Deloitte Access Economics

# Living with Parkinson's Disease

## An updated economic analysis 2014

Parkinson's Australia Inc.

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Deloitte.

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# Glossary

| | |
|---|---|
| ABS | Australian Bureau of Statistics |
| ADL | activities of daily living |
| AIHW | Australian Institute of Health and Welfare |
| BEACH | Bettering the Evaluation and Care of Health |
| COMT | catechol-O-methyltransferase |
| CPI | Consumer Price Index |
| DALY | disability-adjusted life year |
| DCIS | Disease Costs and Impact Study |
| DES | Disability Employment Services |
| DOHA | Department of Health and Ageing |
| DSP | disability support pension |
| DWL | deadweight loss |
| EACH | Extended Aged Care Program |
| FAHCSIA | Department of Families, Housing, Community Services and Indigenous Affairs |
| GP | General Practitioner |
| HACC | Home and Community Care Program |
| HSE | Health and Safety Executive |
| H&Y | Hoehn and Yahr |
| IT | information technology |
| MIBG | metaiodobenzyguanidine |
| MRI | magnetic resonance imaging |
| MS | multiple sclerosis |
| NDIS | National Disability Insurance Scheme |
| NHS | National Health Service |
| NHPAC | National Health Priority Action Council |
| NICE | National Institute for Health and Care Excellence |
| NPV | net present value |
| NRCP | National Respite for Carers Program |
| OBPR | Office of Best Practice Regulation |

| | |
|---|---|
| PA | Parkinson’s Australia |
| PBS | Pharmaceutical Benefits Scheme |
| PC | Productivity Commission |
| PD | Parkinson’s disease |
| PDNS | Parkinson’s disease nurse specialist |
| PET | photon emission tomography |
| PWP | People with Parkinson’s disease |
| SDAC | Survey of Disability, Ageing and Carers |
| STN | subthalamic nucleus |
| UK | United Kingdom |
| VHC | Veterans Home Care Program |
| VSL | value of a statistical life |
| VSLY | value of a statistical life year |
| WHO | World Health Organization |
| WTP | willingness to pay |
| YLD | years of healthy life lost due to disability |
| YLL | years of life lost due to premature death |

# Executive summary

Since the 2007 Access Economics report 'Living with Parkinson's disease: Challenges and positive steps for the future' and the subsequent 2011 Deloitte Access Economics update report 'Living with Parkinson's Disease – update' was published, limited progress has been made in relation to the recommended 'positive steps'. This report again highlights that a growing number of Australians are people living with Parkinson's disease (PWP), and that Parkinson's disease (PD) will continue to be associated with significant and growing health system costs, productivity losses and other costs. Overall, the total economic cost of PD per annum has increased by 46% since 2005, which is comprised of a 103% rise in the financial cost of PD per annum, and a 42% rise in the estimated value of the burden of disease per annum.

## Key findings

**PD is a chronic, progressive, incurable, complex and disabling neurological condition.** PWP and their carers are confronted with major issues of disability including tremor (trembling in hands, arms, legs, jaw and face), rigidity and stiffness of limbs and trunk, sudden slowness and loss of spontaneous movement and impaired balance and coordination. However, in many cases, PD results in impaired speech and various mental health issues, such as depression and anxiety arising from both the impacts of the disease on individuals, the pathology of the disease and the side effects of medications. Other symptoms include sleep disruptions, difficulty with chewing and swallowing and urinary and constipation problems.

### Prevalence and mortality

**It is conservatively estimated that in 2014[1] there were 69,208 Australians living with PD, of which 53% were male and 47% were female. This equates to 294 per 100,000 in the total Australian population, or 867 per 100,000 among the population aged over 50. Based on these estimates, approximately one in every 340 people in Australia lives with PD.**

- The number of PWP has grown by 14,500 since 2005, and is expected to continue to grow in coming years with population ageing.
- Over 82% of PWP are aged over 65 years. However, people are diagnosed as young as 30 years. This report estimates that in 2014 there were 2,391 PWP aged in their 30s and 40s.

[1] Throughout the report, '2014' refers to the financial year 2013-14 (i.e. June 2013 – June 2014).

- There were 12,181 Australians of working age (15-64) estimated to be living with PD, comprising 18% of PWP.
- An estimated 11,544 new cases of PD were diagnosed in 2014, equivalent to more than 31.5 new diagnoses every day.
- The median time from onset to death is 12.4 years, though many PWP live with the disease for well over 20 years.
- In 2014, an estimated 8,461 PWP are residing in aged care facilities, of which 201 are aged younger than 65 years (equal to 1.6% of all PWP aged younger than 65 years). Since 2005, the total number of PWP residing in aged care facilities has increased by 55%.
- PD is a surprisingly prevalent condition – in 2014, estimated prevalence was higher than a number of diseases and injuries considered National Health Priority Areas (NHPAs) 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.
- Compared to other neurological conditions, in 2014, PD had the second highest prevalence and number of deaths, estimated at 1,743. This was exceeded only by dementia.

### Costs

**The total financial cost of PD per annum in 2014 was almost $1.1 billion (an estimated $1,064.9 million). This has more than doubled since 2005 ($527.8 million). Individuals bore 17% of these costs, governments 57%, employers 3%, and the rest of society bore 24%.**

These are real economic costs. In addition, there were $116.1 million of transfers associated with PD. These transfers include taxation revenue lost and welfare payments made by the Government to support PWP and their carers as they may no longer work. Such payments change the distribution of who bears the costs – from individuals and their families to the Government – and are associated with real efficiency losses from reallocation of resources, called 'deadweight losses' (DWL). DWLs occur as the Government must raise tax elsewhere to cover the reduced income from lost taxes, and the increased welfare payments. This causes a distortion and imposes a cost to the economy as measured by DWLs.

The cost components of the financial PD costs are:

- health system costs, which totalled $567.7 million (53%), which is an increase of 65% since 2005;

- productivity losses represented the next greatest cost at $182.4 million (17%) – an increase of just over 230% since 2005 – which is mostly borne by the individual with PD;
- DWL accounted for $173.5 million (16%) of the total – an increase of just over 110% since 2005;
- cost of informal care provided to PWP was $78.2 million (7%) – over 14 times the value in 2005 which is comprised of both an increase in the number of carers since 2005 (31%) and an increase in the opportunity cost of carers' time; and
- 'other financial costs' at $63.1 million (6%) – an increase of just over 55% since 2005 – which is largely made up of the costs related to mobility aids and home/vehicle modifications.

Health system costs related to PD are the largest component of PD financial costs in Australia. Within total health system costs, aged care costs and hospital inpatient and outpatient costs make up more than 71% of the total combined. **Health expenditure on PD per PWP per year is relatively higher than many other diseases including prostate cancer and breast cancer**, in part due to the higher use of residential aged care. Health expenditure per PWP per year is exceeded only by dementia, all cancers,[2] multiple sclerosis, certain types of injuries and infectious and parasitic diseases.

The average financial cost per PWP in 2014 was around $15,400, an increase of 61% since 2005. However, financial costs in relation to PD are incurred for many years. Although the median years lived with PD is 12.4 years, many people live with the disease for well over 20 years. **For someone living with PD for 12 years, the average lifetime financial cost is around $161,300, which is on par with the average lifetime financial cost of cancer ($145,000).** While this is lower than many childhood cancers, it is significantly higher than prostate and breast cancer (both around $82,000).[3]

In addition to financial costs, the burden of disease – the suffering and premature death experienced by people with PD – is estimated to cost an additional 48,491 disability adjusted life years (DALYs) (years of healthy life lost), with 78% due to disability and the remaining 22% due to premature death. **The net value of the burden of disease was $8.9 billion in 2014 – an increase of $2.6 billion since 2005.** This is comparable with other national health priorities with much higher prevalence such as visual disorders ($7.1 billion) and asthma ($13.2 billion)

[2] All cancers per person costs are higher on average due to non-hodgkin lymphoma, leukaemia and other cancers, while colorectal cancer, breast cancer and prostate cancer are all below the average costs reported (AIHW, 2013a).

[3] Based on 2007 cost of $114,500 for all cancers, $64,800 for prostate cancer, and $64,300 for breast cancer from Access Economics (2007b), inflated to 2014.

assuming the burden of disease for these conditions has grown in line with population demographics.

**PWP experience extremely high levels of disease burden.** Living with PD in the initial stages is considered more burdensome than blindness and deafness; living with PD in the intermediate stages is more burdensome than primary progressive multiple sclerosis and on-par with severe depression; and living with PD in the final stages is more burdensome than living with disseminated colorectal cancer, and on par with terminal stage cancer or severe dementia.

Consequently PWP experience more DALYs per person over their lifetime compared to many other diseases and injuries, especially since:

- PWP live with the disease for a relatively long time, compared to diseases such as cancer; and
- PWP are generally younger than people with dementia.

**The total economic cost[4] of PD in 2014 was over $9.9 billion for the year 2014. This represents an increase of $3.2 billion since 2005, or 46%.**

Individuals bore most of these costs, which largely comprise the burden of disease. However, the Government bore over $600 million (57%) of the financial costs associated with PD (Table i). Surprisingly, only 64% of Government cost is related to health system expenditure. The remainder primarily represents lost revenue – both lost taxes associated with reduced work of PWP and their carers, and welfare payments to replace lost income for these people.

**Table i: Total cost of PD ($m), 2014**

| | PWP | Family /Friends | Federal Govt. | State Govt. | Employers | Society /Other | Total |
|---|---|---|---|---|---|---|---|
| Burden of disease | 8,877.3 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | **8,877.3** |
| Health system costs | 101.0 | 0.0 | 235.0 | 152.7 | 0.0 | 78.9 | **567.7** |
| Productivity costs | 89.0 | 0.0 | 65.3 | 0.0 | 28.1 | 0.0 | **182.4** |
| Carer costs | 0.0 | 50.2 | 28.0 | 0.0 | 0.0 | 0.0 | **78.2** |
| Other financial costs | 56.0 | 0.9 | 6.2 | 0.0 | 0.0 | 0.0 | **63.1** |
| Deadweight loss | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 173.5 | **173.5** |
| Transfers | -60.7 | -55.4 | 116.1 | 0.0 | 0.0 | 0.0 | **0.0** |
| **Total** | **9,062.7** | **-4.3** | **450.7** | **152.7** | **28.1** | **252.4** | **9,942.2** |

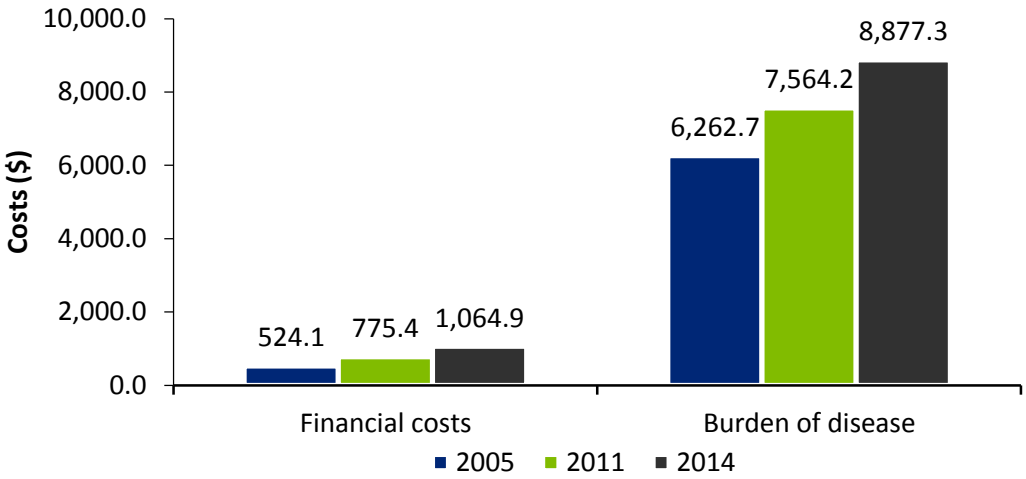
Source: Deloitte Access Economics' calculations.

[4] The net value of the burden of disease plus the financial cost of PD.

### Growth in prevalence and costs

- It is estimated that by 2034 there will be 123,781 PWP, equating to average growth in prevalence of 4% per annum over the next 20 years.
- There were an additional 14,508 PWP in 2014 compared to 2005 (5,164 since 2011, equating to growth of 27% over the 9-year period (8% over the 3-year period since 2011).
- The incidence of PD (i.e. the number of new cases each year) increased at an average rate of 3% per year over the 9-years to 2014.
- The financial cost of PD increased by 103% since 2005, largely due to the growth in health system costs, productivity losses and deadweight losses.
- The estimated value of the burden of disease increased by 42% from the 2005 estimate.
- Overall, the total economic cost of PD per annum has increased by 46% since 2005.

**Chart i: Estimated cost of PD ($m), 2005, 2011 and 2014 (nominal)**




Source: Deloitte Access Economics' calculations.

Relative to 2005 and 2011 estimates, the burden of PD has increased across all age groups and disease stages. Most notably, the financial cost of PD is highest for people aged 50-65 years. This is largely due to the lost earnings from premature mortality and workforce separation, with this effect dissipating from age 65 years onwards.

## Positive steps for the future

### Access to medications and therapies

Improving access to medications and therapies can help reduce the financial burden faced by PWP. PWP seeking access to particular medications and therapies such as

deep brain stimulation can face a financial barrier. Providing further and timely assistance to PWP to access proven therapies and medications would improve outcomes for PWP and may lead to lower financial costs elsewhere in the health sector, such as in PD related hospital admissions.

### Access to PD nurse specialists and multidisciplinary care: benefits and cost savings

Cost effective interventions have the ability to reduce the immediate burden of the disease, help PWP maintain their independence, and ultimately slow growth in future costs of PD and enhance quality of life for PWP and their carers both in the immediate and longer term.

Increasingly, research has indicated the potential benefits associated with provision of specialist services through a PDNS. The benefits found in the UK – such as reductions in unplanned hospital admissions and the number of bed days in the hospitals – can potentially be achieved in Australia. The preliminary findings from the Shoalhaven Project, which was started in 2010 in NSW, highlighted this. Specifically, in the UK, a single nurse specialist helped 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.

Such savings, if replicated in Australia, could lead to a substantial reduction in the cost of PD to Australian society as a whole. However, in order to achieve the benefits and cost savings as seen in the UK, policy makers would need to look into increasing access to PDNS to levels recommended by the National Institute for Health and Care Excellence (NICE) in the UK.

### Improving care in residential aged care

Young-onset PD continues to increase, with over 2,000 additional PWP younger than 65 in 2014 compared with 2005. Ensuring that PWP can continue to receive age appropriate support is important for improving outcomes for PWP. This includes ensuring a smooth transition from the NDIS into residential aged care.

### Investment in research

Research into PD and other neurological conditions continues to greatly increase understanding of underlying causes and best-practice treatment methods for PD. This research should continue to be collaborative and multidisciplinary.

### Deloitte Access Economics

# 1 Background

Deloitte Access Economics was commissioned by Parkinson's Australia to provide an update to the 2011 report, 'Living with Parkinson's Disease'. The report has been prepared for the purpose of estimating the prevalence, cost and burden of disease of Parkinson's disease in Australia in order to raise awareness of the impacts of the condition and contribute to improving policy in this area.

The structure of this report is as follows:

- Chapter 2: Description of PD, its impact on the individual, and treatment pathways;
- Chapter 3: Prevalence, deaths and projections of PD in Australia from 2014-2034;
- Chapter 4: Description of the methodology used to estimate the economic cost of PD;
- Chapter 5: Health system costs;
- Chapter 6: Productivity costs;
- Chapter 7: Informal care costs;
- Chapter 8: Other financial costs;
- Chapter 9: Transfers (income support and taxation revenue impacts);
- Chapter 10: The burden of disease;
- Chapter 11: The total economic impact of PD in Australia;
- Chapter 12: Sensitivity analysis;
- Chapter 13: Comparisons with other health conditions; and
- Chapter 14: Positive steps.

# 2 PD in Australia

This chapter provides a brief description of PD, and its causes and symptoms. It then discusses the prognosis for PWP, current treatment options and recent medical advances for the treatment of PD.

**Key points:**

- PD is a chronic disease (it persists over time) and progressive disease (symptoms get worse over time) with substantial disability.
- There is no definitive test for diagnosing PD, nor is there a cure for PD.
- Drug therapy is commonly used to treat PD, although effective treatments include exercise therapy, physiotherapy, occupational therapy, speech therapy and surgery.

## 2.1 What is PD?

PD is a disease of the Central Nervous System, affecting in particular the Autonomic Nervous System. According to the National Institute of Neurological Disorders and Stroke (NINDS, 2014):

> *Parkinson's disease is a progressive neurological disorder that results from degeneration of neurons in a region of the brain that controls movement. This degeneration creates a shortage of the brain signalling chemical (neurotransmitter) known as dopamine, causing the movement impairments that characterise the disease.*

Healthy nerve cells, or neurons, in an area of the brain known as the *substantia nigra* (a pigmented area in the base of the brain) normally produce a chemical called dopamine. This chemical (a neurotransmitter) assists with transmitting and modulating signals between the *substantia nigra* and the next "relay station" of the brain, the *corpus striatum*, to produce smooth, purposeful muscle activity.

The functioning of the *corpus striatum* is dependent on maintaining a balance between all of its neurotransmitters (including dopamine and acetylcholine). When the neurons die or become impaired, the resulting loss of production of dopamine upsets the balance between the neurotransmitters. Consequently this causes the *corpus striatum* to fire out of control, leaving PWP with postural abnormalities and difficulties with the smooth execution of movement. The lack of dopamine also leads to excitation of the medial segment of the globus pallidus resulting in bradykinesia (see Section 2.3).

### 2.1.1 Types of PD and similar conditions

PD is complex and presents in different ways – which is generally classified as idiopathic or primary PD, and secondary PD. A number of other conditions also have similar symptoms to PD.

**Idiopathic or Primary PD** is defined by the presence of a certain symptom-complex (see Section 2.3) but the cause is unknown. Idiopathic PD falls under the ICD-10 Category G20.

**Secondary PD** has similar symptoms to PD but the cause is known. These diseases fall under ICD-10 Category G21 (Parkinsonism in diseases classified elsewhere, such as Syphilitic Parkinsonism, fall under the ICD-10 category G22). Secondary PD includes:

- Malignant neuroleptic syndrome and other drug-induced parkinsonism: such as that caused by neuroleptic drugs (such as antipsychotics),[5] antiemetic agents (such as prochlorperazine), gastro-intestinal anti-motility drugs (such as metaclopramide), anti-hypertenstive drugs (reserpine), and some calcium-channel blockers.
- Post-encephalitic Parkinsonism.
- Other secondary Parkinsonism such as that caused by environmental toxins, trauma, metabolic derangement, stroke and brain tumour.

Knowing the cause of the PD symptoms can inform the best course of treatment. For example, drug-induced Parkinsonism usually disappears within weeks to months after discontinuing medication (NINDS, 2014). Although diagnosis, medical treatment and prognosis can be very different, both idiopathic and secondary PD have similar impacts on the individual. Needs are similar in terms of access to services and support. Consequently this study will examine the costs associated with both types of PD together.[6]

**Other diseases**, which have symptoms similar to PD (and consequently are often mistakenly misdiagnosed as PD or vice versa) but are not PD, include:

- Essential Tremor;
- Multiple System Atrophy;
- Progressive Supranuclear Palsy;
- Cortico-Basal Degeneration;

[5] Most of these people suffer from psychosis, particularly schizophrenia, and so their needs are often quite different.

[6] The extent to which this is fully possible depends on the definitions used in the individual studies themselves.

- Dementia with Lewy bodies;[7]
- Normal-pressure Hydrocephalus;
- Binswanger's Disease; and
- Vascular Parkinsonism.

Getting an accurate diagnosis of the disease informs the best course of treatment – misdiagnosis will often result in the use of ineffective drug treatments and unnecessary diagnostic testing.

## 2.2 What causes PD?

It is not yet known what causes PD, although most cases are hypothesised to be due to a combination of genetic and environmental factors (Hauser et al, 2015). Possible causes of PD have been identified as follows (NINDS, 2014; Hauser et al, 2015):

- **Accelerated ageing** – PD may be an acceleration of the normal, age-related deterioration of neurons. This is supported by the connection between antioxidants and PD and the fact that loss of antioxidative protective mechanisms is also age-related.
- **Oxidative damage** – Free radicals are unstable and potentially damaging molecules generated through normal chemical reactions in the body. They are unstable and damaging because they lack one electron and thus attempt to replace this missing electron through reactions with other molecules (this process is called oxidation). Usually antioxidants protect cells from this damage. In PWP, levels of glutathione are lower and this indicates reduced protection against formation of free radicals, PWP have high levels of iron and decreased levels of ferritin in the brain which point to the existence of high levels of oxidation.
- **Environmental toxins** – an external or internal toxin which destroys the neurons. Environmental risk factors include pesticides, exposure to herbicides, living in a rural environment, consumptions of well water and proximity to industrial areas, with length of exposure increasing risk of PD (Hauser et al, 2015). Researchers have identified a number of toxins, such as *methylphenyltetrahydropyridine* (MPTP) and neuroleptic drugs, which induce PD symptoms.
- **Genetic predisposition** – People that have a close relative who has experienced PD symptoms are more likely to experience PD. It is still not clear how genetic mutations cause PD although a number of genes have been linked to PD. Current research suggests that abnormal protein aggregation, defective ubiquitin-mediated protein degradation, mitochondrial dysfunction and

[7] However, in practice it is difficult to distinguish between PWP with dementia, and people with dementia with Lewy bodies.

oxidative degradation are associated with mechanisms causing a genetic predisposition to PD (Hauser et al, 2015).

- **Alpha-synuclein** was one of the first genes to be linked to PD. Dysfunction of alpha-synuclein may be central in the pathogenesis of PD as abnormally aggregated alpha-synuclein is a major component of Lewy bodies and Lewy neurites, which are common in PD (Hauser et al, 2015). It is not clear how the PD process begins, and it is thought that environmental triggers may be a factor. However, once the process begins, it may propagate by a prion-like process, whereby dysfunction of alpha-synuclein may also cause surrounding protein molecules to begin to dysfunction. This prion-like process is thought to occur as dopaminergic graft transplants in PWP also develop Lewy bodies, suggesting transmission of the disease (Hauser et al, 2015).

Age is a known risk factor for PD. There are also a number of other potential risk factors, including male gender, Caucasian ancestry, herbicide/pesticide exposure, rural residence, higher intake of dietary fats, metal exposure, family history, stress, depression and head trauma (Hauser et al, 2015; NINDS, 2014).

While there are a large number of risk factors, there are some protective factors which reduce the risk of obtaining PD such as anti-oxidants in diet, early life measles infection, consumption of food and drink containing niacin and caffeine and smoking (Hauser et al, 2015; NINDS, 2014).

## 2.3 Symptoms of PD

The variety of symptoms and levels of severity can vary greatly from person to person and are often shared with other similar diseases. Symptoms include both motor symptoms (symptoms that typically involve a loss of motor coordination or lead to restricted mobility) and non-motor symptoms are present in PWP. The four major motor symptoms of PD are (Hauser et al, 2015):

- **Tremor** – trembling in hands, arms, legs, jaw or face. Tremor usually, but not always, begins in a hand and affects only one part or side of the body – especially during the early stages, although in later stages it may become more general. Tremor usually disappears during sleep or improves with intentional movement.
- **Rigidity** – stiffness of the limbs and trunk. The basic principle of movement is that all muscles have an opposing muscle – thus movement is enabled when one muscle is activated and the opposing muscle is relaxed. Rigidity occurs when, due to brain signals, the opposing muscle remains contracted when one muscle becomes active. Facial expression may also become rigid and inflexible.
- **Bradykinesia** – slowness or loss of spontaneous movement and decreased amplitude of movement. Bradykinesia can be unpredictable in when it occurs and can be the most disabling symptom as it can severely impact on simple, every-day activities – thus reducing independence.

- **Postural instability** – postural instability, impaired balance and coordination. Postural instability can cause PWP to have a stooped posture. PWP may develop a forward or backward lean and can fall easily – which can sometimes result in injury. In later stages walking may be affected – PWP may halt in mid-stride or may walk with a series of quick, small steps as if hurrying forward to keep balance.

Non-motor symptoms are now widely recognised as significant symptoms in PWP and may be early signatures of disease onset, often being manifest prior to noticeable motor symptoms. Major non-motor symptoms include sleep disturbances, olfactory dysfunction, apathy, cognitive dysfunction, anxiety, depression and autonomic dysfunction. However, they frequently remain untreated despite the disability they impose and their effects on health-related quality of life (Zis et al, 2015).

Depression[8], anxiety, dementia[9] and memory loss are commonly experienced by PWP. This is partly because dopamine is involved in the development of these conditions, and partly because dopamine is a precursor for both adrenalin (epinephrine) and noradrenalin (norepinephrine) – two other neurotransmitters connected with these conditions. Furthermore serotonin is depleted in PD, also contributing to the prevalence of depression in PWP. Some of the medications used to treat PD may also result in these side effects (Tarsy, 2015).

Cognitive changes span a wide range of cognitive domains. Global cognitive function, processing ability, attention and executive function may all be affected (Aarsland et al, 2009; Levy et al, 2002; Mahieux et al, 1998; Dalrymple-Alford et al, 2011). Executive function deficits, which involve decision making processes associated with frontostriatal function, are manifest as difficulties in planning, attention, volition, response inhibition and response monitoring (Kehagia et al, 2010; Owen, 2004).

Autonomic dysfunction may be manifest in changes in cardiovascular, gastrointestinal, thermoregulatory, integumentary and genitourinary function. A common problem is orthostatic hypotension that results in dizziness when standing up due to a decrease in blood pressure (Goldstein et al, 2011). This is often exacerbated by Parkinsonian medications. Orthostatic hypotension can also affect executive function which most probably results from reduced cerebral perfusion and consequent decrease in cortical oxygenation (Adler, 2005; Iodice et al, 2011).

Other PD symptoms include (Hauser et al, 2015):

[8] Prevalent in about 30-50% of PWP, depending on the length of disease duration and how long the PWP lives (Hely et al, 2008; Frisina et al, 2008)

[9] Prevalent in about 20-40% of PWP at any one time (Hauser et al, 2015); however, the prevalence of dementia can range from 10-80% of PWP depending on disease duration (Hely et al 2008).

- difficulty with swallowing and chewing;
- decreased sense of smell;
- speech changes;
- urinary problems and constipation;
- sexual difficulties;
- skin problems; and
- sleep problems.

## 2.4 Prognosis

PD is a chronic disease (it persists over time) and progressive disease (symptoms get worse over time) with substantial disability. The stages for severity of PD are classified by the Hoehn and Yahr (H&Y) scale as shown in Table 2.1.[10]

**Table 2.1: Hoehn and Yahr (H&Y) stages of PD severity**

| Stage | Characteristics |
|---|---|
| I | Unilateral involvement only, usually minimal or no functional impairment. Symptoms include tremor of one limb, changes in posture, locomotion and facial expression. |
| II | Bilateral or midline involvement without impairment of balance. Posture and gait affected. |
| III | First signs of postural instability; significant slowing of body movements, individual has some restriction of activities but is capable of leading an independent life; disability is mild to moderate. |
| IV | Severe symptoms: walking limited, rigidity and bradykinesia. Severely disabling disease; individual is markedly incapacitated and is unable to live alone. |
| V | Cachectic stage. Individual is restricted to bed or a wheelchair unless aided. |

Source: Scheife et al (2000)

PWP do not necessarily progress from one stage to the next, but can drop down a stage during treatment or experience accelerated progression.

An Australian study followed 130 PWP over 20 years (Hely et al, 2008; Hely et al, 2005; Hely et al, 1999):

- around 10% of PWP experience delayed progression (symptoms did not progress past Stage II over 10 years, but progressed over the following five years);

[10] Other scales have been developed to supplement the H&Y scale, including the Unified Parkison Disease Rating Scale (UPDRS) and the Non-motor Symptoms Scale (NMSS), which include measures such as behaviour, mood, activities of daily living (ADL) and the severity and burden due to non-motor symptoms of PD.

