

More information on the report can be found at www.parkinsons.org.au/deloitte-report.

Appendix 3: Examples of unavailable/high cost medications and therapies

Medications

There are a number of medications which are used to treat Parkinson's that are either 'off label' or are not available through the Pharmaceutical Benefits Scheme (PBS). Drugs currently falling into this category include:

- Quetiapine (Seroquel) - Psychosis (delusions and/or hallucinations) is a common non-motor feature of Parkinson's. Use of the older 'typical' antipsychotic drugs led to worsening of motor symptoms. The introduction of 'atypical' antipsychotics such as Quetiapine provide a new range of options; however, Quetiapine is only available in the PBS for Bipolar Disorder and Schizophrenia.
- Ropinirole (Repreve) overseas Ropinirole is a commonly used Dopamine Agonist in Parkinson's. In Australia this medication is Therapeutic Goods Administration (TGA) approved but not PBS listed for use in Parkinson's.
- Tolcapine (Tasmar) was originally listed on the PBS as a proven adjunctive treatment to levodopa, the main drug used to treat Parkinson's. Adjunctive therapy with Tolcapone can significantly reduce the dose of levodopa required and improve symptom control. The drug was withdrawn after a suspected adverse reaction in 2006 which has since been discounted. It has not been subsequently relisted on the PBS. Consumers who have not been able to change to other similar medications now have to import the drug at a cost of approximately \$700 month.
- Consumables – several medications which are available on the PBS do not include the price of consumables (e.g. infusion tubing, needles required to administer the drug, etc.). These consumables are not supported by any scheme and patients usually have to fund them at cost of at least \$200-300 per month. For diabetics the cost of their consumables are subsidised through the National Diabetes Supply Scheme. It is inequitable that people living with Parkinson's do not have the same level of support provided to them.

Deep Brain Stimulation

Deep brain stimulation (DBS) is a neurosurgical procedure involving the implantation of a medical device (neurostimulator) which sends electrical impulses, through implanted electrodes, to specific parts of the brain for the treatment of movement disorders. As a result of DBS patients can achieve significantly better control of their symptoms and improved quality of life for a sustained period and it will substantially reduce the need for medications. It should be noted that DBS is not a curative treatment and is only suitable for a relatively small proportion of patients.

Currently access to DBS is very variable depending on the State the person living with Parkinson's lives in. In some States there are minimal numbers of patients treated through the public system with the majority of patients having to access DBS through the private system. In most cases patients unable to access DBS through the public system incur large out of pocket expenses for medical imaging, specialist fees and for the device itself. Even where the patient has private health insurance these expenses often exceed \$20,000 and may be as high as \$50,000.

Specialist Allied Health Services

Many of the symptoms of Parkinson's are responsive to specialist therapies provided by Allied Health Professions. For example, many Parkinson patients experience significant problems with their speech and verbal communication, Speech Therapists can assist by teaching special techniques that will assist patient continue to be able to communicate verbally. There is also very strong evidence that structured exercise programs overseen by exercise physiologists and physiotherapists can improve the symptoms of people with Parkinson's, assist them remain independent, improve cognitive function and reduce complications such as falls associated with Parkinson's.