- of those diagnosed as Stage I or II at baseline, 73% had progressed to at least Stage III, 41% had progressed to at least Stage IV, and 13% had progressed to at least Stage V after 15 years (median time since start of study: 3.5 years, 7 years, and 6 years, respectively);[11]
- of those diagnosed as Stage III at baseline, 74% had progressed to at least Stage IV, and 21% had progressed to at least Stage V after 15 years (median time since start of study: 4.5 years and 6.5 years, respectively);
- after 20 years, only one PWP from the original cohort was at Stage II, 2 were at Stage III, 15 were at Stage IV and the remaining 12 were at Stage V, with the remaining 100 having died since commencing the study; and
- **the median time from disease onset to death is 12.4 years**.[12]

As the mean pre-study disease duration was 23.5 months, these findings equate to around 5 and a half years spent in Stage I and Stage II (45%),[13] around four years in Stage III (33%),[14] two years in Stage IV (16%),[15] and the remaining 0.7 years in Stage V (6%) until death. This implies that PWP can remain in the early stages of the disease for a considerable period of time before moving to the next stages of the disease or dying.

Overall, Hely et al (2008) found that PWP are more around 2.5 times more likely to die (with disease duration between 3 and 20 years), and that PD contributed to 54% of deaths. Pneumonia was the most common cause of death (25% of the total), particularly in the latter stages. However due to deaths from other co-morbid conditions, many do not progress to Stages IV and V.

## 2.5 Diagnosis and current treatment pathways

### 2.5.1 Diagnosis

There is no definitive test for PD – diagnosis is often based on medical history and the presence of the classic symptoms and signs of PD (such as two of the motor symptoms of tremor, rigidity and bradykinesia). Other potential tests to diagnose

[11] These findings are similar to those found by Sato et al (2006) in a large (n=1,183) longitudinal study of PWP in Japan. Sato et al found that of those diagnosed as Stage III or less at baseline, 83.5% had progressed to Stage III, 41.2% had progressed to Stage IV, and 29.4% had progressed to Stage V after 15 years. The higher proportion that had progressed to Stage V after 15 years may be due to including PWP in Stage III at baseline.

[12] Similarly, Sato et al (2006) reported that the mean time from disease onset to death was 12.8 years.

[13] 23.5 months plus 3.5 years to progress to Stage III.

[14] For people in Stage I or II at baseline the time between Stage III and Stage IV was 3.5 years, while for people in Stage III at baseline the time between Stage III and Stage IV was 4.5 years.

[15] Based on people in Stage III at baseline.

PD include genetic testing, autonomic function testing, olfactory tests, drug challenge tests, neurophysiological and neuropsychological tests, and neuroimaging (Berardelli et al, 2013). Recommendations made by the European Federation of Neurological Societies/Movement Disorder Society – European Section (EFNS/MDS-ES) Task Force indicate that available tests in each of these methods can be effective, although some tests are no longer recommended. Newer research also indicates other diagnosis techniques may become recommended in the future.

For example, Berardelli et al (2013) note:

- the Queen Square Brain Bank clinical diagnostic criteria can be effective for diagnosing PD in clinical practice;
- genetic testing for specific gene mutations can be effective and is recommended on an individual basis – specifically noting the importance of family history and age of onset for PD;
- autonomic function tests can detect non-motor symptoms and impairments in PWP, although there was limited evidence available for making a recommendation on effectiveness;
- olfactory tests are fast and can indicate symptoms of PD but they may suffer from low specificity as elderly patients can have olfactory loss without PD, which requires the use of follow-up testing;
- drug challenge tests involve commencing drug therapy and monitoring patient response, which can indicate PD, although these tests are not currently recommended for diagnosing PD specifically rather than other PD-like syndromes;
- neurophysiological tests such as electrical brain activity tests, sleep studies and tremor analysis can help identify PD, and in some cases, differentiate PD from other PD-like syndromes, but no recommendations have been made about the effectiveness of these tests;
- neuropsychological tests to measure cognitive impairment are recommended and can identify PD, and help differentiate it from other PD-like syndromes; and
- neuroimaging such as transcranial sonography, magnetic resonance imaging (MRI), photon emission tomography (PET) can identify PD and differentiate PD from other PD-like syndromes. In particular, transcranial sonography is recommended for the differential and early diagnosis of PD, and detection of people at risk of developing PD. Similarly, there has been recent interest in PET scan techniques such as determining the cardiac uptake of metaiodobenzyguanidine (MIBG), which show promise in identifying PD and differentiating it from PD-like syndromes.

While many of these diagnostic tests can be effective, some of these tests such as neuroimaging are not routinely used in diagnosing PD. Consequently, it can often take up to two years from disease onset before a diagnosis is made (Hely et al, 2005). The presence of other diseases, such as dementia and general ageing can obscure PD symptoms and reduce the chance of an accurate diagnosis – meaning

that some PWP may be either misdiagnosed or under-diagnosed (Section 3.1.1). Furthermore, differences in referral habits and accessibility of medical services in regional areas can also impact the chance of being diagnosed.

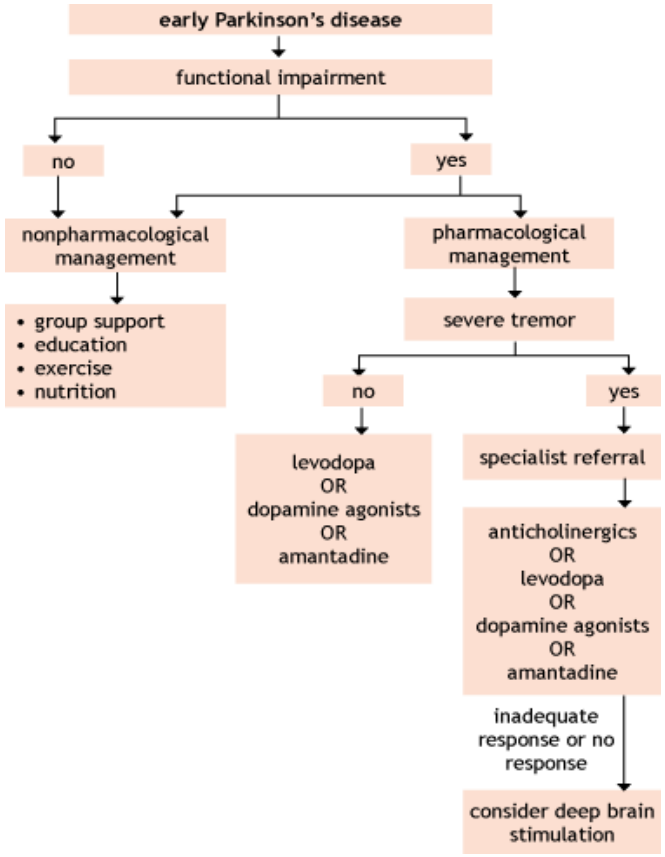
### 2.5.2 Treatment and care options

Currently there is no cure for PD. Treatment options for PD are generally grouped into pharmacological treatment (drug treatment) and non-pharmacological treatment options such as exercise therapy, physiotherapy, occupational therapy, speech therapy and surgery. These options aim to treat both the motor and non-motor symptoms of PD.

There is no standard treatment for PD, and depending on the needs of the patient, each of these options can effectively manage symptoms of PD. Factors that influence appropriate treatment include duration since the onset of PD, age, disease severity, comorbidity and other individual characteristics (Rubenstein et al, 2001). These factors are particularly important in people with young-onset PD.

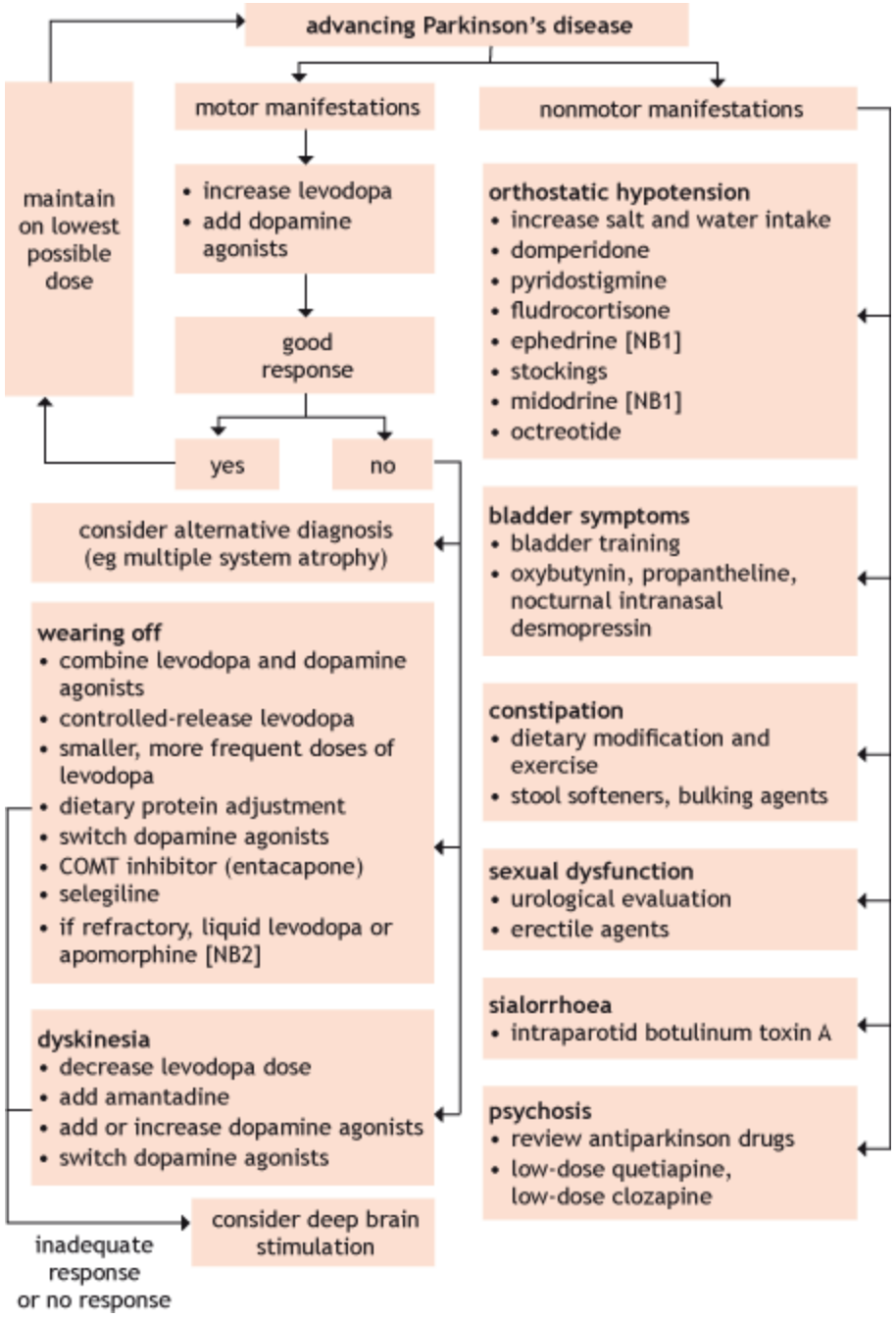
Suggested guidelines for treating and managing PD are shown in Figure 2.1 and Figure 2.2 for early PD and late (or advancing) PD respectively.

**Figure 2.1: Suggested management strategy for early PD**




Source: Therapeutic Guidelines (2007).

**Figure 2.2: Suggested management strategy for late PD and non-motor aspects**




Source: Therapeutic Guidelines (2007).

### 2.5.2.2 Drug treatment options

The main treatment for PD is generally pharmacological – which includes a selection of drugs that attempt to temporarily replenish or mimic dopamine in the brain. Drug treatment regimes can be complex, with continual and slight adjustments in dosages, timing and combinations of drugs to reduce symptoms. Adequate medication management is an important contributor towards reducing unnecessary disease burden for many PWP.

Drug therapies for PD include (Hauser et al, 2015; NINDS, 2014; and Tarsy, 2015):

- **Dopaminergic or Related Therapies**
  - **Levodopa** is the main drug used to treat PD. Nerve cells can use this drug to produce additional dopamine (dopamine cannot be used directly as it does not cross the blood-brain barrier). However it can have significant side effects including nausea, vomiting, low blood pressure, involuntary movements (dyskinesia), restlessness and confusion. The ability for levodopa to reduce the symptoms of PD wears off over time and the level of symptoms may also change suddenly during the day due to responses to the drug – called the "on-off" effect. Levodopa is often combined with Carbidopa to delay its conversion to dopamine until it has crossed the blood-brain barrier.
  - **Carbidopa or benserazide** delays levodopa conversion to dopamine, which improves the effectiveness. It also reduces the side effects of levodopa by allowing PWP to have fewer and smaller doses. It also reduces the "wearing-off" effect.
  - **Selegiline and rasagiline**, also known as deprenyl, inhibits the enzyme monoamine oxidase-B (MAO-B) which metabolises dopamine in the brain and has neuro-protective properties. This can delay the need for levodopa in the early stages of PD and can be used to boost levodopa (to reduce wearing off and on-off effects). Side effects include nausea, orthostatic hypotension and insomnia.
- **Dopamine Agonists**: are a group of synthetic agents that stimulate dopamine receptors. Side effects of dopamine agonists include nausea, vomiting, sleepiness, orthostatic hypotension, confusion and hallucinations.
  - **Bromocriptine, pergolide, pramipexole, cabergoline and ropinirole** mimic dopamine in the brain and can be used as an alternative (in the early stages) or to boost levodopa (to reduce wearing off and on-off effects) – thus delaying the start of levodopa therapy and the associated side effects.
  - **Apomorphine**, given subcutaneously, is a very potent dopamine agonist with a brief duration. It is often recommended for PWP who have found that the effectiveness of oral medications has reduced and their "on-off" fluctuations have increased. Apomorphine is also effective as a continuous daytime subcutaneous infusion.
- **Catechol-O-Methyltransferase (COMT) inhibitors**
  - **Tolcapone and entacapone** extend the duration of the effectiveness of levodopa by inhibiting the enzyme COMT from degrading levodopa. This can reduce levodopa usage and reduce motor fluctuations and the off period of the levodopa dose (NINDS, 2014). Side effects include nausea, sleep disturbances, dizziness, hallucinations and tolcapone may have caused liver disease in some people, although recent evidence has

shown this drug is safe and effective with regular monitoring (Eggert et al, 2014).

- **Anticholinergic agents**, or muscarinic antagonists, block acetylcholine, the effects of which become more pronounced when dopamine levels fall. They are less effective than dopamine and dopamine agonists but can help to control tremor and rigidity. Side effects include dry mouth, constipation, urinary retention, hallucinations, memory loss, blurred vision, changes in mental activity and confusion. Agents include trihexyphenidyl hydrochloride, benztropine mesylate, procyclidine and ethopropazine hydrochloride.
- **Amantadine** is an antiviral drug which reduces symptoms of PD, although the impact wears off after a couple of months. It can increase dopamine release, inhibit dopamine reuptake and stimulate dopamine receptors (Tarsy, 2015). Used in the early stages or to boost levodopa or anticholinergics. Side effects include mottled skin, oedema, confusion, hallucinations and agitation (NINDS, 2014).

#### 2.5.2.3 Surgery treatment options

Surgery is often reserved for PWP whose symptoms can no longer be managed medically. Procedures include neuro-stimulation, thalamotomy and pallidotomy, where a probe is inserted and destroys a small part of the brain (lesioning). Deep brain stimulation is the most-desirable surgical option for treating PD as it does not involve destruction of brain tissue, can be adjusted and is reversible (Hauser et al, 2015).

##### Deep brain stimulation

Rather than surgically destroy areas of the brain, an electrode is implanted to provide high frequency stimulation and block electrical signals in targeted areas of the brain that control movement blocking the abnormal nerve signals that cause tremor and PD symptoms. Targeted areas of the brain include the ventrointermedialis nucleus of the thalamus (VIM), subthalamic nucleus (STN), and globus pallidus pars interna (GPi), although STN is the most commonly targeted site for PD (Hauser et al, 2015).

Before the procedure, a neurosurgeon uses an MRI, computed tomography (CT) scan or microelectrode recording to identify and locate the exact target in the brain generating the PD symptoms.

The deep brain stimulation system consists of three components:

- The lead (also called an electrode)—a thin, insulated wire—is inserted through a small opening in the skull and implanted in the brain. The tip of the electrode is positioned within the targeted brain area.
- The extension is an insulated wire that is passed under the skin of the head, neck, and shoulder, connecting the lead to the neurostimulator.

- The neurostimulator (the "battery pack") is usually implanted under the skin near the collarbone, chest or abdomen.

Once the system is in place, electrical impulses are sent from the neurostimulator up along the extension wire and the lead and into the brain. These impulses interfere with and block the electrical signals that cause PD symptoms (NINDS, 2014).

Deep brain stimulation mimics the effects of surgical destruction but has:

- a markedly reduced risk of permanent side effects;
- the ability to reverse the procedure if a better treatment is developed in the future; and
- the amount of stimulation is easily adjustable—without further surgery—if the condition changes.

This procedure is generally recommended for PWP whose symptoms can no longer be managed medically, but still experience good response to levodopa (Hauser et al, 2015). While most PWP still need to take medication after undergoing deep brain stimulation, many PWP are able to greatly reduce the amount of medication taken.

#### 2.5.2.4 Other therapeutic options

Other therapies for PD include:

- **Transcranial Direct Current Stimulation (tDCS)** – While still developmental, this non-invasive brain stimulation is being explored as a potential new treatment for PWP. There has been some success reported in improving freezing of gait (Valentino et al, 2014).
- **Exercise Physiology** – Exercise physiologists provide structured supervised exercise programs which have been shown to have a positive effect on many aspects of an individual's health and well-being, as well as protecting against disease-specific complications (Speelman et al, 2011; Rosenthal, 2013). Progressive resistance exercise counteracts the profound muscle weakness and slow movement typical in PWP. Aerobic exercise improves cardiovascular fitness and counteracts the fatigue experienced by PWP. Both resistance exercise and treadmill walking improve walking and mobility which improves quality of life, prolongs independent living and has positive effects on mood and cognitive function (Corcos et al, 2013; Shulman et al, 2013).
- **Physiotherapy** – Physiotherapy or muscle-strengthening exercises are often used to help improve mobility (especially balance), gait problems, flexibility, general fitness, and muscles used in speech and swallowing.
- **Speech Therapy** – PD can significantly reduce an individual's ability to communicate with others through the combination of speech disorders (dysarthria) and the reduction in visual cues, such as facial expressions and hand gestures. This causes difficulties in using a telephone or talking to strangers, thus increasing social isolation and depression. Speech therapists can assist in

reducing dysarthria through behavioural treatment techniques (drills and exercises) focusing on pitch, volume, respiration, voice production and intelligibility.

- **Occupational Therapy** – Occupational therapists can help maintain self-care, work and leisure activity for as long as possible, thus maximising independence, and ensure that the home and workplace are safe environments to minimise thee likelihood of injuries. Interventions may include support in organising the daily routine, learning new skills for alternative or adaptive ways to carry out activities such as the use of specialist equipment such as aids or modifications.
- **Dance Therapy** – Dance therapy has been developed with the strong support of ballet companies (e.g. English National Ballet, UK; Queensland Ballet). Benefits have been reported to accrue across social, emotional and physical dimensions to improve health, well-being and quality of life (Houston and McGill, 2013; Heiberger et al, 2011).
- **Education, Counselling and Social Support** – These programs are very important for chronic disease management and can have significant impacts on quality of life through: increasing the understanding of PD; improving coping skills; developing problem-solving strategies; improving health confidence; encouraging the PWP to remain physically and socially active; and optimising medical treatment and compliance rates (Montgomery, 1994). In addition to helping PWP, some of these programs focus on assisting carers learn how to take care of PWP directly or take on new roles within the family unit.

Access to non-drug therapies and education, counselling and social support programs can reduce the burden of disease faced by PWP and help them remain in employment, maintain their independence and reduce the use of other health or aged care services.

#### 2.5.2.5 Residential aged care placement

As PD progresses, activities of daily living (ADL) slowly become hindered and PWP may lose their ability to live independently. In particular, by Stage V PWP are restricted to bed or a wheelchair unless aided. Due to functional impairment, drug complications (such as hallucinations) and comorbidities associated with PD (such as dementia and incontinence), PWP have a higher probability of residential aged care placement than the general population. Residential aged care placement can assist in providing high levels of care to PWP.

The main determinants of placement in residential aged care for PWP (other than age) are dementia, confusion and hallucinations, falls/imbalance, restricted ADL, and disease stage. Placement in residential aged care is also largely dependent on whether a carer (generally a healthy spouse or child) and access to formal care is available (Aarsland, 2000; Hely et al, 1999).

#### 2.5.2.6 Palliative care

When PD has progressed far enough, some PWP may require palliative care. Palliative care is care that aims to provide physical, psychosocial and spiritual support for patients, their family and friends. Maintaining quality of life and easing symptoms are priorities, with the purpose to help individuals and their families deal with daily living and prepare for the likelihood of death.

Palliative care requires a multidisciplinary team to provide effective care, and is provided is most health settings, including residential aged care, acute care and other specialist and generalist settings.

## 2.6 Recent medical advances

There have been a number of recent medical advances in the diagnosis and treatment of PD. Recent advances include, but are certainly not limited to:

- an increased understanding of the genetic links associated with PD, which may lead to advances in both diagnosing and treating PD;
- improvements in developing medications and other therapies such as nerve growth and gene therapy that offer neuroprotective factors, and a vaccine that can modify the immune system to protect dopamine-producing neurons; and
- continued advances in stem cell therapy, which can be induced to become dopamine producing cells.

For example, a blood test continues to be developed that looks for autoantibodies in the blood that improved diagnostic accuracy. The test focuses on the death of neuromelanin-containing pigmented brain cells, which may be identified through a blood test for a new protein created by the body's immune response. The test can have accuracy as high as 90% in PWP, and correctly identifies those who do not have PD. Research for this diagnosis is ongoing (Han et al, 2012).

Furthermore, imaging techniques are identifying new ways of determining if a person has PD or not, and are becoming more effective at differentiating between PD and PD-like syndromes. For example, PET scan techniques such as determining the cardiac uptake of MIBG show promise in identifying PD and differentiating it from other PD-like syndromes when used in conjunction with other tests as the MIBG uptake in PD can be significantly reduced (Berardelli et al, 2013).

Treatment options are increasingly recognising the need to treat both motor and non-motor symptoms of PD. For example, drug therapy is effective at reducing the motor symptoms of PD, while exercise therapy can also improve or reduce symptoms. Research into the benefits of alternative treatment options including exercise and non-invasive brain stimulation is ongoing.

# 3 Prevalence and mortality of PD

This chapter reviews the prevalence and mortality estimates for PD in Australia from the 2007 and 2011 Deloitte Access Economics studies. The analysis is based on epidemiological estimates from the 2007 study, updated to reflect changes in population demographics over this period. A summary of literature since the 2011 study is presented. This chapter also presents PD prevalence by disease stage, the number of PWP residing in aged care facilities, deaths due to PD, and projections over a 20 year time horizon (2014 to 2034) are provided for the prevalence of PD, deaths due to PD and the number of PWP residing in aged care facilities.

**Key findings:**

- There were an estimated 69,208 PWP in 2014, approximately 14,500 more than in 2005, and 5,100 more than in 2011. This equates to 294 per 100,000 in the total Australian population, or 898 per 100,000 among the population aged over 50. PD now affects 23 additional people per 100,000 compared with 2005 (271 per 100,000).
- In 2014, it was estimated that there were approximately 8,500 PWP residing in aged care facilities, of which 201 were aged younger than 65 years (equal to around 1.65% of all PWP aged younger than 65 years).
- There were estimated to be between 1,501 (underlying) and 1,743 (associated) deaths due to PD in the year 2014.

## 3.1 Prevalence of PD

### 3.1.1 Overview of estimation approach

Currently, there is no definitive test for PD. The "gold standard" for confirmation of diagnosis remains histological confirmation of post-mortem materials which is unavailable when attempting to estimate current prevalence. This gives potential for under-diagnosis and misdiagnosis, meaning there is no confirmed PD diagnosis data to estimate prevalence.

The approach adopted in the 2007 and 2011 Deloitte Access Economics studies to estimate PD prevalence was derived from an analysis of Pharmaceutical Benefits Scheme (PBS) data commonly involved in the treatment of PD. This approach is also adopted in this report.

The risks with this approach are:[16]

- "**Overestimation** of prevalence may occur due to some non-PD conditions being misdiagnosed as PD and because medications used to treat PD can be used for the treatment of other diseases (especially Restless Legs Syndrome, schizophrenia, some types of dystonia in adults and children, pituitary tumours and bladder problems); and
- **Underestimation** of prevalence may occur due to under-diagnosis of PD or the misdiagnosis of PD as non-PD, as this may result in non-medicated cases or the use of other drugs to treat misdiagnosed PD. Furthermore, some cases may be deliberately un-medicated due to:
    - being recently diagnosed or having low levels of disability and the wish to temporarily delay the use of medication (which falls in effectiveness over time);
    - suffering significant side effects; or
    - no longer responding to the available medications."

#### 3.1.1.1 Misdiagnosis

Misdiagnosis is an important issue in PD. Higher rates of misdiagnosis mean that drugs prescribed to reduce symptoms or slow the progression of the disease may be less effective. The misdiagnosis rate is higher in the early stages of the disease as some other neurodegenerative conditions have similar clinical presentations to PD (Duncan et al, 2014).

The misdiagnosis rate varies by study type and diagnosis method. Recent studies have found misdiagnosis rates ranging from 10-35% in post-mortem studies and 12-26% in community-based studies (Newman et al, 2009; National Collaborating Centre for Chronic Conditions, 2006).

#### 3.1.1.2 Under-diagnosis

Studies have shown that the reduction of dopamine is already well advanced in the brains of PWP with only mild symptoms – thus the underlying disease process has been progressing over a number of years (at least four) before clinical deficits present. Even when symptoms become noticeable, it is sometimes up to two years before a definite diagnosis is made (Hely et al, 2005). The presence of other diseases, such as dementia and general ageing can obscure PD symptoms and reduce the chance of an accurate diagnosis. Differences in referral habits and accessibility of medical services across countries can also impact the chance of being diagnosed (de Rijk et al, 1995).

[16] Other minor issues that may result in underestimation of prevalence include: Ineligibility for PBS or RPBS; use of private patients, doctor's bag, hospital issue drugs; and use of non-PBS or RPBS listed drugs (such as orphenadrine hydrochloride, procyclidine hydrochloride, ropinirole hydrochloride and tolcapone).

The rate of under-diagnosis of PD varies greatly by study and region – as low as 8% in Japan and as high as 70% in Australian studies (de Rijk et al 1997; Chan et al 2001; 2005; Zhang et al 2005; Yamakawi et al 2009; Osaki et al 2010; Seijo-Martinez et al 2011; Khedr et al 2012). The weighted average – based on sample size – across these studies gives an under-diagnosis rate of 29.6%. In other words, there are around 3 undiagnosed cases for every ten diagnosed cases.

#### 3.1.1.3 Prevalence estimates

To estimate the prevalence rates of PD, Dr J. F. Slattery from the Central West Parkinson's Disease Research Project analysed individual's records from the PBS Item and Patient data and cross-matched with Medicare data. This type of analysis, which focuses on unique individuals, removes the problem of double counting PWP. Using the age-gender specific usage patterns of anticholinergics and/or dopaminergics, these rates were adjusted by the age-gender specific proportion of medications (55% overall) that were prescribed explicitly for PD, as determined by data from the General Practice Research Network. This removes those individuals who are prescribed PD medications for other diseases. No adjustments are made for misdiagnosis of PD or under-diagnosis of PD as it assumed that these would cancel each other out. The prevalence rates calculated using this methodology are shown in Table 3.2.

Based on existing literature, there is a wide range of methodological approaches taken to estimate the prevalence of PD. The wide ranging approaches make comparisons between literature studies difficult and, at the same time, produce highly variable results. However, the prevalence estimated in this report is likely to represent a conservatively low to mid-range estimate, taking the risk factors of overestimation and underestimation into consideration.

### 3.1.2 New information from the literature since the 2011 report

A literature search was conducted to evaluate new literature published since the 2011 Deloitte Access Economics report. The focus was on PD prevalence in Australia and other developed countries. A number of international studies were identified, although no epidemiological studies have recently been published in Australia.[17]

As noted in Deloitte Access Economics' 2007 and 2011 reports and above, the wide range of methodologies for estimating prevalence make comparisons difficult.

[17] Deloitte Access Economics understands that in collaboration with the Florey Institute of Neuroscience and Mental Health, Monash University is currently conducting a research project on estimation the prevalence of Parkinson's disease in Victoria. At the time of writing this report, the findings have yet to be published.

International comparisons are further complicated by differences in diagnosis rates, healthcare services and survival rates between countries. Generally, there are four types of study:

- Population surveys – ranging from once-off, door-to-door surveys to longitudinal approaches, where typically medical records for individuals identified as having PD were confirmed by a neurologist;
- Systematic review and meta-analysis based on existing literature publications;
- Service-based epidemiological studies – ranging from surveys of local health services to more detailed studies, e.g. recruiting patients through health services to have PD diagnosis confirmed by a specialist neurologist; and
- Prescription database searches for PD medications – such as within primary care databases, combined with medical records review to confirm PD diagnosis.

Table 3.1 presents relevant new information by type of study that have been undertaken since 2011.

**Table 3.1: A brief description of new literature since 2011**

| Type of study | Brief description |
|---|---|
| Population study | Del Brutto et al (2013) conducted a door-to-door survey of a rural coast village of Ecuador, with cases confirmed by neurologists. The authors found prevalence of PD to be similar to other regions of the world despite its small sample size, with a rate of 312 per 100,000 in those aged 40 or older. |
| | Khedr et al (2012) conducted a three stage community-based survey in a region of Egypt. This was the first epidemiological study in Egypt. A screening questionnaire was administered by a trained team, with a neurologist reviewing and referring cases of PD. The age-adjusted prevalence rate was 562 per 100,000 population, 777 per 100,000 for males and 445 per 100,000 for females. |
| Systematic review and meta-analysis | Ma et al (2014) conducted a systematic review and meta-analysis of community based door-to-door surveys undertaken in China to estimate the prevalence and incidence in China. The review found that prevalence of PD was 797 per 100,000 person years, increasing with age. They found that the prevalence of PD was lower in China than in developed countries, although previous community based studies in China have suggested that it may be similar to developed countries (Zhang et al, 2005). The prevalence for males and females was 173 per 100,000 and 153 per 100,000 for males and females, respectively. |
| | Pringsheim et al (2014) conducted a systematic review and meta-analysis of door-to-door surveys to establish the prevalence of PD to see how it varies by age, gender and geographic region, using epidemiological studies. The study found that prevalence increased by age as is expected, and that "some differences in prevalence by geographic location…" exist. |

| Type of study | Brief description |
|---|---|
| Service-based epidemiological studies | Kowal et al (2013) used nationally representative survey data to estimate the prevalence of PD in the US. Surveys included national medical expenditure surveys, hospital survey data, and nursing home survey data. The prevalence rate increased by age, ranging from 0.02% to 1.85%. The authors noted that the prevalence derived from national surveys was conservatively low compared to previously published literature, with small sample sizes possibly contributing to under-reporting of the true prevalence. |
| | Bauso et al (2012) estimated the incidence and prevalence of PD in a health maintenance organisation in Argentina using retrospective analysis of medical records. The prevalence was found to be 394 per 100,000 in the population older than 40 years, with males more likely to have PD than females. Prevalence by age groups was not reported however. |
| | Bhidayasiri et al (2011) utilised a national PD registry in Thailand and capture-recapture methodology to estimate the prevalence of PD. The database included data from hospitals and self-registration, but did not account for undiagnosed cases. The age-adjusted rate was found to be around 425 per 100,000 population, similar to the rate found in other Asian countries excluding undiagnosed cases. |
| | Gordon et al (2013) calculated the prevalence of PD among residents of the Navajo Nation, a large reservation for American Indians in the US, based on the Shiprock Service Unit Indian Health Service database. The database contained information from all clinical encounters. The age-adjusted prevalence rate was 336 per 100,000. |
| Prescription database search for PD medications | Chillag-Talmor et al (2011) developed an algorithm for PD assessment based on purchase history profiles of anti-parkinsonian drugs in Israel and validated the algorithm against clinical diagnoses. The prevalence rate was found to be 256 per 100,000 in 2007. Chillag-Talmor et al noted that it may include cases where the prescription was provided for reasons other than PD, although a conservative approach was taken. |
| Self-reported survey | The Sax Institute (2011; 2014) have undertaken a large scale baseline and follow-up survey of various health factors in an Australia population aged 45 and over – the '45 and Up Study'. Self-reported total prevalence rates for PD were 0.63% at baseline and 0.82% at follow-up. Prevalence by age groups is not reported. |

Source: As indicated in the table above.

Applying the weighted average prevalence rates based on the articles described in Table 3.1 to the Australian population, prevalence estimates ranged between a low of 40,000 and a high of over 130,000. Using prevalence rates from older Australian studies such as Chan et al (2005) and Mehta et al (2007) produced an even wider range of around 28,000 to over 180,000. The self-reported rates found in the 45

and Up Study applied to the Australian population aged 45 and older provide a prevalence range between 58,000 (baseline results) and 76,000 (follow-up results).

The variations were mainly due to differences in defining the condition, types of study and sample sizes, among other factors (Muangpaisan et al, 2011). For instance, Pringsheim et al (2014) also found differences by geographic region and noted that this may be due to environmental or genetic factors. A better measure of prevalence is therefore required (Mellick, 2013).

> Existing literature studies suggested wide ranging prevalence estimates for PD due to variation in methods and definitions. These studies provide further evidence that the prevalence estimates in this report based on PBS data represents a conservatively low to mid-range result.

### 3.1.3 Prevalence of PD in 2014

Table 3.2 presents the prevalence rates and the estimated number of PD cases in Australia in 2014 using a similar approach described in the 2007 and 2011 reports. Overall, there was a 27% increase in the number of PD cases since 2005 (approximately 14,500 additional cases) reflecting the ageing of the Australian population.

> There were an estimated 69,208 PWP in 2014, approximately 14,500 more than in 2005, and 5,100 more than in 2011. This equates to 294 per 100,000 in the total Australian population, or 898 per 100,000 among the population aged over 50. PD now affects 23 additional people per 100,000 compared with 2005 (271 per 100,000).

Chart 3.1 shows prevalence of PD by age group in 2005, 2011 and 2014.[18] Just over half (53%) of PWP were males, broadly unchanged since 2005. The prevalence of PD increased substantially with age. People of working age (15-64 years) comprised 18% of PWP in 2014, although this group represented approximately 66% of the total population.

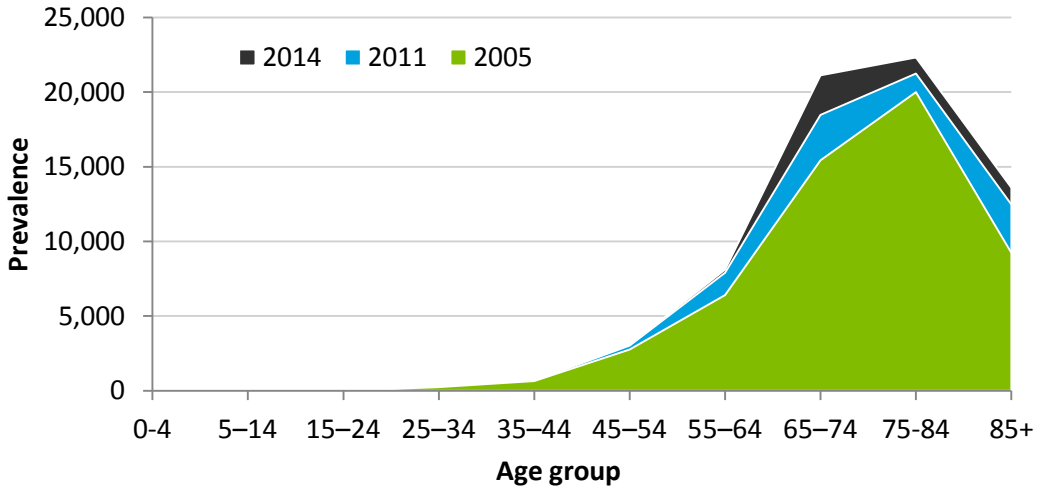
[18] Since the 2011 report, the underlying population estimates used to derive these results have changed to reflect updates to the ABS population estimates derived using the 2011 Census. This complicates comparisons with the 2007 report. However, as an indication of the bias, this results in slightly lower than expected prevalence in 2014 than was expected at the time of the 2011 report, or in other words, the prevalence in 2011 was slightly overstated. Revisiting the 2011 prevalence estimate indicates that the average annual growth in prevalence between 2005 and 2011 was approximately 2.5%, while the average annual growth between 2011 and 2014 was approximately 3.3%.

**Table 3.2: Estimated prevalence rates and cases of PD, 2014**

| Age | Prevalence rates (%) | | | Cases, 2014 | | | Additional cases, 2005-14 | | |
|---|---|---|---|---|---|---|---|---|---|
| | Males | Females | Total | Males | Females | Total | Males | Females | Total |
| 0-4 | 0.00 | 0.00 | 0.00 | 0 | 0 | 0 | 0 | 0 | 0 |
| 5–14 | 0.00 | 0.00 | 0.00 | 0 | 0 | 0 | 0 | 0 | 0 |
| 15–24 | 0.00 | 0.00 | 0.00 | 0 | 0 | 0 | 0 | 0 | 0 |
| 25–34 | 0.02 | 0.00 | 0.01 | 281 | 0 | 281 | 37 | 0 | 37 |
| 35–44 | 0.03 | 0.01 | 0.02 | 516 | 190 | 705 | 39 | 17 | 54 |
| 45–54 | 0.14 | 0.06 | 0.10 | 2,180 | 901 | 3,081 | 223 | 96 | 319 |
| 55–64 | 0.36 | 0.25 | 0.30 | 4,677 | 3,436 | 8,113 | 965 | 741 | 1,706 |
| 65–74 | 1.22 | 0.98 | 1.10 | 11,545 | 9,574 | 21,119 | 3,210 | 2,478 | 5,688 |
| 75-84 | 2.32 | 1.93 | 2.11 | 11,270 | 11,046 | 22,315 | 1,649 | 672 | 2,321 |
| 85+ | 3.69 | 2.59 | 2.97 | 6,056 | 7,537 | 13,593 | 2,318 | 2,040 | 4,359 |
| **Total** | | | | **36,525** | **32,684** | **69,208** | **8,425** | **6,084** | **14,508** |

Note: Rows and columns may not sum due to rounding.
Source: Deloitte Access Economics' calculations.

**Chart 3.1: Prevalence of PD by age, 2005, 2011 and 2014**




Source: Deloitte Access Economics' estimates.

## 3.2 Incidence of PD

Incidence refers to the number of new cases of PD. Begg et al (2007) used software called DISMOD II to model incidence and duration of PD from estimates of prevalence, remission (assumed to be zero) and the relative risk of mortality. This software was made available in the public domain by the World Health Organization (WHO). A similar methodology was adopted in the 2007 study which estimated the

incidence rates. Applying these rates to the Australian population, the number of new PD cases was estimated to be 8,900 in 2005, 10,500 in 2011 and 11,500 in 2014.

The estimated incidence rates and number of new cases for the year 2014 are presented in Table 3.3.

**Table 3.3: Incidence of PD, 2014**

| Age | Incidence rates (%) | | | New cases, 2014 | | |
|---|---|---|---|---|---|---|
| | Males | Females | Total | Males | Females | Total |
| 0-4 | 0.00% | 0.00% | 0.00% | 0 | 0 | 0 |
| 5–14 | 0.00% | 0.00% | 0.00% | 0 | 0 | 0 |
| 15–24 | 0.00% | 0.00% | 0.00% | 0 | 0 | 0 |
| 25–34 | 0.00% | 0.00% | 0.00% | 0 | 0 | 0 |
| 35–44 | 0.01% | 0.00% | 0.00% | 83 | 0 | 83 |
| 45–54 | 0.02% | 0.01% | 0.01% | 231 | 157 | 388 |
| 55–64 | 0.05% | 0.04% | 0.05% | 719 | 537 | 1,255 |
| 65–74 | 0.16% | 0.12% | 0.14% | 1,506 | 1,133 | 2,640 |
| 75-84 | 0.42% | 0.25% | 0.33% | 2,059 | 1,433 | 3,492 |
| 85+ | 1.10% | 0.65% | 0.81% | 1,797 | 1,889 | 3,686 |
| **Total** | | | | **6,395** | **5,149** | **11,544** |

Note: Rows and columns may not sum due to rounding.
Source: Deloitte Access Economics' estimations.

## 3.3 Prevalence by disease stage

Many of the costs associated with PD increase with disease stage. This is due to the fact that, as the disease progresses, the individual increasingly loses the ability to move freely (or loses predictability in being able to move freely), thus inhibiting the ability to perform everyday tasks. PD also has an increasing impact on mental health, cognitive and social functioning and the ability to communicate with others. Consequently, productivity losses, carer impacts, and the cost of aids and home/vehicle modification are likely to increase with disease stage. This report uses the H&Y staging system to estimate the prevalence of PD by stage.

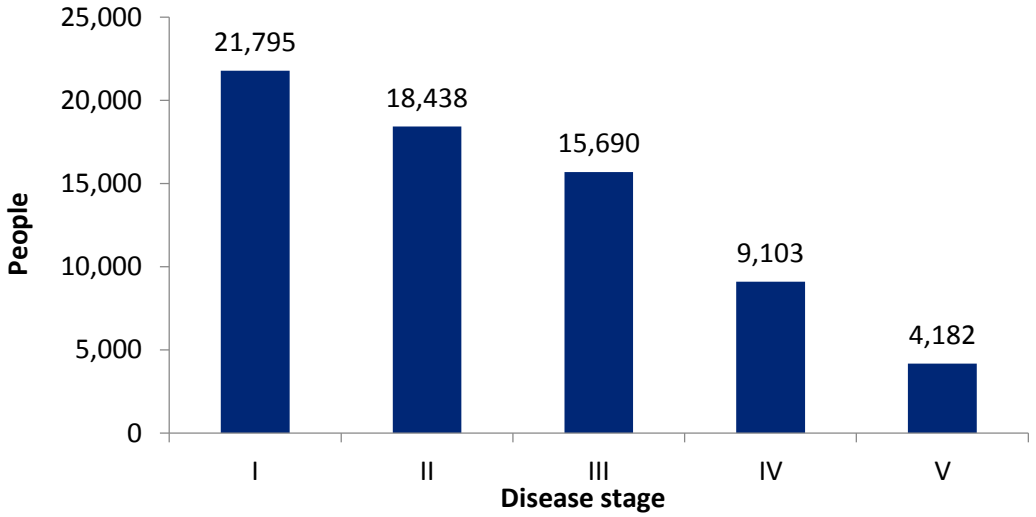
The number of people in each disease stage was estimated by applying the proportion of time spent in each disease stage with the median time from disease onset to death as 12.4 years (Hely et al, 1999; Hely et al, 2005; Hely et al, 2008). This methodology was also adopted in the 2007 and 2011 studies.

In 2014, the prevalence estimates by stages are as follows:

- 55,900 PWP in the initial stages of PD (Stages I to III) – compared with 44,300 in 2005;

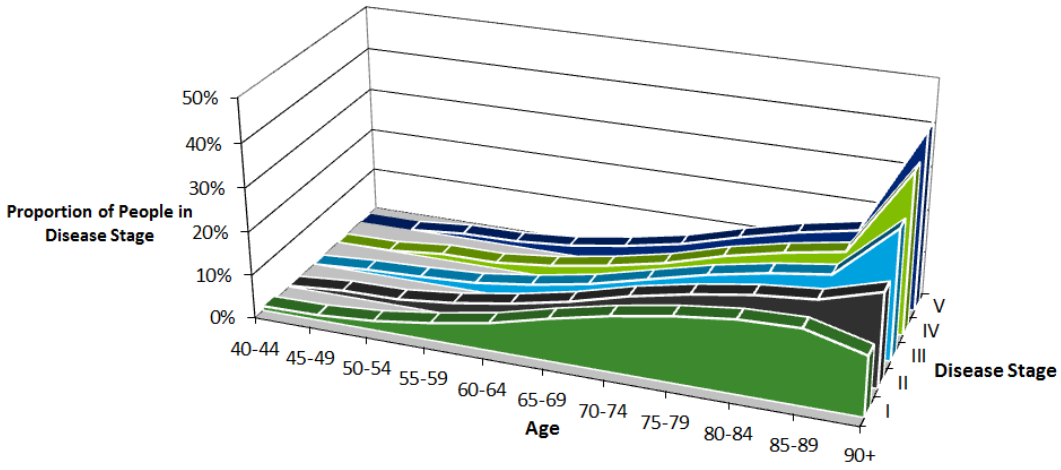
- 9,100 PWP in the intermediate of PD (Stage IV) – compared with 7,100 in 2005; and
- 4,200 PWP in the end stage of PD (Stage V) – compared with 3,300 in 2005.

**Chart 3.2: Prevalence of PD, by disease stage**



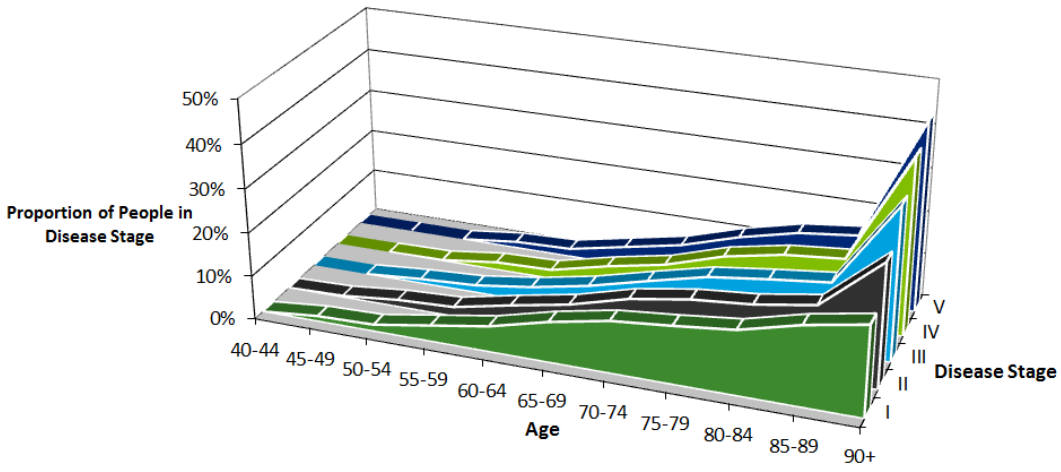

Source: Deloitte Access Economics' calculations.

**Chart 3.3: Age distribution of PWP, by disease stage, males**




Source: Deloitte Access Economics' calculations.

**Chart 3.4: Age distribution of PWP, by disease stage, females**




Source: Deloitte Access Economics' calculations.

## 3.4 PWP residing in residential aged care facilities

With ADL slowly being hindered as the disease progresses to later stage, the chance of being placed in a residential aged care facility increases. That said, not all PWP would be admitted into residential aged care. If they have a carer such as a healthy spouse or child who lives with them and have access to additional formal home care, most often they are still able to stay at home.

However, due to functional impairment, drug complications such as hallucinations and comorbidities associating with PD (i.e. dementia and incontinence), PWP have a higher probability of residential aged care placement relative to the general population.

Specifically, Hely et al (1999) and Aarsland et al (2000) examined the determinants of residential aged placement and found that the most significant risk factors influencing residential aged care admissions (other than age) were dementia, confusion and hallucination, falls/imbalance, restricted ADL and disease stage. As most of the factors identified were significantly related to increased disease stage, it was not surprising that in the multivariate analysis that disease stage was no longer an influencing factor. This was especially so when age was included as a variable in the regression analysis.

Table 3.4 and Table 3.5 present the proportion of PWP residing in residential aged care as well as the relative risk compared to the general population. The population of PWP residing in residential aged care facilities was thus estimated by applying the relative risk ratios of residential aged care admission for Stages IV to V by age group to the rate of admission in the general population.

**Table 3.4: Residential aged care admission (% of PWP), by age and disease stage**

| Disease stage | Aged 30-69 | Aged 70-79 | Aged 80-89 | Aged 90+ | All ages |
|---|---|---|---|---|---|
| I | 0.0% | 0.0% | 0.0% | | 0.0% |
| II | 0.0% | 1.1% | 0.0% | | 0.2% |
| III | 0.7% | 0.9% | 0.0% | | 0.7% |
| IV | 4.3% | 25.3% | 26.1% | | 17.3% |
| V | 42.9% | 88.0% | 80.0% | | 70.5% |
| **All stages** | **2.1%** | **13.6%** | **32.1%** | | **7.6%** |
| **General population** | **0.11%** | **2.04%** | **11.17%** | **35.94%** | **1.5%** |

Source: Deloitte Access Economics' calculations.

**Table 3.5: Residential aged care admission (relative risk compared to general population)**

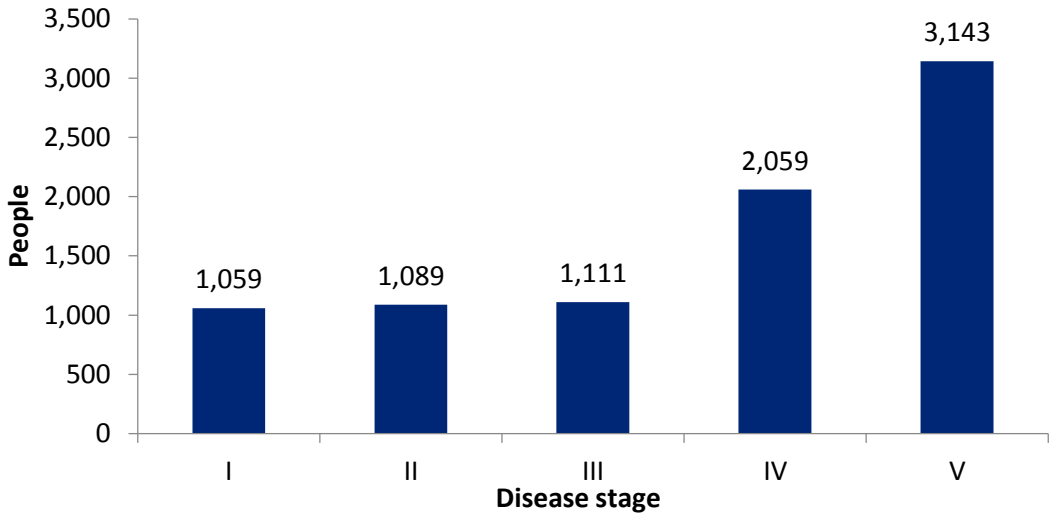
| Disease stage | Aged 30-69 | Aged 70-79 | Aged 80-89 | Aged 90+† | All ages |
|---|---|---|---|---|---|
| I | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 |
| II | 0.0 | 0.5 | 0.0 | 0.0 | 0.2 |
| III | 3.4 | 0.4 | 0.0 | 0.0 | 0.5 |
| IV | 20.6* | 12.4* | 2.3 | 0.7 | 11.9* |
| V | 203.2* | 43.2* | 7.2* | 2.2 | 48.3* |
| **All stages** | **10.0*** | **6.7*** | **2.9*** | **0.9** | **5.2*** |

Note: * Statistically significant (P<0.05); † Assuming PWP aged 90+ experiences at least the same amount of residential aged care admission as 80-89 year olds.

Source: Deloitte Access Economics' calculations.

In 2014, it was estimated that there were approximately 8,500 PWP in residential aged care facilities, of which 201 were aged younger than 65 years (equal to around 1.65% of all PWP aged younger than 65 years). Almost all PWP aged younger than 65 years who were residing in aged care facilities were in Stages IV or V (see Chart 3.5).

**Chart 3.5: Estimated PWP in aged care facilities by disease stage, 2014**




Source: Deloitte Access Economics' calculations.

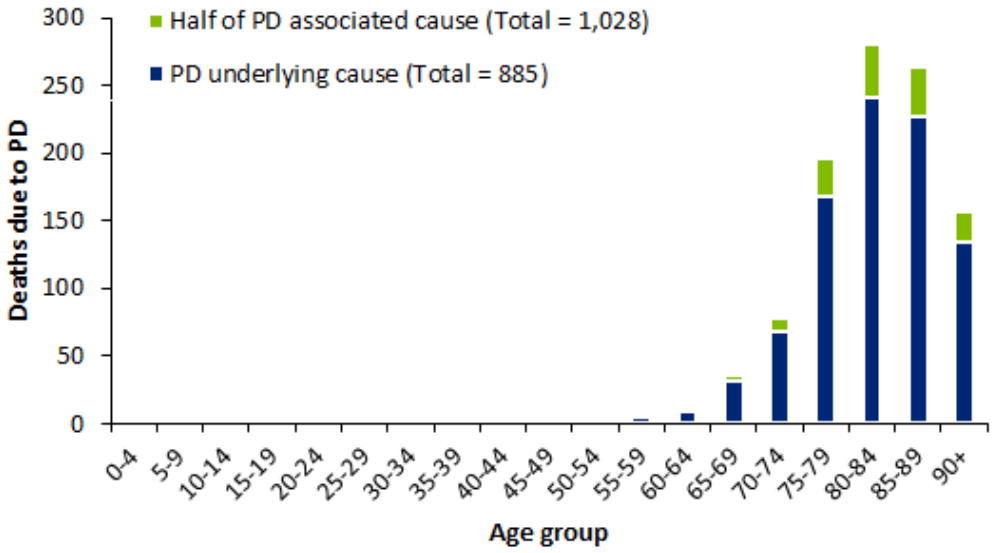
## 3.5 Deaths due to PD

The 2007 Deloitte Access Economics study found that Australian Bureau of Statistics' (ABS) data for underlying cause of death was likely to understate actual deaths for PD because a death may be attributed to another cause on the death certificate (excluding PD). This issue was addressed by deriving age-gender specific mortality rates from an analysis of associated causes of death from specially requested ABS data as well as findings from existing literature.

A similar methodology was adopted for estimating the number of deaths due to PD for the year 2014. An analysis was conducted of associated causes of death from a new ABS data request. According to ABS data, in 2012 there were a total of 3,061 deaths where PD was an *associated* cause, of which a total of 1,407 deaths (46%) classified PD as *the underlying* cause of death (ABS, 2014).

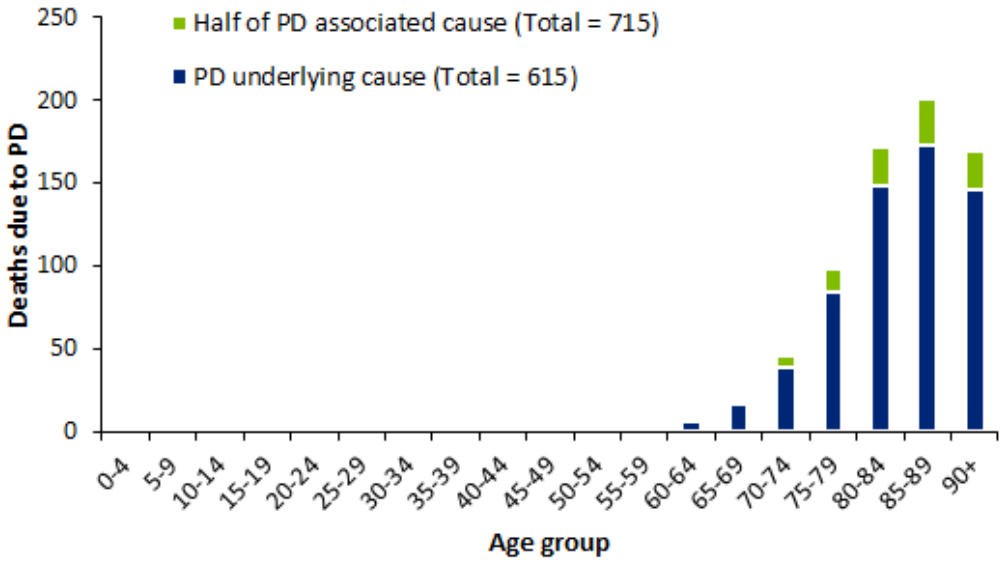
Inflating using age-gender specific mortality rates, and applying the findings from Hely et al (2008) who found that PD was considered to have contributed around 53.4% of the total number of patients who died of pneumonia, inanition (malnutrition), pulmonary embolism and suicide, it was estimated that there were between 1,501 (underlying) and 1,743 (associated) deaths due to PD in the year 2014.

**Chart 3.6: PD deaths, males, 2014**




Source: Deloitte Access Economics' calculations based on special request from ABS (2014).

**Chart 3.7: PD deaths, females, 2014**




Source: Deloitte Access Economics' calculations based on special request from ABS (2014).

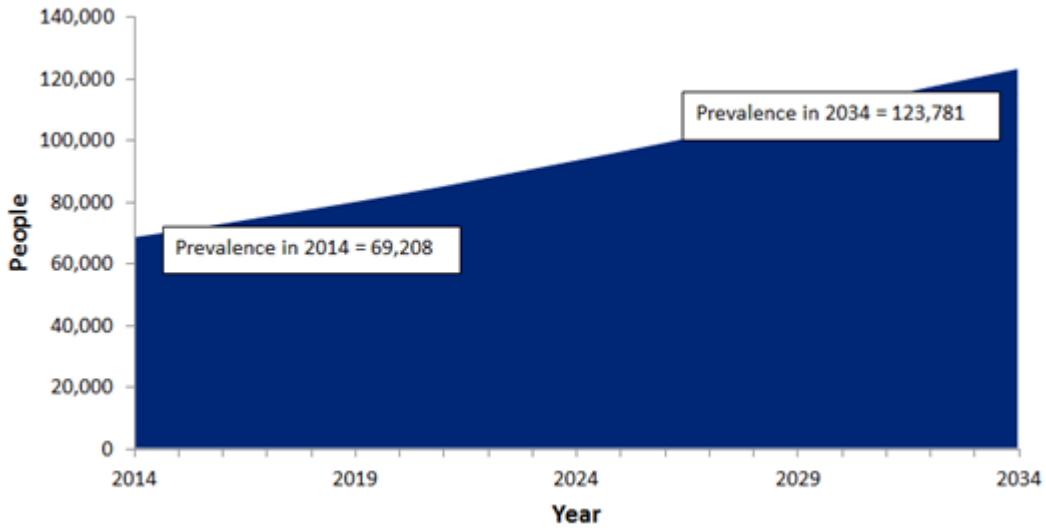
## 3.6 Projections

Updated projections of PD prevalence, deaths due to PD, and PWP residing in aged care facilities for the period 2014 to 2034 are shown in Chart 3.8, Chart 3.9, and Chart 3.10. As in the 2007 and 2011 Deloitte Access Economics studies, the

projections were made on the basis of age-sex specific prevalence and mortality rates, updated to reflect current demographic data and projections from the ABS population data. Therefore, these projections do not take into account changes in the prevalence of risk factors or the possibility that new treatments will become available in the future, which may affect prevalence and death rates. These projections also assume that patterns for entering aged care facilities remain the same over time, and that there are enough aged care spaces available to meet this need.

**An estimated 69,200 PWP in 2014 is projected to grow to 94,000 in 2024 and 123,800 by 2034 (i.e. 36% increase from 2014 to 2024, and 79% increase from 2014 to 2034).** This is equivalent to annual growth of 4% per annum between 2014 and 2034. Females represent approximately 47% of PWP. People of working age (15-64 years) comprise 18% of PWP in 2014, which is projected to decline to 13% by 2034, as a result of population ageing.

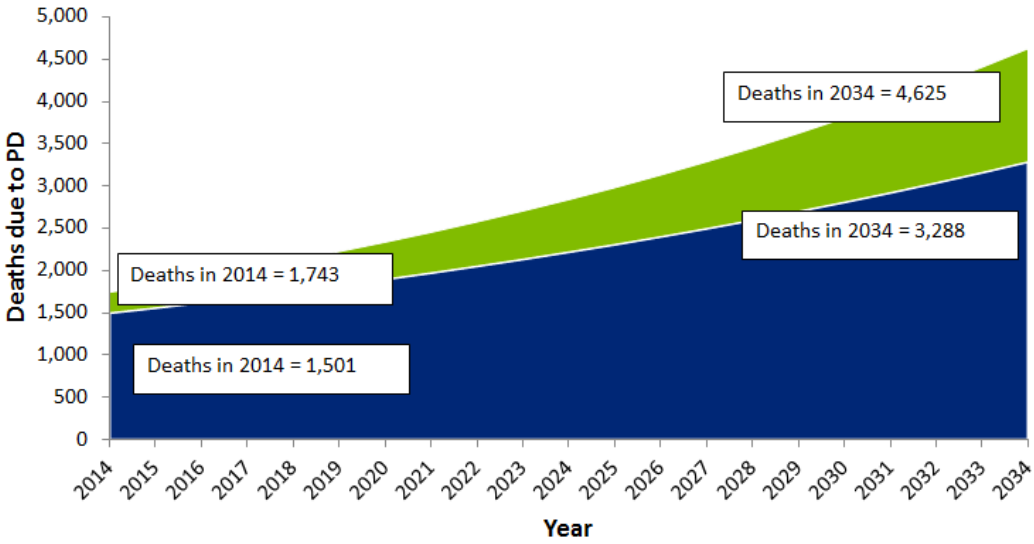
**Chart 3.8: Projected PD prevalence, 2014-2034**




Source: Deloitte Access Economics' projections.

**There are estimated to be between 1,501 and 1,743 deaths from PD in 2014, increasing to between 2,221 and 2,840 deaths in 2024 and to between 3,288 and 4,625 deaths in 2034.** Females comprised 41% of estimated deaths in 2014, falling slightly to 38% in 2024 and 2034. People of working age comprised 1.5% of deaths in 2014, which is projected to fall to 1.3% in 2024 and 1.0% in 2034, as a result of population ageing.

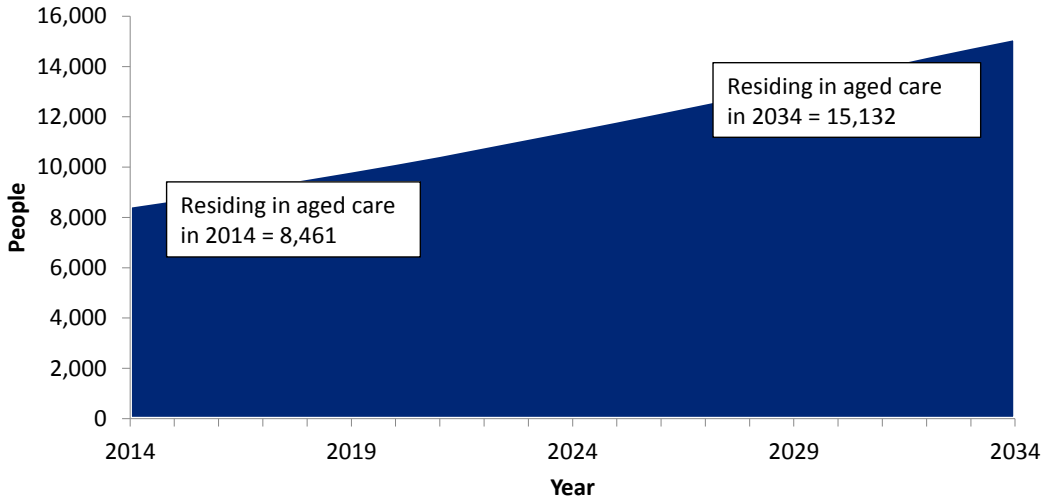
**Chart 3.9: Projected deaths due to PD, 2014-2034, underlying and associated estimates**




Source: Deloitte Access Economics' projections based on special request from ABS (2014).

**There are estimated to be 8,460 PWP residing in aged care facilities in 2014, which is projected to grow to 11,500 in 2024 and 15,100 by 2034.** Females comprised 59% of PWP in aged facilities in 2014, falling slightly to 58% in 2024 and 2034. People of working age comprised 2.4% of PWP in aged facilities in 2014, which is projected to fall to 2.1% in 2024 and 1.8% in 2034, as a result of population ageing.

**Chart 3.10: Projected PWP residing in aged care facilities, 2014-2034**




Source: Deloitte Access Economics' projections.

# 4 Estimating the economic costs of PD

This chapter describes the approach taken to estimate the economic costs of PD in Australia, and outlines some of the key economic terms, how costs are borne by members of society, and some of the underlying methodology present throughout all chapters. Specific methodologies for each of the costs associated with PD are outlined further in the chapter where they are discussed.

## 4.1 Incidence and prevalence approaches

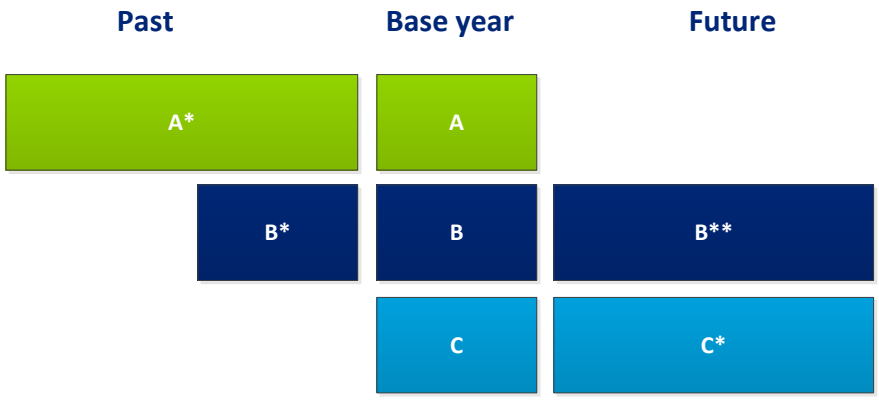
In line with 2007 and 2011, this report utilises a **prevalence (annual costs) approach** to estimate the costs of PD in Australia for the year 2014. The alternative approach is the incidence (lifetime costs) approach. The difference between incidence and prevalence approaches is illustrated in Figure 4.1.

Consider three different cases of people with PD:

- a, who was diagnosed with PD in the past and has incurred the associated costs up to the year in question, with associated lifetime costs of A + A*, shaded in green;
- b, who was diagnosed with PD in the past and has incurred the associated costs in 2014 as well as in the past and future, with associated lifetime costs of B + B* + B**, shaded in dark blue; and
- c, who was diagnosed with PD in 2014, with lifetime costs of C + C*, shaded in light blue.

All costs should be expressed as present values relative to 2014.

**Figure 4.1: Incidence and prevalence approaches to measurement of costs**



**Annual prevalence-based costs in the base year = Σ(A + B + C);**
**Annual incidence-based costs in the base year = Σ(C + present value of C*)**

Note that Figure 4.1 also defines the lifetime costs of PD for each person, as follows:

**Lifetime cost for person c (= Incidence cost) = C + present value of C***
**Lifetime cost for person b = B + present values of B* and B****
**Lifetime cost for person a = A + present value of A***

Using an incidence approach, only cases like 'c' would be included, with the total cost estimate equivalent to the sum of all the costs in the base year (ΣC) plus the present value of all the future costs (ΣC*). Costs associated with PWP diagnosed in an earlier year would be excluded.

Using a prevalence approach, costs in 2014 relating to a, b and c would all be included, with total costs equal to Σ(A + B + C). Costs in all other years are excluded.

## 4.2 Classification of costs

Conceptual issues relating to the classification of costs include the following.

- **Direct and indirect costs**: Although literature often distinguishes between direct and indirect costs, the usefulness of this distinction is dubious, as the specific costs included in each category vary between different studies, making comparisons of results somewhat difficult.
- **Real and transfer costs**: "Real costs use up real resources, such as capital or labour, or reduce the economy's overall capacity to produce (or consume) goods and services. Transfer payments involve payments from one economic agent to another that do not use up real resources. For example, if a person loses their job, as well as the real production lost there is also less income taxation, where the latter is a transfer from an individual to the government. This important economic distinction is crucial in avoiding double-counting. It has attracted some attention in the literature." (Laing and Bobic, 2002: 16, Laurence and Spalter-Roth, 1996: 14)
- **Economic and non-economic costs**: Economic costs encompass loss of goods and services that have a price in the market or that could be assigned an approximate price by an informed observer. 'Non-economic' costs include the loss of wellbeing of the individual as well as of their family members and carers. This classification is ill-defined, since 'non-economic' costs are often ascribed values with the available methodologies now being more widely accepted. Some controversy still surrounds the valuation of 'non-economic' costs and the results should be interpreted cautiously.
- **Prevention and case costs**: This study distinguishes between: the costs following from, and associated with a disease; and costs directed towards

preventing the disease. Prevention activities include public awareness and education about PD. In similar vein, costs of insuring against impacts of the disease are excluded, but the study includes the gross costs of the impacts themselves.

There are six types of costs associated with PD.

- **Direct financial costs to the Australian health system** include the costs of running hospitals and residential aged care facilities (buildings, care, consumables), GP and specialist services reimbursed through Medicare and private funds, the cost of pharmaceuticals (PBS and private) and of over-the-counter medications, allied health services, research and "other" direct costs (such as health administration).
- **Productivity costs** include productivity losses of the PWP (long-term employment impacts), premature mortality and the value of informal care (including lost income of carer).
- **Administrative costs and other financial costs** include government and non-government programs such as respite, community palliative care, out-of-pocket expenses (such as formal care, aids, equipment and modifications that are required to help cope with illness, and transport and accommodation costs associated with receiving treatment), and funeral costs.
- **Transfer costs** comprise the deadweight losses associated with government transfers such as taxation revenue foregone, welfare and disability payments.
- **Non-financial costs** are also very important—the pain, suffering and premature death that result from PD. Although more difficult to measure, these can be analysed in terms of the years of healthy life lost, both quantitatively and qualitatively, known as the "burden of disease".

Different costs of disease are borne by different individuals or sectors of society. Clearly the PWP bears costs, but so do employers, government, friends and family, co-workers, charities, community groups and other members of society.

It is important to understand how the costs are shared in order to make informed decisions regarding interventions. While the PWP will usually be the most severely affected party, other family members and society (more broadly) also face costs as a result of PD. From the employer's perspective, depending on the impact of PD, work loss or absenteeism will lead to costs such as higher wages (i.e. accessing skilled replacement short-term labour) or alternatively lost production, idle assets and other non-wage costs. Employers might also face costs such as rehiring, retraining and workers' compensation.

While it may be convenient to think of these costs as being purely borne by the employer, in reality they may eventually be passed on to end consumers in the form of higher prices for goods and services. Similarly, for the costs associated with the health system and community services, although the Government meets this cost, taxpayers (society) are the ultimate source of funds. However, for the purpose of

this analysis, a 'who writes the cheque' approach is adopted, falling short of delving into second round or longer term dynamic impacts.

Society bears both the resource cost of providing services to PWP, and also the 'deadweight' losses (or reduced economic efficiency) associated with the need to raise additional taxation to fund the provision of services and income support.

Typically six groups who bear costs and pay or receive transfer payments are identified, namely the:

- PWP;
- friends and family (including informal carers);

} The Household

- employers;
- Federal government;
- State and local government; and
- the rest of society (non-government, i.e. not-for-profit organisations, private health insurers, workers' compensation groups etc).

Classifying costs by six cost categories and allocating them to six groups enables a framework for analysis of these data to isolate the impacts on the various groups affected by PD. This includes different levels of government, the business sector and community groups.

## 4.3 Net present value and discounting

Where future costs are ascribed to the year 2014 throughout the report the formula for calculating the NPV of those cost streams is:

$$NPV = \Sigma C_i/(1+r)^i \text{ where } i=0,1,2....n \quad \text{where}$$

**$C_i$ = cost in year i, n = years that costs are incurred and r = discount rate.**

Choosing an appropriate discount rate is a subject of some debate, as it varies depending on what type of future income or cost stream is being considered. The discount rate should take into consideration risks, inflation and positive time preference.

Generally, the minimum option that one can adopt in discounting future expected healthy life streams is to set future values on the basis of a risk free assessment about the future that is assuming the future flows would be similar to the almost certain flows attaching to a long-term Government bond. Another factor to

consider is inflation (price increases[19]), so that a real rather than nominal discount rate is used. If there is no positive time preference, the real long term government bond yield indicates that individuals will be indifferent between having something now and in the future. In general, however, people prefer immediacy, and there are different levels of risk and different rates of price increases across different cost streams.

Taking inflation, risk and positive time preference into consideration, a real discount rate of 3% is traditionally used in discounting healthy life, and is also used in discounting other cost streams in this report, for consistency.

[19] The Reserve Bank has a clear mandate to pursue a monetary policy that delivers 2% to 3% inflation over the course of the economic cycle. This is a realistic longer run goal and a consumer price inflation rate of around 2.5% per annum on average has been achieved over recent years.

# 5 Health system costs

Health system costs due to PD reflect the fact that PD is a chronic and progressive disease and treatment is varied and complex. This chapter outlines the total health system costs associated with PD, and provides a breakdown by type of cost (for example, in-hospital, out-of-hospital, and pharmaceuticals amongst other types), disease stage and other additional costs associated with PD.

**Key findings:**

- In 2014, the health system costs of PD, including the additional costs from associated falls and pneumonia, were approximately $567.7 million, an increase of $223.8 million since 2005. The average health system cost per person with PD was $8,202 per annum in 2014.
- Costs were dominated by the residential aged care setting (48%), hospitals (23%) and pharmaceuticals (15%).
- Cost per PWP increases with disease stage with the total health system costs per PWP estimated to be around $5,500 in Stage I to over $15,000 in Stage V.
- Governments bore around two thirds of the health system costs (68.3%), while individuals bore 17.8%, and other parties (private health insurance, charities) bore the remaining 13.9%.

## 5.1 Total health system costs

Health expenditure data for PD was sourced by special request from the Australian Institute of Health and Welfare (AIHW). The AIHW derives its expenditure estimates from an extensive 'top-down' process developed in collaboration with the National Centre for Health Program Evaluation for the Disease Costs and Impact Study (DCIS). The approach measures health services utilisation and expenditure for specific diseases and disease groups in Australia. The DCIS methodology (Mathers et al, 1998) has been gradually refined over the 1990s to now estimate a range of direct health costs from hospital morbidity data, case mix data, Bettering the Evaluation and Care of Health (BEACH) data, the National Health Survey and other sources.

The data obtained from the AIHW related to DCIS data released on 12 May 2004 (AIHW, 2004) for the year 2000-01 disaggregated by age, gender and type of cost (Table 5.1). These data use burden of disease categories based the Tenth Revision of the International Classification of Disease published by the World Health Organisation and the International Classification of Primary Care Version 2. In 2000-01, it was estimated that $192.7 million was spent on treating PD.

**Table 5.1: Health system costs ($m in $2000-01)**

| Age | Males | Females | Total |
|---|---|---|---|
| 0-4 | 0.027 | 0.068 | 0.095 |
| 5–14 | 0.013 | 0.003 | 0.015 |
| 15–24 | 0.031 | 0.196 | 0.227 |
| 25–34 | 0.214 | 0.044 | 0.258 |
| 35–44 | 0.667 | 0.663 | 1.330 |
| 45–54 | 1.587 | 3.350 | 4.938 |
| 55–64 | 12.724 | 5.916 | 18.640 |
| 65–74 | 34.853 | 18.312 | 53.165 |
| 75-84 | 46.294 | 34.870 | 81.164 |
| 85+ | 12.231 | 20.666 | 32.897 |
| **Total** | **108.641** | **84.088** | **192.730** |

Note: A special request was made in 2007 to obtain the health system costs for PD for the purpose of developing the 2007 Deloitte Access Economics' study.

Source: AIHW (2004).

At the time of writing this report, a new special request was made to the AIHW to obtain the latest data on health system expenditure. However, due to limited resources, AIHW was unable to process this special request.[20] Consequently, the 2000-01 data provided by the AIHW were used as the basis of the 2014 estimates. The costs were adjusted using health cost inflation sourced from the AIHW as well as estimated growth in PD prevalence based on ABS population data for each age group.

Note also that the AIHW include only 86% of total recurrent health expenditure in their estimates of expenditure by disease and injury, referred to as 'allocated' health expenditure. The 'unallocated' remainder includes capital expenditures, expenditure on community health (excluding mental health), public health programs (except cancer screening), health administration and health aids and appliances. Allowance is made for the unallocated component. The health system cost estimates do not include additional funding for health research announced in recent years' Federal Budgets.

[20] Our understanding is that AIHW is currently working on a disease expenditure database that spans ten years which will have a larger scope than previous disease expenditure databases. This new database will enable time series analysis over a period of ten years with a view for completion in mid-2015.

In 2014, the total health system costs were estimated to be approximately $464.7 million[21] with the per person health system costs at around $6,715. The 2014 per person cost was 27% higher than in 2005 and 7% higher than in 2011. Table 5.2 presents the estimated health system costs for the year 2014.

**Table 5.2: Health system costs, 2014**

| Age | Males | | Females | | Total | |
|---|---|---|---|---|---|---|
| | Total | per PWP | Total | per PWP | Total | per PWP |
| | *$m* | *$* | *$m* | *$* | *$m* | *$* |
| 0-4 | 0.00 | 0 | 0.00 | 0 | 0.00 | 0 |
| 5–14 | 0.00 | 0 | 0.00 | 0 | 0.00 | 0 |
| 15–24 | 0.00 | 0 | 0.00 | 0 | 0.00 | 0 |
| 25–34 | 0.43 | 1,541 | 0.00 | 0 | 0.43 | 1,541 |
| 35–44 | 1.26 | 2,440 | 1.28 | 6,765 | 2.54 | 3,602 |
| 45–54 | 3.15 | 1,444 | 6.75 | 7,495 | 9.90 | 3,214 |
| 55–64 | 31.99 | 6,841 | 15.35 | 4,466 | 47.34 | 5,835 |
| 65–74 | 86.16 | 7,463 | 43.43 | 4,536 | 129.59 | 6,136 |
| 75-84 | 107.34 | 9,525 | 69.72 | 6,312 | 177.06 | 7,935 |
| 85+ | 41.82 | 6,906 | 56.06 | 7,438 | 97.88 | 7,201 |
| **Total** | **272.16** | **7,451** | **192.59** | **5,893** | **464.75** | **6,715** |

Note: Estimates for females below 35 years and for males below 25 years shown as zeros due to rounding.
Source: Deloitte Access Economics' calculations based on AIHW (2004).

## 5.2 Health system costs by type of cost

Chart 5.1 shows the main health system cost components for PD in 2014.[22, 23]

- **Aged care ($272.5 million, $3,937 per PWP or $32,208 per PWP in an aged care facility)**: residential aged care placement is often required, particularly in the later stages of PD due to functional impairment, drug complications (such as

[21] Goss (2008) provided projections of expenditure by disease for Australia for the period 2003 to 2033. The projection model combined demographic factors of population ageing and population growth, and non-demographic factors of changes in disease rates, volume of services per treated case, treatment proportions (i.e. the proportion of cases that receive treatment) and health price changes. These were applied to project health and residential aged care expenditure for each disease. For PD, it was projected that the health and residential aged care expenditure was around $488 million (in 2006-07) dollars, which is higher than our estimate due to different methods. Our estimate can thus be considered conservative.

[22] These costs exclude the additional health system costs discussed in later sections.

[23] The cost components were based on AIHW (2004). As indicated earlier, AIHW was unable to process our special request due to a lack of resources.

hallucinations) and comorbidities associated with PD (such as dementia and incontinence).

- **Pharmaceuticals ($70.7 million or $1,022 per PWP)**: drug treatments for PD — includes drugs listed on the PBS and RPBS (such as levodopa), non-subsidised prescription drugs (such as ropinirole) and over-the-counter drugs (such as paracetamol and vitamins).
- **Inpatient & outpatient hospital services ($70.6 million or $1,020 per PWP)**: usually for the purpose of confirming diagnosis and levodopa responsiveness, or for the management of motor fluctuations and dyskinesias (Temlett, 2006). Hospital admission may also be required for treatment for falls and other accidents, depression, some invasive surgery (such as lesioning or neuro-stimulator placement), aspiration pneumonia, and autonomic nervous system disorders, such as severe constipation, and urinary disorders arising from PD or PD medication.
- Other health system costs include:
    - **General practitioner (GP) services ($7.1 million or $103 per PWP):**[24] on-going consultations with GPs are required to manage symptoms, prescribe drugs, and treat complications.
    - **Out-of-hospital specialists ($4.4 million or $64 per PWP):**[25] neurologists are often consulted to diagnose PD and to advise on appropriate treatment pathways.
    - **Other health practitioners ($14.6 million or $210 per PWP)**: PWP may also be referred to physiotherapists, speech therapists, occupational therapists, clinical psychologists, exercise physiologists, podiatrists and specialist PD nurses.
    - **Imaging and pathology ($3.4 million or $49 per PWP)**: some services may be used during the diagnosis stage to rule out other possible causes of symptoms, but some of these costs may be avoidable. Additional services may also be required to investigate PD complications – such as the extent of fractures due to accidental falls.
    - **Research ($21.4 million or $310 per PWP)**: ongoing epidemiological research into the causes of idiopathic PD, basic research (e.g. brain functions), applied research (e.g. synthesising large molecule

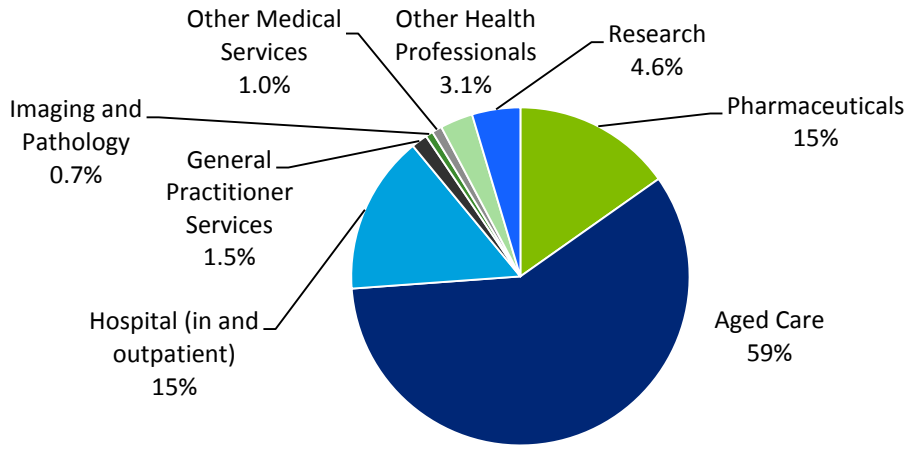
[24] The underlying source used by AIHW to measure the cost of GP services is the BEACH database 1999–00 to 2001–02. The proportion of problems by disease was used to split top-down total expenditure (based on Medicare). Consequently this may be an underestimate of the total GP costs associated with PD because: individuals may consult the GP for more than just PD-related issues (even though PD may be the primary reason), and issues regarding identifying encounters for rarer diseases using BEACH (Access Economics, 2007).

[25] GP referral patterns from BEACH were used to allocate total specialist expenditure (from AIHW). This may be an underestimate of total specialist costs associated with PD depending on the rates of GP referral to specialists for PD (see Access Economics, 2007a).

interactions) and developmental research for new treatments (e.g. drug therapies).

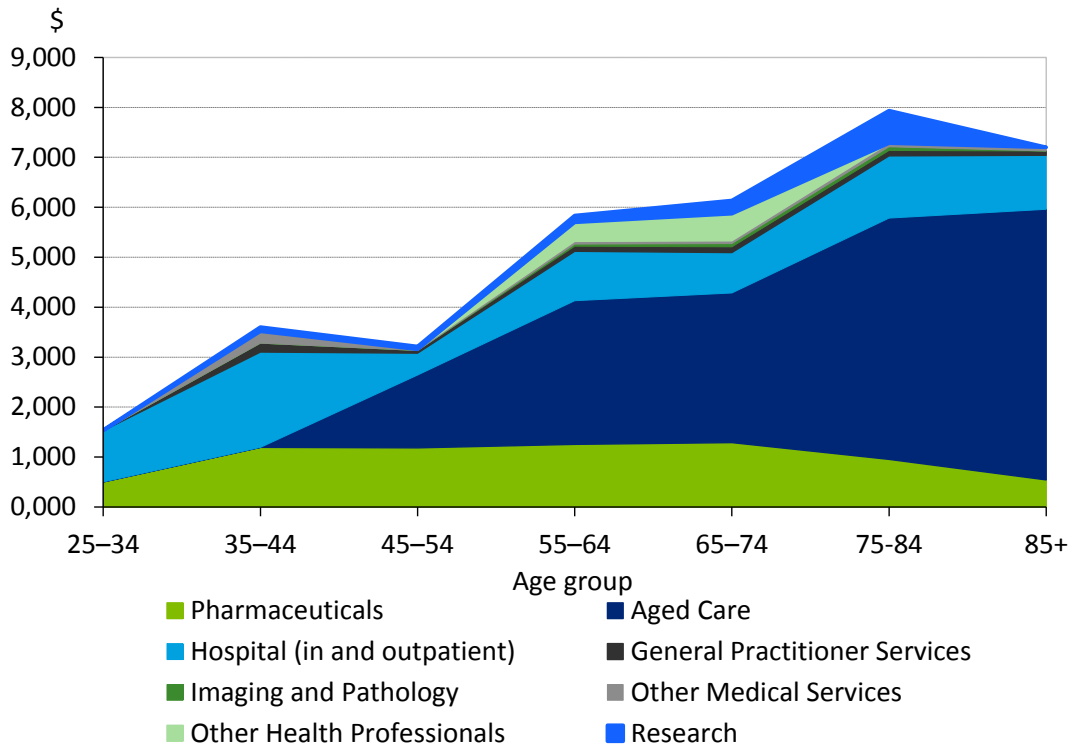
These health costs vary considerably by age — with pharmaceuticals declining in share of health system costs over time, and aged care costs increasing in share over time (Chart 5.2).

**Chart 5.1: Health system cost components, 2014**



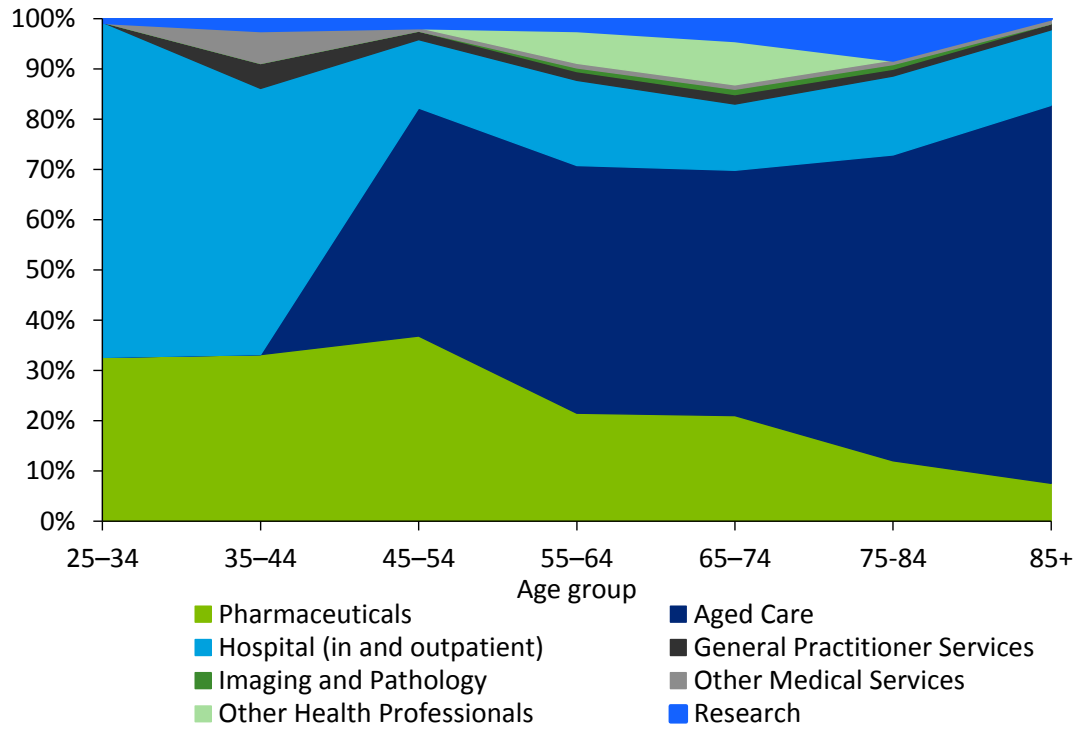

Source: Deloitte Access Economics' calculations.

**Chart 5.2: Health system costs per person, component and age, 2014**




Source: Deloitte Access Economics' calculations based on AIHW (2004).

**Chart 5.3: Health system costs per person, component and age, 2014**




Source: Deloitte Access Economics' calculations based on AIHW (2004).

## 5.3 Health system costs by disease stage

In the previous Deloitte Access Economics' reports, two studies were identified to estimate the health system costs by disease stage.

- Findley (2003) surveyed 428 PWP in the UK in 1998 and estimated health system costs, social services, and private expenditure by disease stage. Health system costs included: pharmaceutical; GP; other health professionals; and hospital inpatient and outpatient costs. The study found that average health system costs were £2,298 per PWP and were three times higher for PWP in Stage V compared to PWP in Stages I and II.
- Spottke et al (2006) surveyed 145 PWP in Germany between 2000 and 2002 and estimated drug, medical and non-medical direct costs by disease stage. Spottke (2006) only reported direct costs from the statutory health insurance authority's perspective (i.e. the total direct costs largely excludes the cost of nursing care and patient co-payments, for which there is no data by disease stage). The study found that average health costs (drug and direct medical) were €3,378 and were three times higher for PWP in Stage V compared to PWP in Stages I and II.

Recent studies such as Winter et al (2010) compared resource utilisation in two cohorts of PWP recruited in 2000 and 2004. Disease severity was identified as a

strong cost-predictor. For example, in 2004, the mean direct costs for the PWP in stages III to IV was around £17,380 compared to only £9,880 for those PWPs who were in the early stages of the disease. Similar findings were observed in other studies such as McCrone et al (2007) and Winter et al (2010a) who analysed total annual costs (i.e. direct and indirect costs).

To estimate the distribution of health costs (i.e. direct costs) by disease stage in Australia, three studies which analysed direct costs by disease stage were used (Table 5.3). For each study, the average health system costs were estimated using the distribution of PWP by disease stage in Australia (Section 3.3). The ratios of health system costs compared to this average were then estimated for each disease stage (Table 5.3). The final results were adjusted so the total health expenditure by disease stage equals that in Section 5.1.

**Table 5.3: Health system costs per PWP (ratio to average), by disease stage**

| Disease stage | % of PWP in each stage | Findley (2003) | Spottke (2006) | Winter (2010) | Weighted average |
|---|---|---|---|---|---|
| Stage I | 31% | 0.66 | 0.63 | 0.77 | 0.67 |
| Stage II | 27% | 0.67 | 0.57 | 0.77 | 0.67 |
| Stage III | 23% | 1.22 | 1.14 | 1.32 | 1.22 |
| Stage IV | 13% | 1.69 | 2.01 | 1.32 | 1.69 |
| Stage V | 6% | 1.90 | 2.07 | 1.32 | 1.84 |
| **All stages** | | **1.08** | **1.15** | **0.88** | **1.06** |

Source: Deloitte Access Economics' calculations.

Health system costs in Australia by disease stage were estimated by applying the weighted average of these ratios to the average health system costs as estimated in Table 5.3. In 2014, it was estimated that the total health system costs per PWP was approximately $6,715. As the disease progresses from Stage I to Stage V, the cost per PWP increases from $4,453 to $12,489.

**Table 5.4: Health system costs per PWP, by disease stage, 2014**

| Disease stage | Health system cost per PWP ($), 2014 |
|---|---|
| Stage I | 4,453 |
| Stage II | 4,470 |
| Stage III | 8,207 |
| Stage IV | 11,456 |
| Stage V | 12,489 |
| **All stages** | **6,715** |

Source: Deloitte Access Economics' calculations.

## 5.4 Additional health system costs

As discussed in the 2007 and 2011 reports, the variation of the health system cost estimate is largely dependent on the underlying estimates of the use of the health system by PWP. For example, GP visits, hospital separations and deaths due to PD may underestimate health system costs through the incorrect attribution of the use of these services to other diseases or injuries (for example, costs associated with accidental falls or pneumonia due to the symptoms of PD would be attributed to accidental falls or pneumonia separately, respectively).

The methodology used to attribute various pharmaceutical costs to PD would also impact on estimates. For example, the use of PD drugs for non-PD reasons would overestimate pharmaceutical costs, whereas use of non-PD drugs to treat PD symptoms would underestimate costs.

Furthermore health system costs would be strongly affected (either over or underestimated) by the level of undiagnosed and misdiagnosed cases of PD. For example PWP who also have dementia in aged care facilities, if their admission was counted as “due to dementia” rather than “due to PD”.

To date, the most relevant study is still Temlett and Thompson (2006) who analysed admissions of PWP into the Royal Adelaide Hospital between 1999 and 2004. In the hospital each admission was coded according to the primary diagnosis (the reason for admission based on the acute problem treated), although additional information on secondary diagnoses was also recorded (other existing diseases which also require management during the hospital stay). The study found that where PD was a secondary diagnosis, the associated primary diagnosis was often directly attributable to the effects of PD or the complications of treatment: namely, accidental falls and fractures (due to problems with gait and balance), pneumonia (due to dysphagia), dementia (commonly associated with PD), syncope and encephalopathy (through adverse drug reactions). Gastrointestinal and genitourinary infections may also be a complication of PD in some cases.

Overall it was found that for every hospital admission directly due to PD, there were at least two additional admissions due to complications that were coded to a different disease or injury. However, this does not take into account other comorbidities that may increase the likelihood (i.e. visual impairment) or severity (i.e. osteoporosis) of the hospital admission.

Table 5.5 presents the additional health system costs due to additional hospitalisation from accidental falls and pneumonia.

**Table 5.5: Additional health system costs, 2014**

| | PD hospital admissions (2012-13) | Additional hospital admissions (2014) | | Health system cost per hospital admission ($) | | Additional health system cost ($m) | |
|---|---|---|---|---|---|---|---|
| | | Falls | Pneumonia | Falls | Pneumonia | Falls | Pneumonia |
| **Males** | | | | | | | |
| 0–44 | 49 | 36 | 34 | 9,424 | 42,343 | 0.3 | 1.5 |
| 45–54 | 92 | 67 | 64 | 11,021 | 27,128 | 0.7 | 1.7 |
| 55–64 | 308 | 224 | 216 | 14,043 | 27,848 | 3.1 | 6.0 |
| 65–74 | 700 | 509 | 490 | 16,990 | 21,221 | 8.6 | 10.4 |
| 75-84 | 919 | 668 | 643 | 8,231 | 16,397 | 12.2 | 10.5 |
| 85+ | 339 | 246 | 237 | 18,962 | 14,855 | 4.7 | 3.5 |
| **Females** | | | | | | | |
| 0–44 | 34 | 25 | 24 | 11,317 | 43,447 | 0.3 | 1.0 |
| 45–54 | 44 | 32 | 31 | 15,687 | 38,711 | 0.5 | 1.2 |
| 55–64 | 197 | 143 | 138 | 13,695 | 30,126 | 2.0 | 4.2 |
| 65–74 | 403 | 293 | 282 | 17,691 | 28,220 | 5.2 | 8.0 |
| 75-84 | 535 | 389 | 374 | 14,258 | 19,760 | 5.5 | 7.4 |
| 85+ | 188 | 137 | 132 | 15,398 | 16,792 | 2.1 | 2.2 |
| **Total** | **3,808** | **2,768** | **2,666** | | | **45.3** | **57.6** |

Source: AIHW special data request, AIHW National Hospital Morbidity DataCube, Deloitte Access Economics' calculations.

Specifically, in 2013, there were 3,555 hospital admissions due to idiopathic PD and 253 due to secondary PD (i.e. a total of 3,808 hospital admissions) – thus, in 2014, there were estimated to be 2,768 hospital admissions for accidental falls that were a complication of PD, and 2,666 hospital admissions for pneumonia that were a complication of PD.

Assuming that the costs of treating accidental falls and pneumonia per PWP are the same regardless of underlying cause, there would be at least $102.9 million in additional health system costs to treat the complications of PD – of which, $45.3 million is to treat accidental falls, and $57.6 million is to treat pneumonia (Table 5.5). Health system costs due to accidental falls and pneumonia represent an additional 22% of the total health cost of PD. This translates to around $1,487 per PWP (Table 5.6), or $654 per PWP for accidental falls and $833 per PWP for pneumonia. The additional health system costs ranged between $1,020 and $2,542 depending on disease stage (Table 5.7).

**Table 5.6: Additional health system costs per PWP, by age and sex, 2014**

| Age | Male ($) | Female ($) | Total persons ($) |
|---|---|---|---|
| 0–44* | 2,243 | 6,929 | 3,144 |
| 45–54 | 1,139 | 1,880 | 1,356 |
| 55–64 | 1,956 | 1,780 | 1,881 |
| 65–74 | 1,649 | 1,373 | 1,524 |
| 75-84 | 2,017 | 1,172 | 1,599 |
| 85+ | 1,354 | 572 | 920 |
| **All ages** | **1,735** | **1,209** | **1,487** |

* Per person costs are large for males and females in 0-44 age group due to small sample sizes and different data sources for prevalence and health cost data; high standard errors may thus mean the 0-44 group estimates are not reliable taken in isolation, and all-age averages may provide better estimates for this age group.

Source: Deloitte Access Economics' calculations.

**Table 5.7: Additional health system costs per PWP, by disease stage, 2014**

| Disease stage | Cost per PWP ($) |
|---|---|
| Stage I | 1,107 |
| Stage II | 1,020 |
| Stage III | 1,765 |
| Stage IV | 2,379 |
| Stage V | 2,542 |
| **All stages** | **1,487** |

Source: Deloitte Access Economics' calculations.

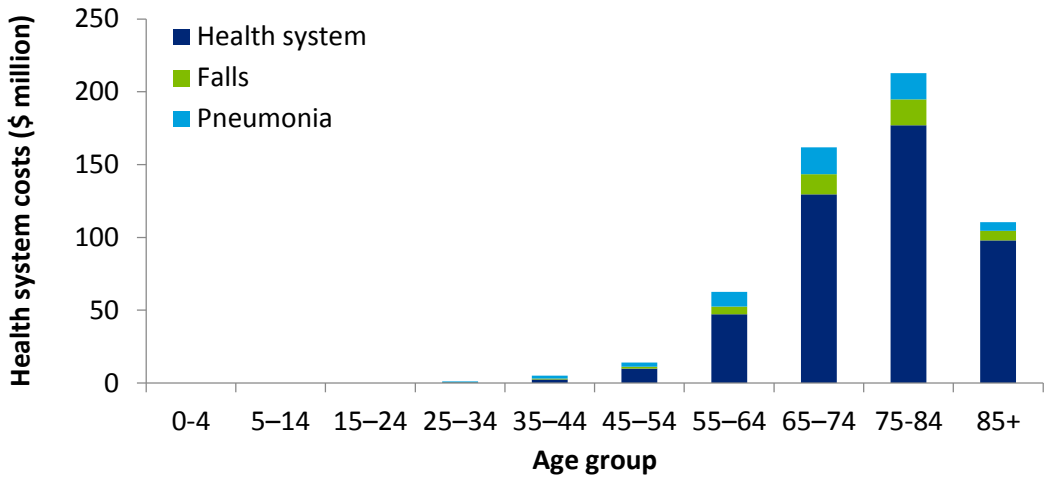
## 5.5 Summary of health system costs

In 2014, the health system costs of PD were approximately $567.7 million (Chart 5.4). This includes the additional costs from associated falls ($45.3 million) and pneumonia ($57.6 million). Total health system costs of PD have increased by $224 million since 2005 – a 65% increase.

Of total health expenditure in 2014:

- 41% was spent treating women with PD and 59% was spent treating men with PD.
- 14.6% was spent treating people aged less than 65 years.

**Chart 5.4: Health system costs of PD, including from falls and pneumonia ($ million), by age**

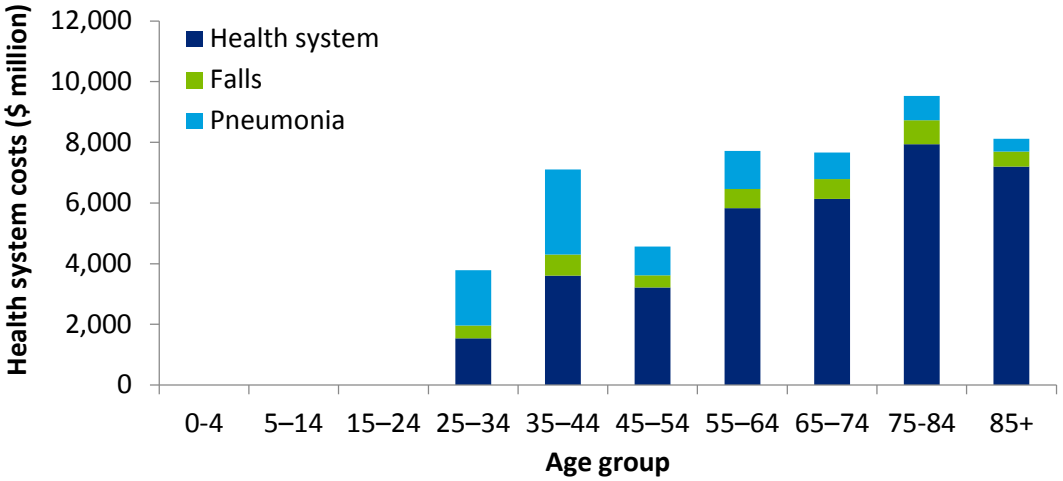



Source: Deloitte Access Economics' calculations.

The average health system cost per person with PD was $8,202 per annum. This includes costs from associated falls ($654 per annum) and pneumonia ($833 per annum).

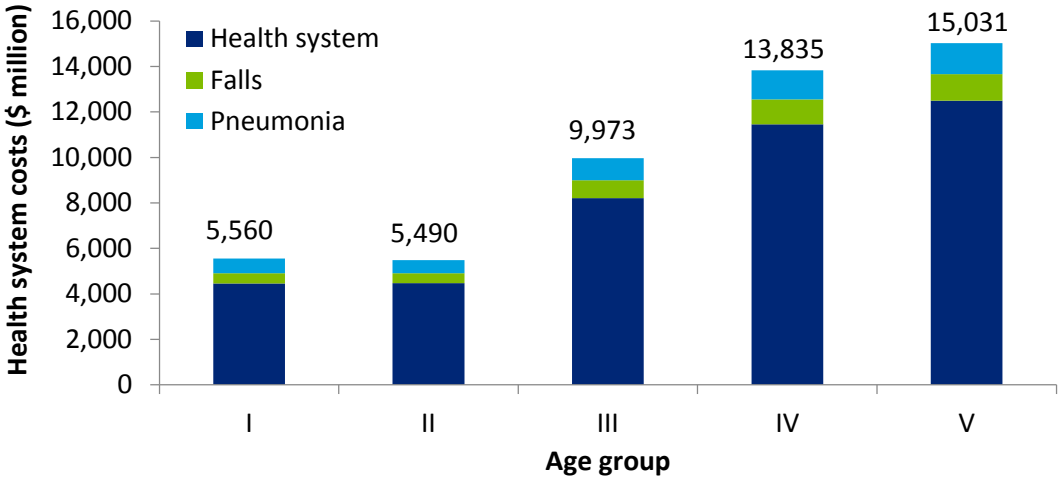
- Cost per PWP was the lowest in the youngest age group of 25-34 years, and the highest in the 75-84 year age group, where residential aged care is the dominant cost element (Chart 5.5).
- Cost per PWP increases with disease stage as expected with the total health system costs per PWP estimated to be around $5,500 in Stage I to over $15,000 in Stage V (Chart 5.6).

**Chart 5.5: Health system costs per PWP, including from falls and pneumonia ($), by age**




Source: Deloitte Access Economics' calculations.

**Chart 5.6: Health system costs per PWP, including from falls and pneumonia ($), by disease stage**

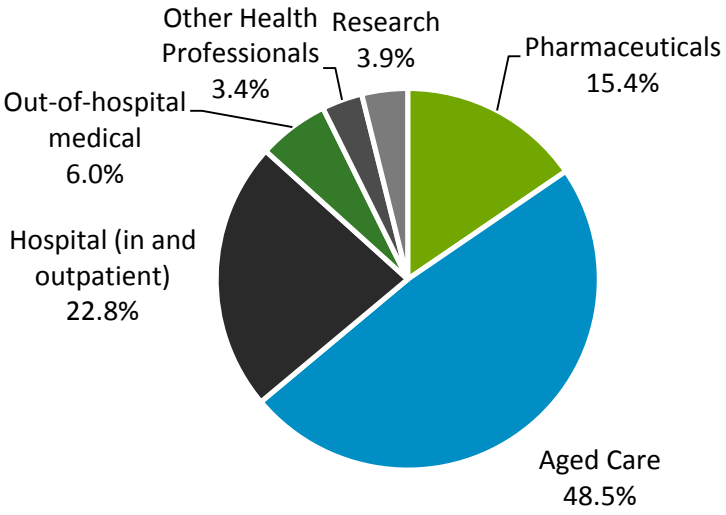



Source: Deloitte Access Economics' calculations.

The health cost profile for PD, including for associated falls and pneumonia, was dominated by residential accommodation or 'aged care' - $275.1 million (48.5%).

- The second largest cost component for PD was hospital costs (22.8% of total costs in 2014 or $129.6 million), while the third largest cost component for PD was pharmaceuticals (15.4% of total costs in 2013 or $87.6 million).
- Unreferred attendances (GPs), imaging and pathology costs and other out-of-hospital medical specialists were $34.0 million (6.0%); and other (allied) health practitioners $19.5 million (3.4%).
- Research into PD is estimated at $21.9 million in 2014 (3.9% of total health expenditure on PD).

**Chart 5.7: Health system costs by cost component, 2014**

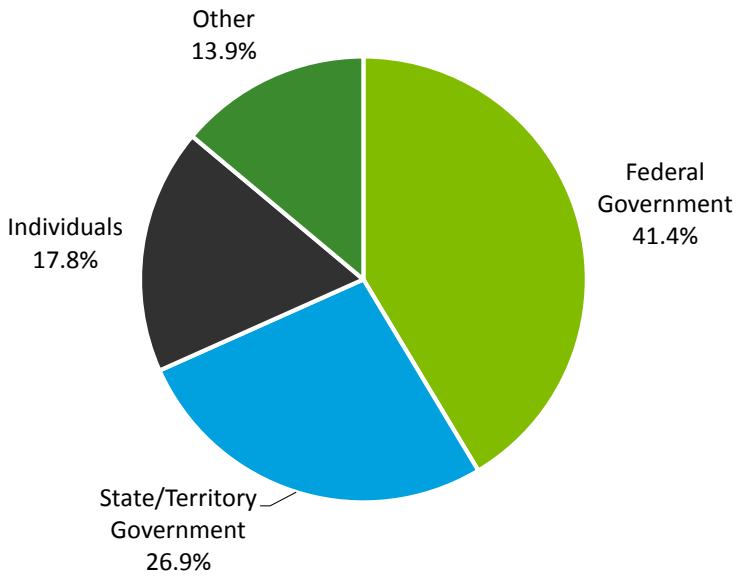



Source: Deloitte Access Economics' calculation based on AIHW (2005).

### Costs by who bears the cost

- Governments bore around two thirds of the health system costs (68.3%), while individuals bore 17.8%, and other parties (private health insurance, charities) bore the remaining 13.9%.

**Chart 5.8: Health system costs, by who bears the cost**




Source: Deloitte Access Economics' calculation based on AIHW (2014).

# 6 Productivity costs

This chapter describes the approach to estimating productivity costs associated with PD in Australia, including a literature review of productivity factors associated with PWP. Productivity costs occur for both PWP and their carers (Chapter 7).

**Key findings:**

- In 2014, the estimated productivity cost of PD was around $182.4 million, of which the most expensive source of productivity loss was premature workforce separation. Compared to 2011 estimates, this represents almost a 70% increase in productivity losses which was predominantly due to a widening employment gap between PWP and the general population.
- The productivity cost of PD borne by workers was around $89.0 million ($1,286 per PWP), an increase from $26.6 million ($500 per PWP) in 2005.
- The productivity cost of PD borne by employers was around $28.1 million ($406 per PWP), an increase from $8.3 million ($200 per PWP) in 2005.
- The productivity cost of PD borne by the government was around $65.3 million ($944 per PWP), an increase from $20.3 million ($400 per PWP) in 2005.

## 6.1 Approach

PD can affect individuals' capacity to work. They may work less than they otherwise would, retire early, be absent from work more often, or die prematurely. If employment rates are lower for people with PD, this loss in productivity represents a real cost to the economy. Additionally, informal carers may also work less or not work entirely in order to care for their loved one with PD, and this represents an additional productivity loss.

Initially, PD may result in lower productivity while at work, which may include reduced hours, lower capacity while at work, restricted activities or changed responsibilities or occupation. Health concerns associated with PD may cause PWP to be temporarily absent from paid employment more often than the general population. Furthermore, these health concerns may result in premature workforce separation or retirement. This is often influenced by economic needs, the workplace environment, and work-life balance factors and sense of worth in the current role. Finally, each of these factors lead to administrative costs.

Using the same approach as for the 2007 and 2011 reports, this report measures the lost earnings and production due to health conditions using a 'human capital' approach. The lower end of such estimates includes only the 'friction' period until the worker can be replaced, which would be highly dependent on labour market conditions and unemployment/underemployment levels. In an economy operating

at near full capacity, a better estimate includes costs of temporary work absences plus the discounted stream of lifetime earnings lost due to early retirement from the workforce, reduced working hours (part-time rather than full time) and premature mortality, if any. These approaches are outlined in Section 6.1.1 and Section 6.1.2.

### 6.1.1 Short run productivity losses

The economic cost of short run productivity losses (temporary absenteeism) are estimated using the friction method. This approach estimates production losses for the time period required to restore production to its pre-incident state, which is when the PWP returns to work, or is replaced. This method generally assumes that there is unemployment, and that a person who was previously not earning an income replaces the person not working due to PD.

In the meantime, employers often choose to make up lost production through overtime or employment of another employee that attracts a premium on the ordinary wage. The overtime premium represents lost employer profits. On the other hand, the overtime premium also indicates how much an employer is willing to pay to maintain the same level of production. Thus, if overtime employment is not used, the overtime premium also represents lost employer profits due to lost production. While productivity remains at the same level, the distribution of income between wages and profits changes. For this study it is assumed that the overtime rate is 40%.

Average employment rates and average weekly earnings are based on ABS data for all calculations on productivity losses.

### 6.1.2 Long run productivity losses

The economic cost of long run productivity losses (premature workforce separation and premature mortality) are estimated using the human capital method. The human capital method estimates production losses based on the remaining expected lifetime earnings for the individual.

A full economic analysis of the effects of a disease on the economy would also examine the long-run situation where the lost productive capacity of the labour force (incurred via the worker or the employer) is passed onto society through adjustments in wages and prices. However, this study assumes that, in the absence of the disease, PWP would participate in the labour force and obtain employment at the same rate as the general Australian population, and earn the same average weekly earnings. The implicit and probable economic assumption is that the numbers of such people would not be of sufficient magnitude to substantially influence the overall clearing of the labour market.

The following methodology is used to estimate lost long run productivity costs.

- The expected retirement age by the current age of the worker is calculated based on the participation rates at each age group. Similar to life expectancy, the older the person, the less time it is expected the person will remain in the workforce but the older they are when they do leave the workforce. Note that this methodology takes into account the probability that the PWP is working.
- As the person ages, the annual income (based on average weekly earnings) is multiplied by the average employment rate at each age group while alive. Income earned at each age is then summed to calculate the expected total income over a person's lifetime (discounted back to present values).

Consequently:

- For permanent disability: the expected remaining lifetime earnings are reduced by the percentage reduction in employment during the period the individual has a lower level of employment.
- For premature death: the entire expected remaining lifetime earnings for the individual are lost. The productivity costs of premature mortality are allocated to the year that the person died.

### 6.1.3 Administrative costs

The employer also incurs administrative costs associated with short run and long run productivity costs.

- Processing employees who take time off work – each day a PWP is temporarily absent from work it is estimated that 2.5 hours of management time is lost processing those absent employees (Health and Safety Executive, 2011). This includes the time of line managers in rearranging work and the time of back office personnel. The value of managers' time is $40 per hour (ABS, 2014b).
- Search, hiring and training replacement workers – premature retirement and premature mortality results in increased employee turnover costs. These costs are estimated to be equal to 26 weeks salary of the incumbent worker (Access Economics, 2004). However this cost is merely 'brought forward' a number of years because there would be some normal turnover of PWP – approximately 15% per annum (which implies that people change jobs, on average, approximately once every 6.7 years (Access Economics, 2004).

## 6.2 Literature review and data analysis

As indicated in the 2007 and 2011 reports, on average between 20% and 29% of PWP retired or were unemployed due to PD (Spate, 1999; Le Pen, 1999; Clarke, 1995). Not surprisingly, however, the rates of retirement and unemployment increased with disease progression. Specifically, Chrischilles (1998) found that only 3.7% of PWP retired or were unemployed during Stage I of the condition, due to the

PD. The proportion rose to more than 35% by Stage IV as indicated in Table 6.1[26, 27]. Even though Chrischilles (1998) was published more than a decade ago, the results remain the most relevant today by presenting results by disease stage. However, there have undoubtedly been changes in retirement patterns in Australia since this study was undertaken. Consequently, the average employment rates for PWP observed in the SDAC (Section 6.2.2) are used in this report.

**Table 6.1: Retired or unemployed due to PD (% of PWP), by disease stage**

| Disease stage: ^ | 1 or 1.5 | 2 | 2.5 | 3 | 4 | Overall |
|---|---|---|---|---|---|---|
| Retired or unemployed due to PD | 3.7% | 29.7% | 23.9% | 50% | 36.4%* | 26.9% |

Note: *Decrease in retirement or unemployment due to PD may be due to proportionally more PWP in Stage IV being older than 65 years than those in earlier disease stages, and thus would have retired by that stage anyway. ^ Disease stages were based on a modified but aligned H&Y staging system where the total number of stages are: 0, 1, 1.5, 2, 2.5, 3, 4, 5; however, in this study no participants were assessed as stage 5.
Source: Chrischilles (1998).

In addition to lower employment rates, PWP may also be temporarily absent from paid employment due to being unwell more often than the average worker (for instance, more bed days). Le Pen (1999) found that, of the 7% of PWP still working (average age 68 years), on average they incurred 4.8 sick days per six months – mainly from fatigue and recurrent falls.

Again the amount of temporary absenteeism would differ according to the individual's disease stage. For example, Chrischilles (1998) found that 'mean bed or restricted days' increased with the disease stage (Table 6.2).

**Table 6.2: Number of bed or restricted days, by disease stage**

| Disease stage^ | 1 or 1.5 | 2 | 2.5 | 3 | 4 | Weighted average |
|---|---|---|---|---|---|---|
| Mean bed or restricted days | 0.8 (1.6) | 4.6 (1.0) | 3.6 (1.2) | 6.4 (1.6) | 7.0 (2.6) | 4.2 |
| Number of respondents | 28 | 76 | 50 | 28 | 11 | |

Note: Standard errors in brackets. ^ Disease stages were based on a modified H&Y system.
Source: Chrischilles (1998).

[26] This finding is also supported by Hagell (2002) who found that initially 37.5% of PWP aged younger than 65 years were working and then five years later only 25% of the same people still aged younger than 65 (but now with a higher level of disability) were working.

[27] No participants were assessed as being stage V in this analysis. Consequently, for the purpose of this report it is assumed that stage V is at least as bad as stage IV. That is, the proportions for stage IV are applied to stage V (see Table 6.3).

While not necessarily directly related to employment, this pattern is assumed to be similar to the likely pattern of the effects of PD on temporary absenteeism by disease stage and is applied to average sick days as in Le Pen (1999) by multiplying them by the ratio of mean bed or restricted days to the weighted average of mean bed or restricted days in Chrischilles (i.e. 4.2).[28]

**Table 6.3: Lost paid and unpaid days, per six months**

| Disease Stage^ | 0.5 to 2.5 | 3 | 4 | 5 | Weighted Average |
|---|---|---|---|---|---|
| Mean bed or restricted days | 3.6 | 6.4 | 7.0 | 7.0 | 4.2 |
| Ratio to average | 0.9 | 1.5 | 1.7 | 1.7 | 1.0 |
| Temporary absenteeism from paid work (days) | 4.1 | 7.3 | 8.0 | 8.0 | 4.8 |

Note: Stages 0.5 to 2.5 are a weighted average of stages 1 or 1.5, 2 and 2.5 based on number of respondents in Chrischilles (1998). ^ Disease stages were based on modified H&Y system.

Source: Deloitte Access Economics' calculation based on Chrischilles (1998) and Le Pen (1999).

The impacts of PD on temporary absenteeism from paid employment will only be applicable to PWP who are still working, which is highly dependent on both age and disease stage. As there are insufficient data to control for comorbidities, it is not known whether the PWP would have experienced temporary absenteeism due to another chronic disease, regardless of the presence of PD. Consequently the estimated costs of temporary absenteeism should be interpreted as costs *associated* with PD rather than costs *due to* PD.

### 6.2.2 Survey of Disability, Ageing and Carers

Ultimately it would be best to use large Australian studies of the general community to identify the impact of PD on productivity. The application of results of the international studies to the Australian context is often limited due to differences in the social security system and access to health care, which impact on the ability for PWP to continue working.

The 2012 Survey of Disability, Ageing and Carers (SDAC) is a national survey conducted by the ABS, from April to December. The primary objective of the survey

[28] While these results are more than a decade old, there is no evidence in the recent literature to contradict the overall average rate found in these studies. For example, Kowal et al (2013) estimated the economic costs associated with PD in the United States, finding that PWP missed 10.9 additional days per year (rather than implicit 11.1 days per year derived in this report). Similarly, Lageman et al (2014) surveyed PWP to determine productivity impacts of PD, and found that PWP missed 1.2 hours of work per week, or 7.8 days per year. Kowal et al (2013) and Lageman et al (2014) did not report their findings by disease stages.

is to collect detailed information about three population groups (ABS, 2014a). They are:

- people with a disability;
- older people (i.e. those aged 60 years and over); and
- people who provide assistance to older people and people with disabilities.

Information was also collected on people who were not in these populations, allowing for comparison of their relative demographic and socioeconomic situations. In addition to people living in private dwellings, those in cared accommodation, such as residential aged care, were also surveyed. Data on long-term health conditions was based on self-identification rather than clinical diagnosis, and time elapsed since diagnosis was not reported. The survey uses questions about activity limitation to screen respondents before asking questions about conditions present, and thus may miss people with PD without activity limitation – for example those in the very early stages of diagnosis. Consequently the SDAC estimate of prevalence is more likely to identify people currently undergoing treatment.

To improve precision because of small survey sample size (i.e. prior to weighting), the overall average employment rate for PWP was calculated. Relative to the general population, it was found that PWP have a lower employment rate of approximately 34%, which was higher than in Chrischilles (1998) of 26.9% (Table 6.1). This proportion was used to estimate the impact of productivity losses due to PD in this report.

## 6.3 Summary of findings

In 2014, the estimated productivity cost of PD was around $182.4 million, of which the most expensive source of productivity loss was premature workforce separation. Compared to 2011 estimates, this represents almost a 70% increase in productivity losses which was predominantly due to a widening employment gap between PWP and the general population.

**Table 6.4: Summary of productivity costs ($ million)**

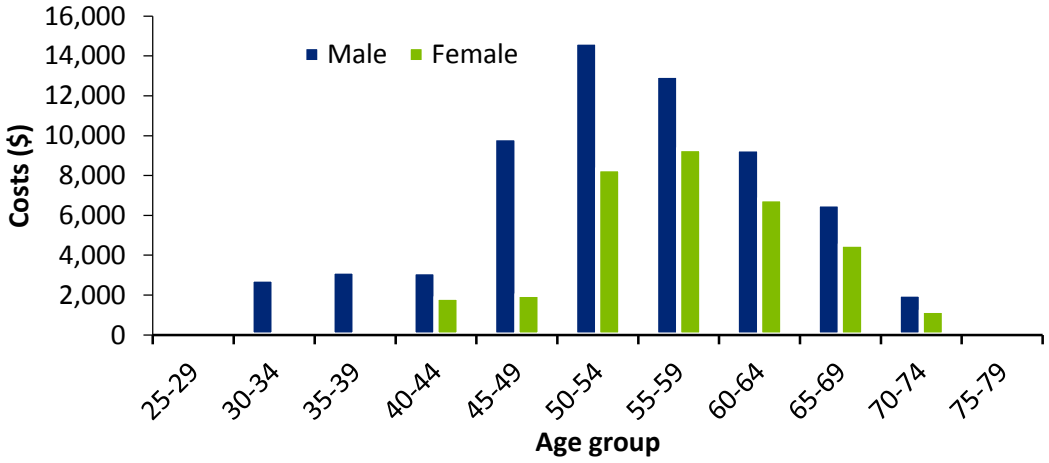
| Source of productivity loss | 2014 $m |
|---|---|
| Temporary absenteeism from work (including management time) | 48.1 |
| Premature workforce separation | 114.4 |
| Premature mortality* | 19.8 |
| Search, hiring and training costs | 0.1 |
| **Total** | **182.4** |

* Includes half of deaths associated with PD.

Source: Deloitte Access Economics' calculations.

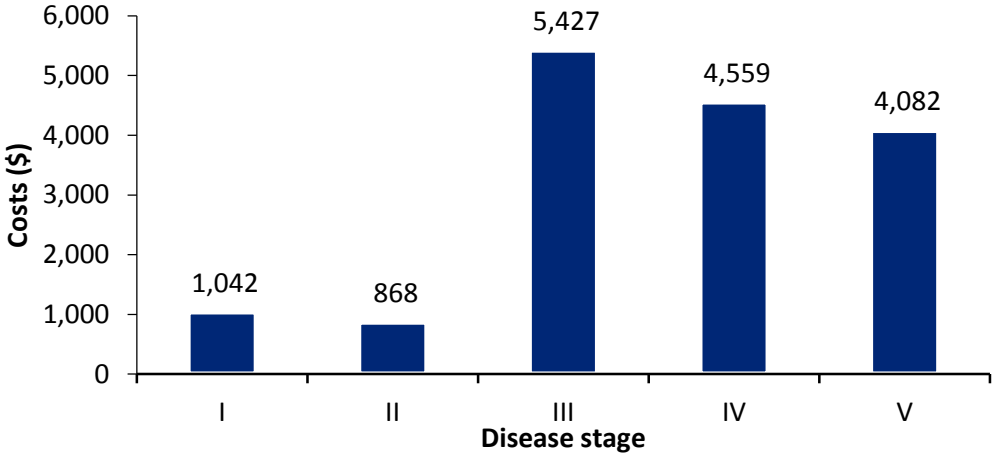
The average productivity cost was around $2,636 per PWP with costs differing significantly by disease stage, age and sex (Chart 6.1 and Chart 6.2). Costs were higher for males than females and peaked at around 50-54 years old. Costs were largest for Stage III of the disease which reflected the fact that PWP in Stages IV and V were mostly above the working age (and their potential productive capacity is lower, regardless of PD).

**Chart 6.1: Productivity costs per PWP ($), by age and sex**




Source: Deloitte Access Economics' calculations

**Chart 6.2: Productivity costs per PWP ($), by disease stage**



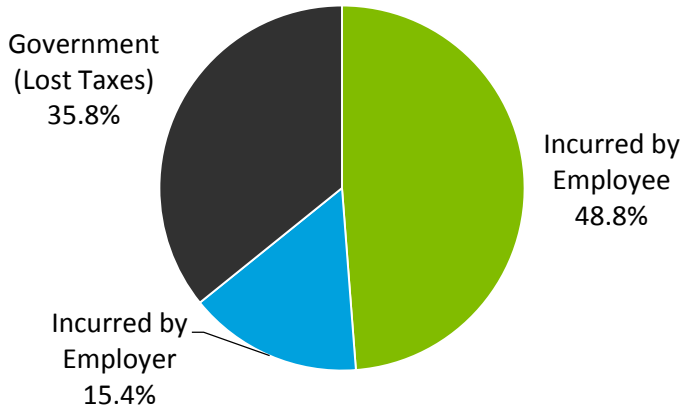

Source: Deloitte Access Economics' calculations.

Productivity costs are shared between the worker, the employer and governments (through tax losses). Post-tax:

- Workers: The productivity cost of PD borne by workers was around $89.0 million ($1,286 per PWP) – largely consisting of lost remaining lifetime earnings due to premature mortality and reduced lifetime earnings of survivors. This has increased from $26.6 million ($500 per PWP) in 2005.

- Employers: The productivity cost of PD borne by employers was around $28.1 million ($406 per PWP) – largely consisting of overtime and management costs of temporary absenteeism, and search, hiring and retraining costs of workers that leave paid employment. This has increased from $8.3 million ($200 per PWP) in 2005.
- Governments: The productivity cost of PD borne by the government was around $65.3 million ($944 per PWP) – entirely consisting of lost taxation revenue. This has increased from $20.3 million ($400 per PWP) in 2005.

**Chart 6.3: Distribution of productivity costs**




Source: Deloitte Access Economics' calculations.

The productivity costs associated with PD have increased substantially since 2005, both overall and per PWP. This reflects both increases in the prevalence of PD, and changes to the data underlying the productivity cost calculations. For example, the increased chance of being unemployed found in the SDAC data results in a substantial increase in premature workforce separation costs, while changes to the amount of time managers spend searching for and replacing staff account for a large change in temporary absenteeism costs.

**Table 6.5: Comparison of productivity costs, 2005 and 2014 ($ million)**

| Source of productivity loss | 2005 $m | 2014 $m | % change |
|---|---|---|---|
| Temporary absenteeism from work (including management time) | 15.3 | 48.1 | 214 |
| Premature workforce separation | 33.1 | 114.4 | 246 |
| Premature mortality* | 6.8 | 19.8 | 191 |
| Search, hiring and training costs | 0.02 | 0.1 | 400 |
| **Total** | **55.2** | **182.4** | **230** |

* Includes half of deaths associated with PD.

Source: Deloitte Access Economics' calculations.

# 7 Informal care costs

This chapter reviews the available data on the amount of time carers provide to PWP, and estimates the costs associated with this time. Carers are people who provide informal care to others in need of assistance or support. Most informal carers are family or friends of the person receiving care. Carers may take time off work to accompany PWP to medical appointments, stay with them in hospital, or care for them at home. Carers may also take time off work to undertake many of the unpaid tasks that the PWP would do if they did not have the disease and were able to do these tasks.

**Key findings:**

- In 2014, there were an estimated 10,150 carers of PWP, of which, around 1,560 carers were of working age. These carers provided around 19.0 million hours of care in 2014 – equivalent to around 275 hours per PWP per annum across all PWP.
- In 2014, the total carer costs in Australia for PD was $78.2 million, based on the opportunity cost estimation approach. The value of informal care has increased from $5.4 million, or $100 per PWP, in 2005 – primarily due to a rise in the number of carers (31%) and an increase in the opportunity cost of carers' time.

## 7.1 Methodology

The impact of PD on the ability to perform everyday tasks, mental health, cognitive and social functioning and the ability to communicate to others, progressively restricts the PWP's independence and leads to increasing dependence on carers – either from family carers or though the community care sector. Role changes within families are not uncommon. Other family members often may assume tasks previously the responsibility of the PWP, including gardening, housework, driving, shopping, childcare, handling finances, motor vehicle maintenance, and entertaining at home. This may mean the acquiring of appropriate skills by the carer. Children may also have to assume a 'parental' role in caring for a parent with PD.

Many studies identified in the literature review examined the ability of PWP to perform ADL. Bathing and walking are typically identified as the ADL with which PWP have the most problems (Whetten-Goldstein, 1997, and Rubenstein, 2001) and many PWP also experience difficulties eating (Whetten-Goldstein, 1997).

As PD progresses PWP increasingly require help with their ADL (see Table 7 2).

**Table 7.1: Ability to perform activities, by disease stage (% of PWP)**

| | 1 or 1.5 | 2 | 2.5 | 3 | 4 |
|---|---|---|---|---|---|
| Activities of Daily Living (ADL) | | | | | |
| Difficulty with at least one | 25.0 | 48.7 | 72.0 | 64.3 | 27.3 |
| Help with at least one | 0.0 | 2.6 | 2.0 | 25.0 | 72.7 |
| Inability to perform certain activities | 33.3 | 54.7 | 62.2 | 78.6 | 81.8 |

Note: Given the definition of Stage V, it is assumed that 100% of PWP in Stage V require help.

Source: Chrischilles (1998)

PD carers tend to be the similarly aged spouses of the PWP (or sometimes grown up children) and thus PD carers are older on average (66 years (Dunn and Hammond, 1999)) than the typical carer in Australia (47.6 years (Access Economics, 2005a)). Consequently the age/gender distribution of PWP receiving informal care is likely to match the age/gender distribution of carers. Informal care is distinguished from services provided by people employed in the health and community sectors (formal care) because the care is generally provided free of charge to the recipient and is not regulated by the government.

While informal care is provided free of charge, it is not free in an economic sense, as time spent caring is time that cannot be directed to other activities such as paid work, unpaid work (such as housework or yard work) or leisure. As such, informal care is a use of economic resources.

There are three potential methodologies that can be used to place a dollar value on the informal care provided.

- Opportunity cost is the value of lost wages forgone by the carer.
- Replacement valuation is the cost of buying a similar amount of services from the formal care sector.
- Self-valuation is what carers themselves feel they should be paid.

The self-valuation method is not commonly used, as there are no reliable Australian studies of the amount Australian carers feel they should be compensated. Estimates of the value of informal care are very sensitive to the estimation methodology used. In this study and consistent with 2007 and 2011 studies, Deloitte Access Economics has adopted the opportunity cost method as it provides the most accurate estimate of carer costs based on average weekly earnings.

## 7.2 Estimating cost of informal care

### Number of primary carers

The SDAC data provides the most recent and comprehensive profile of Australians with health conditions and disability, and the people who provide them with

assistance and support (see Section 6.2.2). As highlighted earlier, to improve precision, the number of carers and care hours are analysed at the aggregate level. According to SDAC, there were 9,560 primary carers of PWP in 2012 and adjusting for prevalence growth, this was equivalent to around 10,150 carers in 2014.

The number of carers was further apportioned using a similar distribution as for the 2007 and 2011 reports to obtain the number of carers by age, sex and disease stage, which was required to estimate the opportunity cost of their time spent on caring for PWP. In doing so, **it was estimated around 1,558 carers were of working age.**

PWP in Stage IV were more likely to receive informal care than all of the other stages due to the high level of disability at this stage and their lower likelihood than in Stage V of receiving help in a residential aged care setting. While all PWP in Stage V receive informal care when they are not in residential aged care, only 25% reside outside a residential aged care setting. In contrast, and despite the high level of disability experienced by PWP in Stage IV, only 23% do reside in a residential aged care setting. Thus, there are many more informal carers for PWP in Stage IV than there are in Stage V.

**Table 7.2: Carers of PWP, by disease stage**

| Disease stage | Number of carers | Carers per 100 PWP |
|---|---|---|
| Stage I | 0 | 0 |
| Stage II | 397 | 2 |
| Stage III | 3,625 | 23 |
| Stage IV | 5,092 | 56 |
| Stage V | 1,034 | 25 |
| **Total/average** | **10,147** | **15** |

Note: components may not sum to total due to rounding.

Source: Deloitte Access Economics' calculations.

## Time spent caring for PWP

SDAC only reported hours of informal care provided per week for primary carers. The total number of informal care hours was obtained at the aggregate level (rather than by age and sex), for greater precision due to standard errors in the smaller groups. According to SDAC, the average number of hours provided to PWP was around 36.1 hours per week. This is similar to the number of carer hours provided in the UK (Parkinson's Disease Society, 2009), i.e. 39 hours per week, using a similar calculation approach as noted in Table 7.3. In Australia, carers provided around 19.0 million hours of care in 2014 – equivalent to around 275 hours per PWP per annum across all PWP i.e. those who received informal care and those who did not.

**Table 7.3: Total hours of informal care provided to PWP**

| | Person |
|---|---|
| <20 hours per week | 25.2% |
| 20-39 hours per week | 18.0% |
| 40+ hours per week | 56.8% |
| Average hours per week | 36.1 |

Note: 9.5, 29.5, and 50 hours per week was imputed in the <20 hours, 20-39 hours, and 40+ hours per week groups, respectively.

Source: Source: ABS (2014a).

## 7.3 Summary of informal care costs

Overall in 2014, informal care provided to PWP cost around $78.2 million, or $1,130 per PWP. This represents $4.12 per hour of informal care, since an opportunity cost approach based on whether carers would be working otherwise, is used. It is not a replacement valuation approach, which would yield a higher cost estimate (Section 12.3).

- Carers (post-tax) bore around $50.2 million ($725 per PWP) while the government bore the remaining costs through lost taxation revenue ($28.0 million, or $404 per PWP).
- The cost of informal care is the highest for PWP in Stage IV (around $4,310 per PWP) due to the higher likelihood of requiring care but the lower chance of being in residential aged care.

In 2014, the total carer costs in Australia for PD was $78.2 million, based on the opportunity cost estimation approach. The value of informal care has increased from $5.4 million, or $100 per PWP, in 2005 – primarily due to a rise in the number of carers (31%) and an increase in the opportunity cost of carers' time.

# 8 Other financial costs

In addition to productivity costs, there can be other less burdensome (but still material) costs, such as the costs of respite for informal carers, costs of formal care, mobility aids, modifications to the homes or vehicles of PWP, travel and accommodation costs to health services, the cost of other government programs, and funeral costs.

**Key findings:**

- PWP spend around $610 on aids per person per year, on average, and around $200 on formal care, accommodation and travel costs per person per year, on average. Overall, the cost of other financial costs for PWP was estimated to be around $63.1 million in 2014.
- Other financial costs have increased by 56% since 2005, primarily due to increased rates of accessing respite services, increased use of formal care (based on literature estimates), and varying costs and usage patterns for aids and modifications.

## 8.1 Out-of-pocket expenses

### 8.1.1 Use of aids and modifications

In the early stages of the disease, many PWP are able to perform their ADL and remain independent. However, as symptoms worsen over time their ability to perform these activities becomes restricted (such as getting in and out of a bathtub, standing up from a chair, or walking). Aids and modifications help PWP in performing these activities to remain independent for as long as possible.

According to the 2012 SDAC survey, it was found that 50% of PWP with a disability used a mobility aid. This was approximately 2.4 times higher than the general population (Table 8.1). It is interesting to note that the mobility aid usage of both PWP and others has almost doubled since 2005. In 2005, 27% of PWP used a mobility aid while 8% of others used one. The figures have increased to 50% and 15% in 2012 respectively.

**Table 8.1: Use of mobility aids by persons with a disability**

| | PWP | Others | Difference | T-Stat |
|---|---|---|---|---|
| Male | 51.7% | 11.9% | 335% | 10.29 |
| Female | 48.0% | 17.3% | 177% | 5.48 |
| **Persons** | **50.0%** | **14.7%** | **240%** | **9.37** |

Source: ABS (2014a).

More recent literature such as Giles et al (2015) and Matinolli et al (2009) also reported the use of mobility aids by PWP. According to these articles, around 33.6% to 38% used a mobility aid. Where usage in the general population was reported or could be analysed, this was used to calculate the odds ratio for the use of aids and modifications for PWP. The 2012 SDAC data showed that PWP with a disability were 2.4 times more likely to use aids and modifications than the general population, with the range being 1.7 and 3.8 for each type of aid or modification. Including previous literature such as Rubenstein et al (1997), Whetten-Goldstein (1997) and Chrischilles (1998), the average proportion of PWP using aid and modification, is found in Table 8.3.

**Table 8.2: Use of aids and modifications by type**

| Type of aid/ modification | Usage (%) | | | | | |
|---|---|---|---|---|---|---|
| | SDAC (2012) | Chrischilles (1998) | Rubenstein (1997) | Whetten-Goldstein (1997) | Giles et al (2015) | Matinolli et al (2009) |
| Any mobility aid | 50.0% | | | | 38.0% | 33.6% |
| Walker, cane or crutches | 37.2% | 28% | 38.1% | 40.2% | | |
| Wheelchair | 20.7% | | 38.1% | | | |
| Grab bars or railings | 13.6% | 40% | 21.4% | | | |
| Shower seats or raised stools | 14.1% | 20% | 23.8% | | | |
| Raised toilet | 14.1% | | 19.1% | | | |
| Portable toilet | 14.1% | | 11.9% | | | |

Source: Deloitte Access Economics' calculations based on indicated survey and articles.

**Table 8.3: Additional use of aids and modifications by type**

| | Average | | Additional usage |
|---|---|---|---|
| | Usage | OR | |
| Walker, cane or crutches | 35.8% | 2.84 | 19.4% |
| Wheelchair | 32.6% | 4.01 | 21.8% |
| Grab bars or railings | 25.0% | 2.45 | 13.0% |
| Shower seats or raised stools | 19.3% | 5.01 | 14.8% |
| Raised toilet | 16.6% | 5.21 | 12.9% |
| Portable toilet | 13.0% | 3.86 | 9.3% |

Source: Deloitte Access Economics' calculations.

Further to the discussion in the 2007 report, Hely et al (2005), an Australian study, found that urinary incontinence became more frequent with increasing disease stage – from 14% in Stage II to 62% in Stage V. While no PWP were catheterised, some used urodomes or pads. In a later study, Hely et al (2008) found that urinary incontinence had increased to 71% in Stage V for the same cohort five years later. The range 14% to 71% was used to determine the use of incontinence pads by disease stage. On average, it was assumed that eight incontinence pads were used per day.

Table 8.4 presents the average cost of aids per year by disease stage. As expected the average cost of aids for PWP at Stage I of their condition was only $63 per annum, while at Stage V, the annual cost could be as high as $2,349.

**Table 8.4: Average cost of aids per year, by disease stage**

| Aid | Average cost per person per year | Additional usage by disease stage | | | | |
|---|---|---|---|---|---|---|
| | ($) | I | II | III | IV | V |
| Walker, cane or crutches | 128 | 13% | 18% | 28% | 30% | 30% |
| Wheelchair | 206 | 15% | 20% | 32% | 34% | 34% |
| Grab bars or railings | 44 | 9% | 12% | 19% | 20% | 20% |
| Shower seats or raised stools | 63 | 10% | 14% | 21% | 23% | 23% |
| Raised toilet | 60 | 9% | 12% | 19% | 20% | 20% |
| Incontinence Pads | 3,100 | 0% | 14% | 33% | 52% | 71% |
| Wheelchair Maintenance | 10 | 15% | 20% | 32% | 34% | 34% |
| **Average Cost per Year ($)** | | **63** | **522** | **1,160** | **1,760** | **2,349** |

Note: The average cost and expected longevity of the aid is calculated using cost information obtained from Daily Living Products online and Chemist Warehouse online.[29] An additional 5% for wheelchair maintenance is assumed.

Source: Deloitte Access Economics' calculations.

Applying the average cost per year per PWP to the number of PWP not in residential aged care yields a **total cost of aids and modifications of $42.1 million in 2014**. In 2011, the cost was estimated to be $51.4 million. This fall in cost was largely due to a lower unit price for some types of aids.

### 8.1.2 Use of formal care, accommodation and travel costs

The costs associated with formal care, accommodation and travel are also important for many PWP. These involve additional assistance that is provided to

[29] http://www.daily.com.au/ and http://www.chemistwarehouse.com.au/, accessed on 27 January 2015.

supplement informal care that is already provided by family and friends. The additional assistance can include help with childcare, housekeeping, gardening, shopping and private nursing that is not covered by private health insurance or the government. This assistance helps PWP to remain living at home. These costs are out-of-pocket expenses borne by the individual and their family.

Travel and accommodation costs are incurred as PWP travel to their nearest specialist to attend appointments or obtain medications. These costs are frequent and costly for those living locally and in more remote areas, and can involve nights away from home. Depending on the level of disability, a carer may also need to accompany the person. Examples of travel costs incurred may include petrol, maintenance, accommodation, meal costs and luggage costs.

As in the 2007 and 2011 reports, the literature review did not identify any Australian studies that examined additional formal care, travel and accommodation costs due to PD. Three international studies were identified that reported travel costs and formal care.

- Spottke et al (2006) found that home help/social services and transportation cost an additional 0.6% compared to total medical costs incurred by the statutory health insurance authority (excluding PWP's contribution to these costs).
- Kowal et al (2013) in a study of economic costs of PWP in the United States found that formal care accounted for 2.65% of total direct costs. Travel costs and home modifications accounted for 3.8% of total direct costs, however no split between these components was provided, and travel costs were excluded.
- Wang et al (2006) in a study of economic costs of PWP in Shanghai found that transportation costs accounted for 2.67% of total direct medical costs. Wang et al also reported on formal care costs; however, their definition included more than just home help services, and was therefore excluded for the purpose of this report.

Taking an average of the formal care costs reported in Spottke et al (2006) and Kowal et al (2013), formal care costs accounted for 1.47% of total direct medical costs. Similarly, taking an average of Spottke et al (2006) and Wang et al (2006), transportation costs accounted for 1.49% of total direct medical costs (Table 8.5).

**Table 8.5: Cost of formal care and transport costs per PWP**

| Cost | Cost of home help | Formal care % of total direct costs | Transport costs | Transport % of total direct costs |
|---|---|---|---|---|
| Spottke et al (2006) (EUR) | 10 | 0.3% | 10 | 0.3% |
| Kowal et al (2013) (USD) | 339 | 2.65% | - | - |
| Wang et al (2006) (RMB) | - | - | 115 | 2.67% |
| **Average % of total direct costs** | | **1.47%** | | **1.49%** |

Source: Deloitte Access Economics' calculations.

Together formal care and transportation represent around 3.0% of total direct health system costs. This is applied to the per person health system costs reported in Table 5.4 and Table 5.7 and multiplied by the number of PWP not in residential aged care (60,748 people in 2014[30]). **The total costs of formal care and transportation are estimated to be $13.9 million in 2014, or $200 per PWP.**

### 8.1.3 Summary of out-of-pocket expenses

Many PWP are older and already receive help in an aged care residential setting and thus do not pay for many aids and modifications, formal care, accommodation and travel costs. Therefore, to estimate the proportion of people incurring these types of costs by age, gender and disease stage (and to avoid double counting with health system costs) the proportion of people receiving care in an aged care residential setting must be excluded.

The proportion of people likely to be receiving care in an aged care residential setting is estimated based on the age-gender distribution in each disease stage and residential aged care data from the AIHW (2012). The remaining PWP not in an aged care residential setting incur aids costs as contained in Table 8.4, and formal care, accommodation and travel costs as contained in Table 8.5.

**Overall PWP spend around $610 on aids per person per year, on average, and around $200 on formal care, accommodation and travel costs per person per year, on average.**

- Overall this represents around 10% of total health system costs per year, a slight decrease from 11% in 2005. This reduction is primarily due to changing usage patterns and lower unit prices for certain types of aids.

[30] This is derived as the difference between total prevalence (Section 3.1) and the number of people in residential aged care (Section 3.4).

# 8.2 Government programs

## 8.2.1 Palliative care

Palliative care is the specialised care provided for people who are dying from active, progressive and far-advanced diseases, with little or no prospect of cure. The aim of palliative care is to achieve the best possible quality of life, both for the person who is dying and for their family.

Table 8.6 presents the Federal and State Government funding for palliative care, based on available information. According to their respective budget statements and/or annual reports, it was budgeted that the funding for palliative care would be around $378.1 million for the year 2014.

**Table 8.6: Federal and State Government funding for palliative care**

| | Total Funding | Funding in 2014 ($m) |
|---|---|---|
| Federal government | $33.8 million in 2013-14 | 33.8 |
| NSW Ministry of Health | $86 million in 2011-12 + $35 million over four years (2012-2016) | 99.1 |
| Queensland Health | $51.3 million in 2010-11 + $17 million in 2011-12 (Federal) + $47 million over 3 years (2011-2014) | 88.3 |
| Victorian State Government | $108 million in 2011-12 | 113.5 |
| Western Australia State Government | $30.6 million in 2013-14 | 30.6 |
| Tasmanian Health Assistance Package | $63.2 million over four years (Federal) (2014-2018) | 15.8 |
| **Total funding** | | **381.1** |

Source: DoH (2010), NSW Ministry of Health (2012), Queensland Health (2012), Palliative Care Victorian Inc. (2012), Government of Western Australia (2014), DoH (2014).

Because the total amount of funding going into palliative care was not specifically for PD only, a similar method as per the 2007 and 2011 reports was utilised to allocate a proportion of the funding to PD. Specifically, the following assumptions were made.

- 0.1% of people who received specialist palliative care was due to PD (McNamara et al, 2004);
- 78% of palliative care services reported the use of volunteer services (Palliative Care Australia, 1998); and

- Number of volunteer hours per week received by each palliative care service was 35.7 (Palliative Care Australia, 1999).

> The total value of community based palliative care services for PD was estimated to be around $0.36 million. However, this value is still likely to be conservative as it excludes palliative care services in the Northern Territory, Australian Capital Territory and South Australia.

While the value of palliative care services has increased substantially compared to the 2011 estimate (i.e. $83,000), this was primary due to the fact that more funding sources were included in the 2014 calculation with the availability of new information.

### 8.2.2 National respite for carers program

Respite for carers of PWP is often required when:

- The carer is undergoing hospital in-patient treatment;
- The burden of caring psychologically overwhelms the carer or PWP;
- Home modifications is being undertaken;
- The carer needs time to shop, socialise, or undertake recreational activities as a break from the burden of caring.

The National Respite for Carers Program (NRCP) enhances the quality of life for older people, people with disabilities, and their carers. The NRCP provides services for at-home carers of people who are unable to look after themselves due to frailty, disability, or chronic illness (most PWP would eventually fall into this category). There are four components of the NRCP (Australian Government Department of Social Services, 2014a):

- Commonwealth Respite and Carelink Centres, which provide information, support and assistance to carers to arrange respite services in the short term;
- Respite Services, which provide ongoing and planned respite for carers and care recipients;
- National Carer Counselling Programme, which provides counselling, emotional and psychological support services to carers; and
- Carer Information Support Service, which provides information and support to carers surrounding the community care system.

Funding for the NRCP was $212 million in 2013-14 (Steering Committee for the Review of Government Service Provision, 2015). According to the 2012 SDAC survey as described in Section 6.2.2, there were a total of 749,016 primary carers in Australia, of which 9,560 were carers of PWP (1.3%). The survey also reported that the rate of accessing respite in the last three months for carers. A total of 42,500 carers accessed respite, of which 1,200 were carers of PWP (2.8%). Applying this

proportion to the total NRCP expenditure in 2014, **the expenditure on respite for carers of PWP was $5.9 million, or $580 per carer**.

### 8.2.3 Home assistance programs

There are other government programs that provide assistance to frail older people and to people with a disability, aimed at allowing them to stay in their homes longer and preventing premature admissions to residential aged care. Table 8.7 outlines the differences between Home and Community Care (HACC) and Home Care Packages. According to the Steering Committee for the Review of Government Service Provision (2015), funding for these programs was $2.06 billion and $1.27 billion in 2014 respectively.

**Table 8.7: Distinctions between the Home and Community Care and Home Care Packages**

| | HACC | Home Care Packages Program |
|---|---|---|
| Range of services[a] | Maintenance and support services | Tailored low to high level care packages |
| Relationship to residential care | Aims to prevent premature or inappropriate admission | Substitutes for low/high care residential places |
| Eligibility | Aged Care Assessment Team assessment not mandatory | Aged Care Assessment Team assessment mandatory |
| Funding | Funded by the Australian Government and client contributions[d] | Funded primarily by the Australian Government and client contributions. State and Territory governments fund younger people on these services |
| Target client groups[b] | Available to frail older people with a greater range of care needs. Not age specific in Victoria and Western Australia | Targets people with care needs similar to low or high level residential care |
| Size of program | $2.06 billion funding in 2013-14<br>At least 775,989 clients in 2013-14[c] | $1.27 billion funding in 2013-14<br>Approximately 66,954 operational places at 30 June 2014. |

**Note:** [a] HACC services such as community nursing, can be supplied to someone receiving Home Care levels 1-2 when additional nursing services are required to support the consumer to remain living at home. [b] Most HACC recipients at the lower end of the scale would not be assessed as eligible for residential care — for example, an individual may receive only an hour of home care per fortnight. At the higher end, some people have levels of need that would exceed the level available under a Home Care place. [c] The total number of clients is higher than those reported. [d] The Victorian and Western Australian state governments also provide funding for HACC.
Source: Adapted from Steering Committee for the Review of Government Service Provision (2015).

However, as there was no information available on the use of these programs by PWP, in line with 2007 and 2011 studies, costs associated with these programs were excluded.

### 8.2.4 Other government support programs

Other government support programs include the National Disability Insurance Scheme (NDIS) and assistance for PWP to return to work provided by the Disability Employment Services (DES) and Employment Assistance and Other Services programs.

#### 8.2.4.1 National Disability Insurance Scheme

The NDIS supports people with disability where that disability prevents participation in everyday activities. NDIS packages are designed to help people with disability achieve goals such as independence, community involvement, education, employment and health and wellbeing. The NDIS is designed to give more certainty, choice and control surrounding supports for people with disability (National Disability Insurance Agency, 2014). The NDIS commenced in July 2013, with a number of trial sites around Australia. The roll out of the full scheme is expected to commence from July 2016 (National Disability Insurance Agency, 2014a). All people who are able to access support under the current National Disability Agreement are covered by the NDIS, and the NDIS is intended to replace the current system (Buckmaster, 2013).

At the end of 2013-14, there were only two trial sites for the NDIS that would cover PWP, and expenditure from the NDIS was small. This was due to the limited sites involved. Further, publicly available data does not provide an indication of how many PWP were covered by the NDIS. As such, no estimates of the cost of packages for PWP are made here. However, as a guide, data from the National Disability Insurance Agency (2014b) shows the total estimated expenditure for primary disability due to 'other neurological' diseases in 2013-14 was $18.5 million, while the average annual cost of a plan was $43,149.

#### 8.2.4.2 Disability Employment Services (DES) and Employment Assistance and Other Services

The DES program and the Employment Assistance and Other Services program are the primary programs that support PWP to return to work in Australia. DES began in 2010 and targets support at individuals with a substantially reduced capacity for work who are assessed as needing specialist support to build capacity or maintain employment. The objective of the program is to help individuals with disabilities, injuries or health conditions to secure and maintain employment. While DES helps individuals to find work, the Employment Assistance and Other Services program targets support at employers to employ individuals with disabilities. This is comprised of programs such as the Employment Assistance Fund, Supported Wage

System, Wage Subsidy Scheme, and National Disability Recruitment Coordinator. As an example, these programs fund work related modifications and services such as awareness training, modifications to work vehicles, and adaptive equipment amongst other funding.

In 2013-14, funding for the DES and Employment Assistance and Other Services program was $515.3 million (Australian Government Department of Social Services, 2014; Australian Government Department of Employment, 2014). Unfortunately, there is no publicly available data for either program that details how many PWP are assisted by these programs. Consequently, no estimate of the expenditure on PWP can be provided.

## 8.3 Funeral expenses

The 'additional' cost of funerals borne by family and friends of PWP is based on the number of deaths due to PD. However, some PWP would have died during this time anyway, and eventually everyone must die, and thus incur funeral expenses – so the true cost is the cost brought forward (adjusted for the likelihood of dying anyway). The BTRE (2000) calculated a weighted average cost of a funeral across all States and Territories, to estimate an Australian total average cost of $3,200 per person for 1996, or $5,089 per person in 2014. **The discounted value of funeral costs associated with premature deaths was $0.9 million, or $488 per death due to PD**.

## 8.4 Other financial costs summary

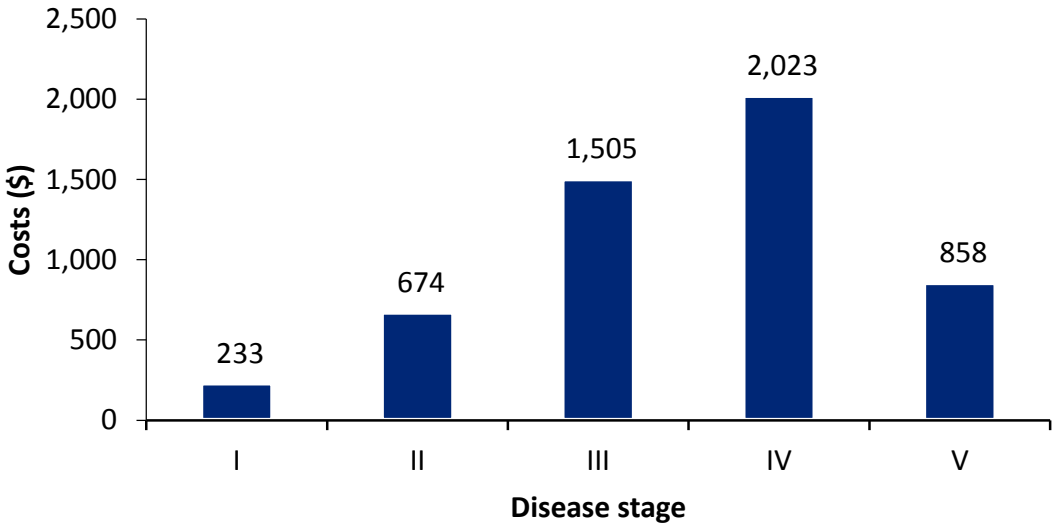
**Overall, the cost of other financial costs for PWP was estimated to be around $63.1 million in 2014**, of which the main cost component was aids and modifications followed by formal care (Table 8.8). The average cost per person was around $912 per PWP and it peaked in Stage IV before many people were admitted to residential aged care (see Section 3.4). Individuals bore almost all of these costs (89%).

**Table 8.8: Other financial costs of PD ($m), 2014**

| | Annual cost ($m) |
|---|---|
| Aids and modifications | 42.1 |
| Formal care | 13.9 |
| Palliative care | 0.4 |
| Respite | 5.9 |
| Funeral costs | 0.9 |
| **Total** | **63.1** |

Source: Deloitte Access Economics' calculations.

**Chart 8.1: Indirect costs per person ($), by disease stage**




Source: Deloitte Access Economics' calculations.

These costs have increased since 2005, primarily due to increased rates of accessing respite services, increased use of formal care (based on literature estimates), and varying costs and usage patterns for aids and modifications.

**Table 8.9: Comparisons of other financial costs of PD ($m), 2005 and 2014**

| | 2005 ($m) | 2014 ($m) | % change |
|---|---|---|---|
| Aids and modifications | 36.5 | 42.1 | 15 |
| Formal care | 1.3 | 13.9 | 960 |
| Palliative care | 0.1 | 0.4 | 300 |
| Respite | 2.1 | 5.9 | 181 |
| Funeral costs | 0.6 | 0.9 | 50 |
| **Total** | **40.5** | **63.1** | **56** |

Note: % change may differ from actual values due to rounding.

Source: Deloitte Access Economics' calculations.

# 9 Transfers

Transfer payments represent a shift of resources from one economic entity to another, such as raising taxes from the entire population to provide welfare payments to PWP. The act of taxation and redistribution creates distortions and inefficiencies in the economy, so transfers also involve real net costs to the economy, known as deadweight losses.

Transfer costs are important when adopting a whole-of-government approach to policy formulation and budgeting. Transfer costs also allow us to examine the distribution of the costs of PD across different parts of society.

There are a number of income support payments available to PWP and their carers. The main sources are the Disability Support Pension (DSP) for PWP, and the Carer Allowance and Carer Payment for carers of PWP.

**Key findings:**

- Approximately $60.7 million in additional welfare payments are paid to working age PWP – or $4,984 per working age PWP.
- PWP lost $138.6 million in wage income due to long-term lost earnings, unpaid temporary absenteeism and premature death. Carers lost $78.2 million in wage income due to caring for PWP. Employers lost $43.8 million in production value on account of absenteeism of the carer, lost management productivity in managing the absenteeism, and direct worker hiring and retraining costs. The lost tax revenue associated with the lower income and revenue was $93.3 million in 2014.
- The deadweight loss associated with health system costs borne by government, lost taxes, welfare payments and other costs borne by government was $173.5 million in 2014, an increase from $82.8 million in 2005.

## 9.1 Income support for PWP

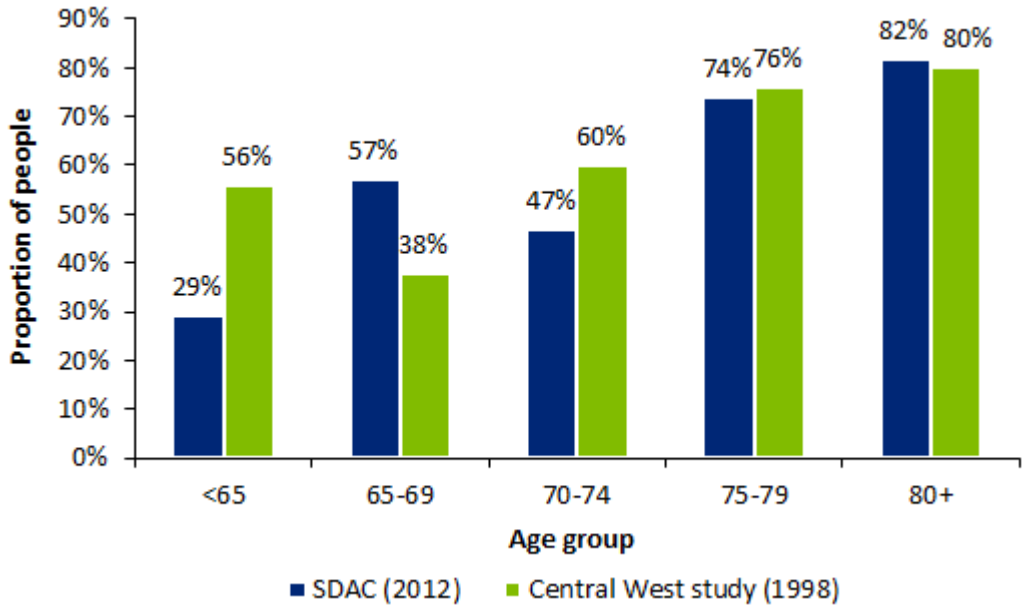
The main source of income support for PWP is the DSP. This is payable to people aged less than 65 years. People aged 65 years and above are eligible for the age pension, but following the method in the 2007 and 2011 reports, this section will focus only on people aged less than 65 who would be receiving the DSP.

In the earlier studies, the proportion of PWP who received DSP was based on the findings from the 1999 Living with Parkinson's Disease in the Central West NSW Study (Dunn and Hammond, 1999). This study surveyed 101 PWP and 69 carers of PWP recruited through local networks of medical practitioners, community-based organisations, hospitals, aged care groups and the local media. The study found

that 56% of PWP aged 55 to 64 year received income support, and that this increased with age. However, based on 2012 SDAC survey, only 29% of PWP under 65 years of age received income support. The proportion of PWP receiving income support appeared to have shifted from younger to older people in the last decade when comparing the two datasets (Chart 9.1).

Using the latest 2012 SDAC survey findings, it was estimated that around 3,545 (out of 12,181) PWP aged less than 65 years of age received income support in 2014. While the number of PWP receiving DSP has decreased, the income support amount appeared to have increased. According to the Department of Social Services' annual report, as of June 2014, there were 827,460 people in Australia who were listed to have received the DSP, at a total cost of $16.1 billion over 2013-14, or $19,469 per person (Department of Social Services, 2014). Subsequently, applying this per person amount, **around $69.0 million in DSP payments were paid to PWP in 2014**.

**Chart 9.1: PWP receiving income support (% of PWP)**




Source: ABS (2014a) and Dunn and Hammond (1999).

However, some of these people would have received DSP payments even in the absence of PD, which must be netted out to estimate the *additional* welfare payments due to PD, using a Melbourne University study (Tseng and Wilkins, 2002) about the 'reliance' of the general population (aged 15-64 years) on income support, of 12% (Table 9.1).

**Table 9.1: Welfare payments to PWP, 2014**

| | Average reliance (%) | | | |
|---|---|---|---|---|
| | Males | Females | Persons* | Additional payments ($m) |
| Disability support | 10.2 | 14.9 | 12.0 | 60.7[31] |

* Weighted average based on statistics on demographics of income support customers.

Sources: Department of Social Services (2014) and Tseng and Wilkins (2002).

**Thus around $60.7 million in additional welfare payments are paid to working age PWP – or $4,984 per working age PWP.**

## 9.2 Income support for carers of PWP

There are two main income support measures available to primary carers:

- **Carer Payment** is a means-tested income support payment payable to people who cannot work full time because they provide home-based care to an adult or child who has a severe and long-term disability or health condition, or the equivalent amount of care to a number of less disabled people.[32]
- **Carer Allowance** is a non-means tested income supplement for people who provide daily care to a person with a long-term disability or health condition.

Information on income support for carers of PWP was specially requested from the Department of Social Services. Data is based on recipients caring for a person with PD as the primary medical condition. The average weekly payment and the number of recipients were recorded as at 27 June 2014, and were used to estimate the total cost per annum. The carer payment average weekly payment was based on those recipients paid at the partnered or single rates and following means testing. The carer allowance average weekly payment and total cost per annum were based on the flat rate of $118.20 per fortnight. In 2014, **around $55.4 million of support was provided to carers of PWP, or $800 per PWP.**

**Table 9.2: Total cost of income support to carers, 2014**

| | Average weekly payment ($) | Number of recipients | Total cost per annum ($m) |
|---|---|---|---|
| Carer payment | 281.93 | 2,324 | 34.1 |
| Carer allowance | 59.10 | 6,932 | 21.3 |
| **Total** | | | **55.4** |

Source: Department of Social Services (2015) special request.

[31] 69.0 – (12% * 69.0) = 60.7.

[32] The PWP must also be in receipt of an income support payment.

## 9.3 Taxation revenue

PWP and their carers in paid employment, who have left the workforce temporarily due to caring responsibilities, or permanently due to premature retirement or death, will contribute less tax revenue to the government. Pre-tax:

- PWP lost $138.6 million in wage income due to long-term lost earnings, unpaid temporary absenteeism and premature death;
- Carers lost $78.2 million in wage income due to caring for PWP; and
- Employers lost $43.8 million in production value on account of absenteeism of the carer, lost management productivity in managing the absenteeism, and direct worker hiring and retraining costs.

Consistent with the methodology adopted in the 2007 and 2011 reports, in terms of allocating these losses to either personal income or company income, only the employer losses were included as lost company revenue, with the remainder allocated as lost personal income in one form or another. The average personal income tax rate is 22.8% and the average indirect tax rate is 13.0%, based on the Deloitte Access Economics' Macroeconomic model. Furthermore the vast majority of company income is distributed to domestic shareholders (as franked dividends) and thus the income is charged at the relevant personal tax rate.

**Together these calculations generate a total loss of tax revenue of $93.3 million.** This represents taxation lost that must be collected from remaining citizens (given no change in expenditure – i.e. small tax changes are unlikely to change the level of demand for expenditure).

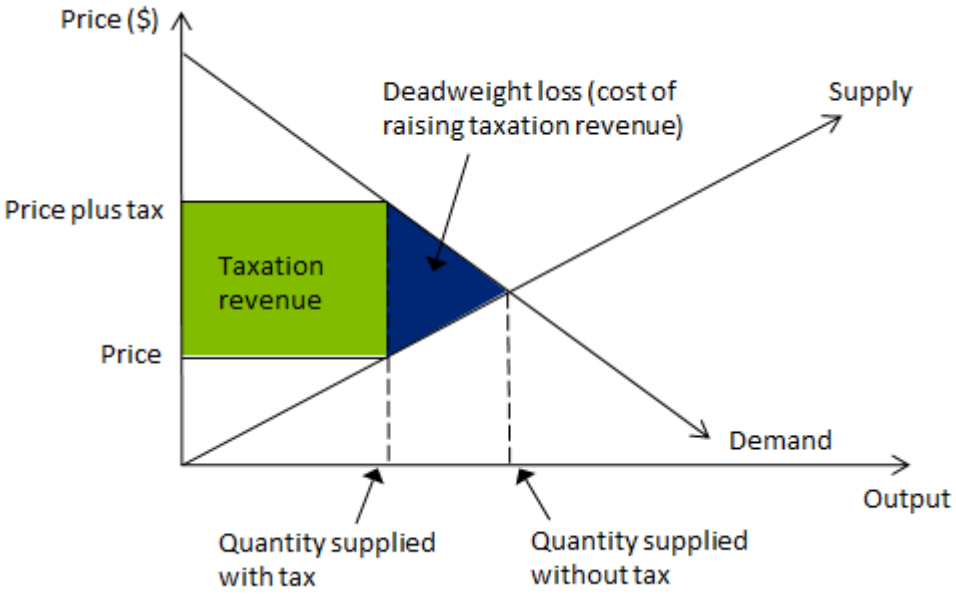
## 9.4 Deadweight loss of taxation payments and administration

Transfer payments (government payments and taxes) are not a net cost to society, as they represent a shift of consumption power from one group of individuals to another in society. If the act of taxation did not create distortions and inefficiencies in the economy, then transfers could be made without a net cost to society. However, through these distortions taxation does impose a deadweight loss on the economy.

Deadweight loss is the loss of consumer and producer surplus, as a result of the imposition of a distortion to the equilibrium (society preferred) level of output and prices (Figure 9.1). Taxes alter the price and quantity of goods sold compared to what they would be if the market were not distorted, and thus lead to some diminution in the value of trade between buyers and sellers that would otherwise be enjoyed. The principal mechanism by which a deadweight loss occurs is the price induced reduction in output, removing potential trades that would benefit both buyers and sellers. In a practical sense, this distortion reveals itself as a loss of

efficiency in the economy, which means that raising $100 dollars of revenue, requires consumers and producers to give up more than $100 of value.

**Figure 9.1: Deadweight loss of taxation**




In line with the 2007 and 2011 reports, the rate of deadweight loss used in this report is 27.5 cents per $1 of tax revenue raised (PC, 2003), plus 1.25 cents per $1 of tax revenue raised for Australian Taxation Office administration. The DWL rate is applied to:

- lost tax revenue from foregone earnings of PWP, their carers and employers (which must be raised from another source);
- welfare payments made to PWP and their carers; and
- government services provided (e.g. the public health system, grants and programs) (since in a budget neutral setting government expenditures require taxation to be raised and thus also have associated distortionary impacts).

## 9.5 Transfer costs summary

Using the rate of deadweight loss (28.75%), **the expected total deadweight loss (DWL) associated with PD was estimated to be $173.5 million in 2014.**

The economic costs associated with transfers have more than doubled since 2005, increasing by almost $92 million (Table 9.3).

**Table 9.3: Comparison of transfers, 2005 and 2014 ($m)**

| | 2005 ($m) | 2014 ($m) | % change |
|---|---|---|---|
| Health system costs borne by government | 233.2 | 387.7 | 66% |
| Lost taxes | 22.2 | 93.3 | 320% |
| Welfare payments | 30.4 | 116.1 | 282% |
| Other costs borne by government | 2.1 | 6.2 | 195% |
| **Total transfers** | **287.9** | **603.5** | **110%** |
| **Resulting DWL** | **82.8** | **173.5** | **110%** |

Source: Deloitte Access Economics' calculations.

# 10 Burden of disease

This Chapter adopts the 'burden of disease' methodology in order to quantify the impact of PD on wellbeing. The approach is non-financial, where pain, suffering and premature mortality are measured in terms of disability adjusted life years (DALYs), with 0 representing a year of perfect health and 1 representing death.

**Key findings:**

- PWP experienced 37,882 years of life lost due to disability (YLDs), and 10,895 years of life lost due to premature death (YLLs), combining to give 48,777 disability-adjusted life years (DALYs) – the burden of PD in 2014.
- The value of the burden of PD was $8.9 billion in 2014, an increase of $2.6 billion (42%) since 2005.

## 10.1 Valuing life and health

The burden of disease as measured in DALYs can be converted into a dollar figure using an estimate of the **value of a 'statistical' life** (VSL). As the name suggests, the VSL is an estimate of the value society places on an anonymous life. Since Schelling's (1968) discussion of the economics of life saving, the economic literature has focused on **willingness to pay** (WTP) – or, conversely, willingness to accept – measures of mortality and morbidity, in order to develop estimates of the VSL.

Estimates may be derived from observing people's choices in situations where they rank or trade off various states of wellbeing (loss or gain) either against each other or for dollar amounts e.g. stated choice models of people's WTP for interventions that enhance health or willingness to accept poorer health outcomes or the risk of such states. Alternatively, risk studies use evidence of market trade-offs between risk and money, including numerous labour market and other studies (such as installing smoke detectors, wearing seatbelts or bike helmets and so on).

The extensive literature in this field mostly uses econometric analysis to value mortality risk and the 'hedonic wage' by estimating compensating differentials for on-the-job risk exposure in labour markets; in other words, determining what dollar amount would be accepted by an individual to induce him/her to increase the probability of death or morbidity by a particular percentage.

In an attempt to overcome some of the issues in relation to placing a dollar value on a human life, a non-financial approach to valuing human life is used. Pain, suffering and premature mortality are measured in terms of Disability Adjusted Life Years (DALYs), with 0 representing a year of perfect health and 1 representing death – this is represented by the white shaded areas in Figure 10.1. This approach was developed by the World Health Organization, the World Bank and Harvard

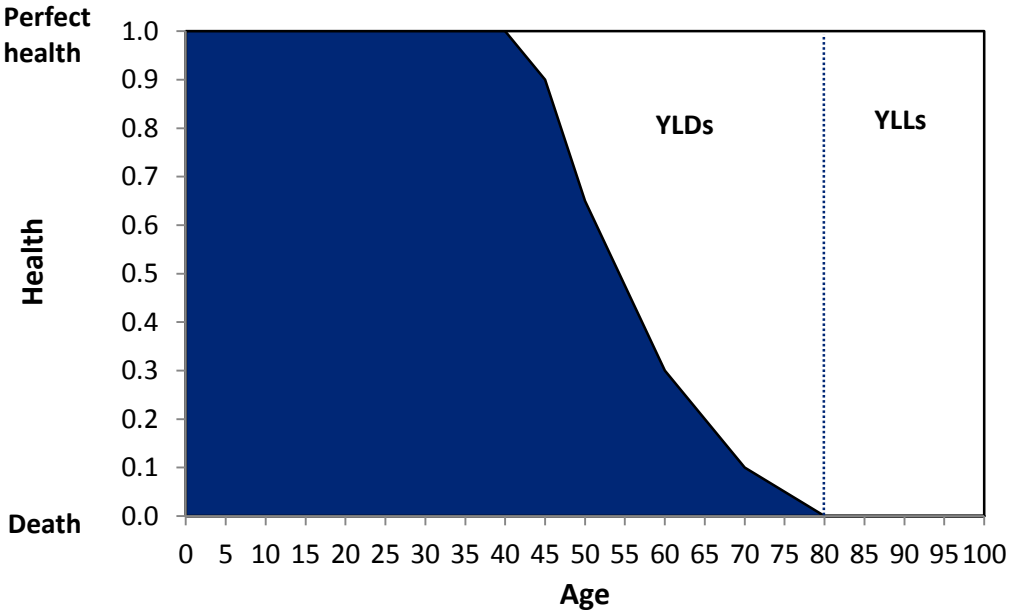
University and provides a comprehensive assessment of mortality and disability from diseases, injuries and risk factors in 1990, projected to 2020 (Murray and Lopez, 1996). Methods and data sources are detailed further in Murray et al (2001).

The DALY approach has been adopted and applied in Australia by the Australian Institute for Health and Welfare (AIHW). Mathers et al (1999) included separate identification of the premature mortality (Years of Life Lost - YLL) and morbidity (Years of Life Lost due to Disability - YLD) components:

DALYs = YLLs + YLDs

In any year, the disability weight of a disease (for example, 0.18 for a broken wrist) reflects a relative health state. In this example, 0.18 would represent losing 18% of a year of healthy life because of the inflicted injury.

**Figure 10.1: Graphic representation of disability-adjusted life years (DALYs)**




Note: YLLs = years of life lost due to premature death, YLDs = years of healthy life lost due to disability.

The DALY approach has been successful in avoiding the subjectivity of individual valuation and is capable of overcoming the problem of comparability between individuals and between nations, although nations have subsequently adopted variations in weighting systems. For example, in some countries DALYs are age-weighted for older people although in Australia the minority approach is adopted – valuing a DALY equally for people of all ages.

As DALYs are enumerated in years of life rather than in whole lives it is necessary to calculate the **value of a 'statistical' life year (VSLY)** based on the VSL. This is done using the formula:[33]

$$VSLY = VSL / \Sigma_{i=0,\ldots,n-1}(1+r)^i$$

Where: n = years of remaining life, and
r = discount rate

The Department of Finance and Deregulation (2008) provided an estimate of the 'net' VSLY (i.e. subtracting financial costs borne by individuals). This estimate was $151,000 in 2007, which inflates to around **$182,000 in 2014 dollars for the VSLY** (Office of Best Practice and Regulation (OBPR), 2014).

## 10.2 Estimating the burden of disease from PD

Burden of disease is estimated by applying the value of a statistical life year of $182,000 (OBPR, 2014) to the total DALYs due to PD.

- Years of healthy life lost due to disability (YLDs) are based on the disability weights used in the Begg et al (2007) multiplied by the number of PWP as estimated in Section 3.1.3 (with a discount rate of 3% and no age weighting).[34] The disability weights for PD range from 0.48 for Stages I to III, 0.79 for Stage IV, and 0.92 for Stage V. In line with 2007 and 2011 reports, Begg et al (2007) disability weights are used in this report.[35]
- Years of life lost due to premature death (YLLs) are based on the number of deaths from PD as estimated in Section 3.5 and years of remaining expected life at the age of death from the Standard Life Expectancy Table (West Level 26) (with a discount rate of 3% and no age weighting).

[33] The formula is derived from the definition:
*VSL = ΣVSLYi/(1+r)^i where i=0,1,2….n*
*where VSLY is assumed to be constant (i.e. no variation with age).*

[34] Note that this is a prevalence methodology for estimating YLDs, rather than an incidence methodology as used in Begg et al (2007).

[35] We are aware of Salomon et al (2012) alternative disability weights for mild, moderate and severe stages of PD of 0.011, 0.263 and 0.549. The definitions used in Salomon et al (2012) for mild, moderate and severe stages are: (a) Mild – the person has mild tremors and moves a little slowly, but is able to walk and do daily activities without assistance; (b) Moderate – the person has moderate tremors and moves slowly, which causes some difficulty in walking and daily activities; and the person has some trouble swallowing, talking, sleeping, and remembering things; and (c) Severe – the person has severe tremors and moves very slowly, which causes great difficulty in walking and daily activities; and the person falls easily and has a lot of difficulty talking, swallowing, sleeping, and remembering things. These definitions are much milder than those used in this report based on HV I to HV V. Consequently, the Begg et al (2007) disability weights were retained in this report.

- YLDs and YLLs are added together to estimate total DALYs.

> Significant proportions of older PWP will also have some common conditions associated with older ages (such as hearing loss, arthritis, heart conditions, diabetes etc). It is not possible to add the disability weights for each of these conditions as the total weights may add to greater than 1 – rather a multiplicative model is best used. However the following estimates of DALYs have not been adjusted for comorbidities because:
>
> - As the disability weights for PD are very high, adjusting the weights for comorbidities will have a very minor impact on DALYs due to PD (a large proportion of the impact will fall on the minor condition); and
> - It is a conservative estimate of total DALYs experienced by PWP (though not entirely due to PD) and PWP actually experience higher DALYs than those estimated, due to comorbidities.
>
> Furthermore, the source studies from which the VSL is drawn implicitly include the individual's net estimation of other personal costs – notably lost earnings (after tax) and out-of-pocket expenses. Thus the net cost of suffering and premature death from PD should exclude these costs to avoid double counting. This is taken into account in the "net" VSLY used to convert DALYs to dollars.

Table 10.1 presents the burden of PD in 2014 by disease stage. **Overall, PWP experienced**

- **37,882 YLDs, or around 0.55 YLDs per PWP;**
- **10,895 YLLs, or around 6.25 YLLs per death; and**
- **48,777 DALYs, or around 0.70 DALYs per PWP.**

**Table 10.1: Burden of PD in 2014, by disease stage**

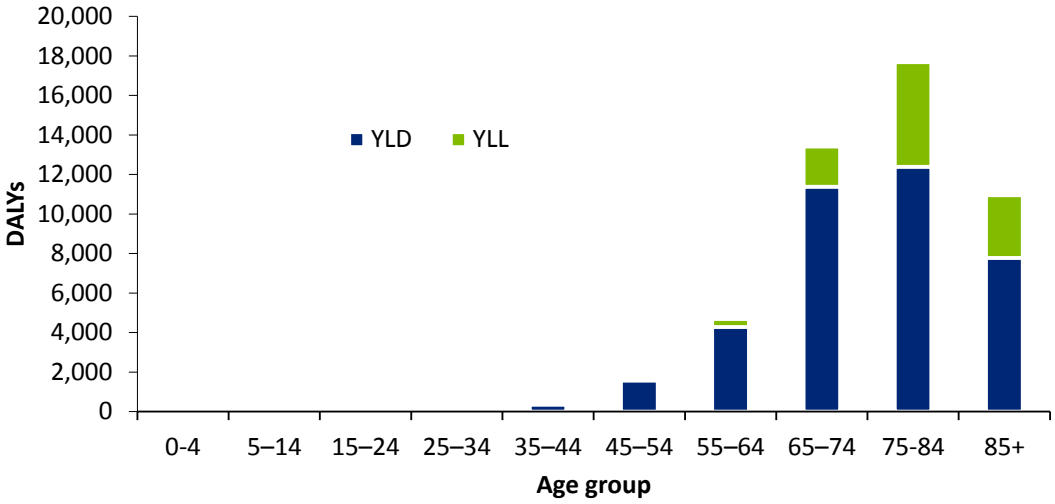
| Stage | YLDs | YLLs | DALYs | Value in 2014 ($m) |
|---|---|---|---|---|
| I | 10,462 | 3,071 | 13,533 | 2,463.0 |
| II | 8,850 | 2,848 | 11,698 | 2,129.1 |
| III | 7,531 | 2,611 | 10,142 | 1,845.9 |
| IV | 7,191 | 1,605 | 8,796 | 1,600.9 |
| V | 3,847 | 759 | 4,607 | 838.4 |
| **Total all stages** | **37,882** | **10,895** | **48,777** | **8,877.3** |

Source: Deloitte Access Economics' calculations.

**The value of the burden of PD was $8.9 billion in 2014 – an increase of $2.6 billion, or 42%, since 2005.**

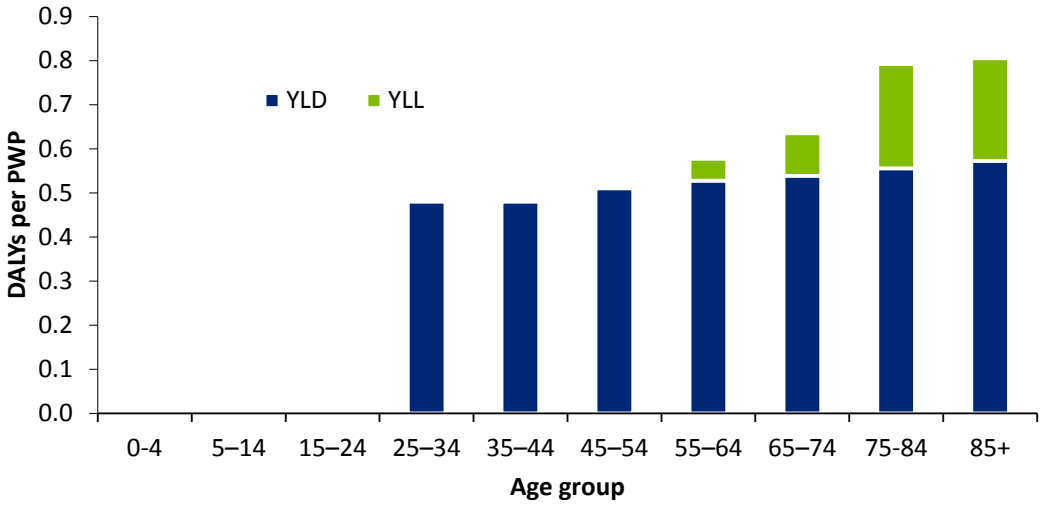
While 75-80 year olds bore the most burden of all the age groups (Chart 10.1), DALYs per PWP consistently increases with age (Chart 10.2). Similarly, while people in the initial stages of PD bear the most burden (Chart 10.3), DALYs per PWP consistently increases with disease stage (Chart 10.4).

**Chart 10.1: Total disability-adjusted life years (DALYs), by age**



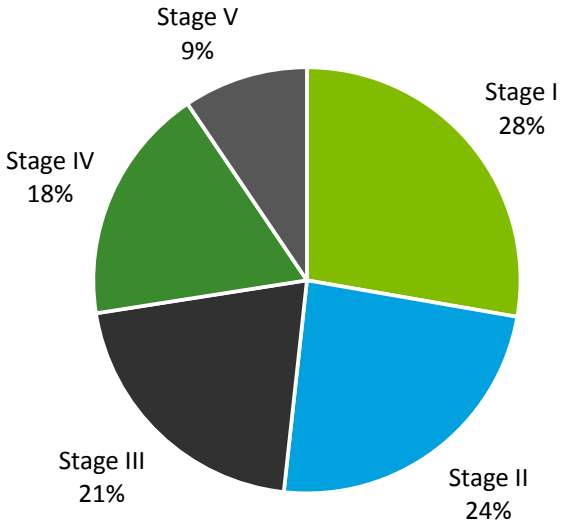

Source: Deloitte Access Economics' calculations.

**Chart 10.2: Disability-adjusted life years (DALYs) per PWP (years), by age**



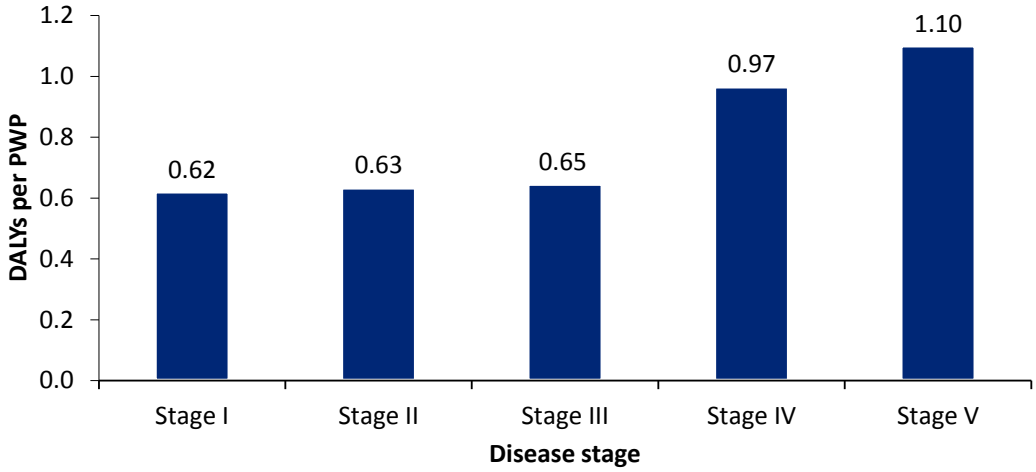

Source: Deloitte Access Economics' calculations.

### Chart 10.3: Distribution of disability-adjusted life years (DALYs), by disease stage




Source: Deloitte Access Economics' calculations.

### Chart 10.4: Disability-adjusted life years (DALYs) per PWP, by disease stage




Note: DALYs per PWP is greater than 1 in Stage V because future YLLs due to PD are attributed to the year that the person dies.

Source: Deloitte Access Economics' calculations.

# 11 The economic cost of PD in Australia

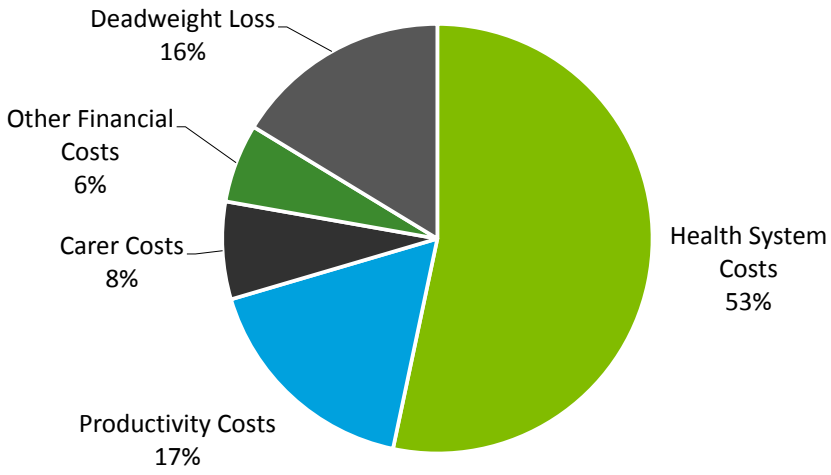
In 2014 in Australia, it is estimated that there were:

- **69,208 people living with PD**;
- **11,544 new cases of PD**; and
- **Between 1,501 (underlying) and 1,743 (associated) deaths due to PD**.

Due to the ageing population, by 2034 it is estimated that there will be around 123,781 people living with PD.

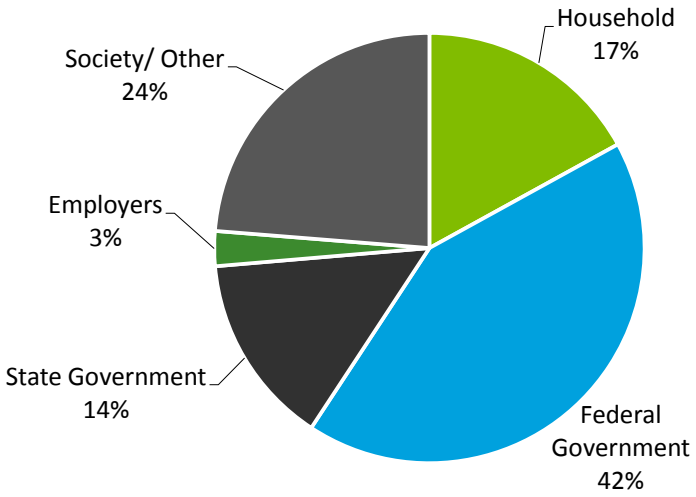
**The total financial cost of PD per annum was around $1.1 billion in 2014. This is an increase of $540.7 million since 2005, or 103%.**

**Chart 11.1: Financial costs of PD, by type of cost**




Source: Deloitte Access Economics' calculations.

**Chart 11.2: Financial costs of PD, by who bears the cost**




Source: Deloitte Access Economics' calculations.

In addition to financial costs, the burden of disease– the suffering and premature death experienced by people with PD – is estimated to cost an additional 48,777 DALYs (years of healthy life lost), with 78% due to disability and the remaining 22% due to premature death. The net value of the burden of disease was $8.9 billion in 2014.

**Thus the total economic cost of PD was $9.9 billion in 2014. This is an increase of $3.2 billion since 2005, or 46%.**

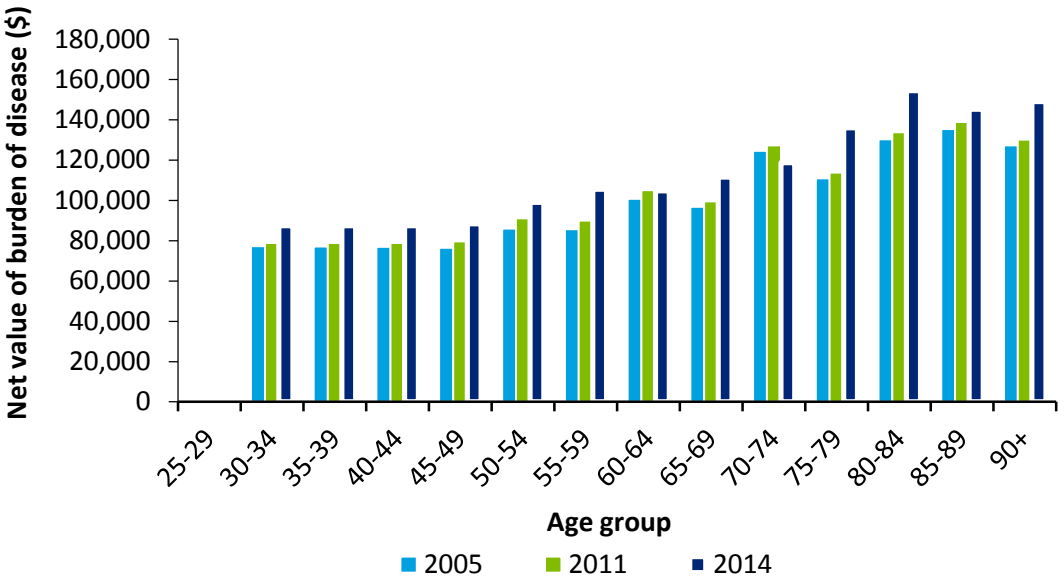
**Table 11.2: Total cost of PD ($m), 2014**

| | PWP | Family /Friends | Federal Govt. | State Govt. | Employers | Society /Other | Total |
|---|---|---|---|---|---|---|---|
| Burden of disease | 8,877.3 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | **8,877.3** |
| Health system costs | 101.0 | 0.0 | 235.0 | 152.7 | 0.0 | 78.9 | **567.7** |
| Productivity costs | 89.0 | 0.0 | 65.3 | 0.0 | 28.1 | 0.0 | **182.4** |
| Carer costs | 0.0 | 50.2 | 28.0 | 0.0 | 0.0 | 0.0 | **78.2** |
| Other financial costs | 56.0 | 0.9 | 6.2 | 0.0 | 0.0 | 0.0 | **63.1** |
| Deadweight loss | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 173.5 | **173.5** |
| Transfers | -60.7 | -55.4 | 116.1 | 0.0 | 0.0 | 0.0 | **0.0** |
| **Total** | **9,062.7** | **-4.3** | **450.7** | **152.7** | **28.1** | **252.4** | **9,942.2** |

Source: Deloitte Access Economics' calculations.

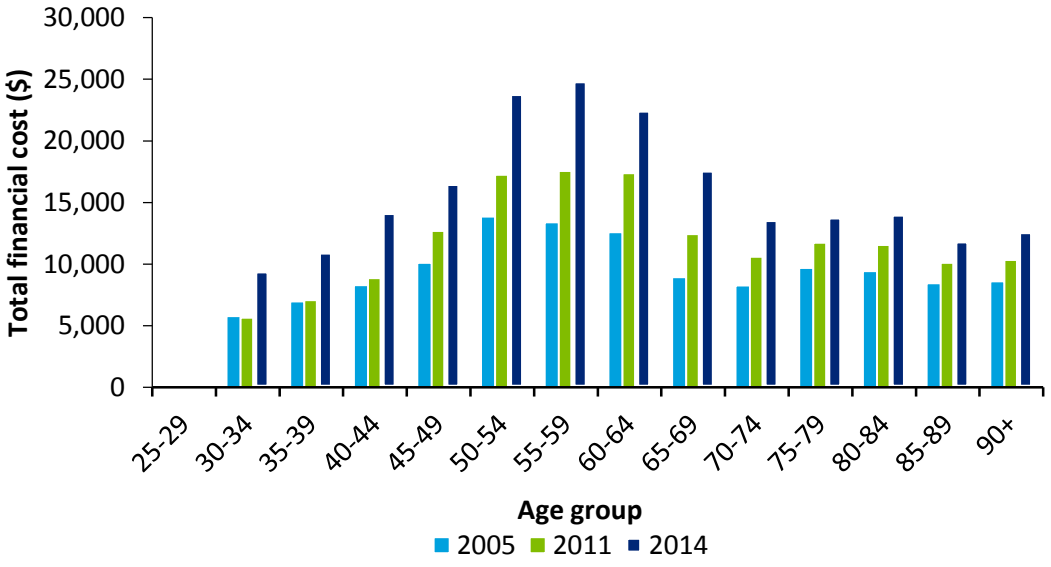
**Relative to 2005 and 2011 estimates, the burden of PD has increased across all age groups and disease stages** (Chart 11.3, Chart 11.4, Chart 11.5 and Chart 11.6). **Most notably, the financial cost of PD is highest for people aged 50-65 years** (Chart 11.4). This is largely due to the lost earnings from premature mortality and workforce separation, with this effect dissipating from aged 65 years onwards.

**Chart 11.3: Net value of burden of disease per PWP ($), by age**



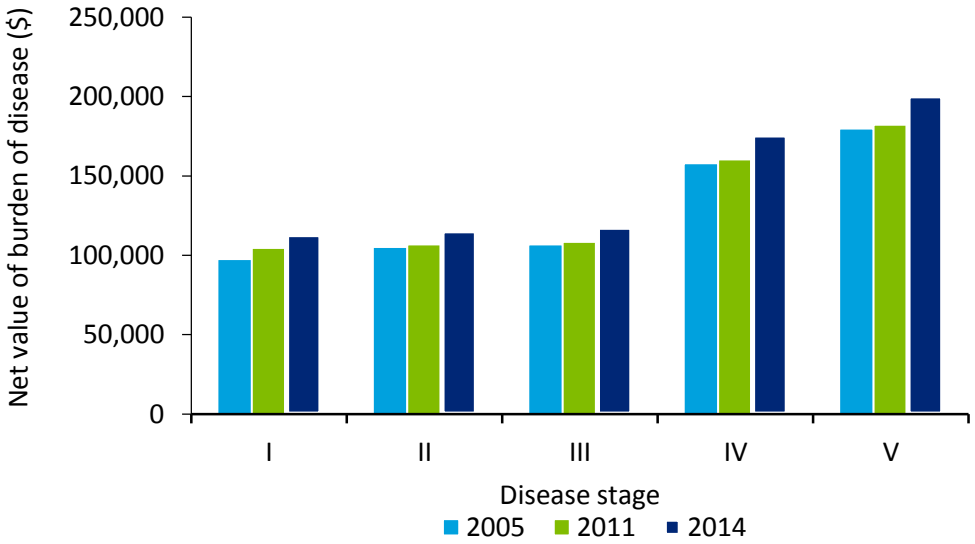

Source: Deloitte Access Economics' calculations.

**Chart 11.4: Financial costs per PWP ($), by age**



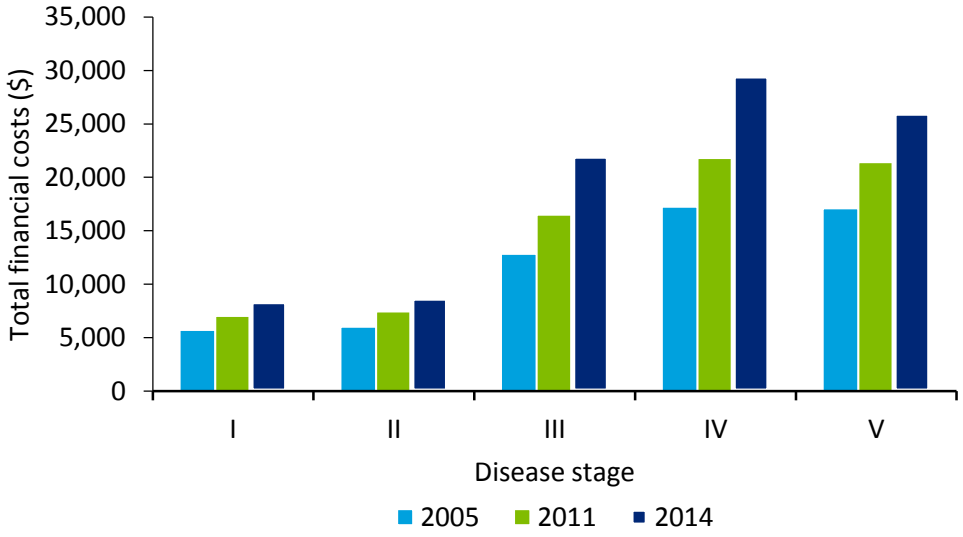

Source: Deloitte Access Economics' calculations.

**Chart 11.5: Net value of the burden of disease per PWP ($), by disease stage**




Source: Deloitte Access Economics' calculations.

**Chart 11.6: Financial costs per PWP ($), by disease stage**




Source: Deloitte Access Economics' calculations.

# 12 Sensitivity analyses

As discussed in Section 3.1, the PD prevalence estimates can vary widely depending on the methods of identifying PD. Since the cost estimations depend on PD prevalence estimates, this chapter presents the findings based on a lower and an upper of prevalence estimates, and a replacement valuation approach for the value of informal care. The base case against which these assumptions are compared represents the methodology and estimates contained in Chapter 4 through to Chapter 11.

**Key findings:**

- Overall, the financial costs of PD range from $970.0 million to $1,630.7 million, while the total costs of PD (including the value of the burden of disease) range from $9.7 billion to $12.2 billion.
- The base case estimate of the costs of PD lies at the conservative side of the spectrum.

## 12.1 Lower bound estimate of prevalence

The lower bound estimate of prevalence was estimated using Begg et al (2007) which is the forefront research report for analysing the burden of disease and injury in Australia. The findings from Begg et al (2007) were based on de Rijk (2000) which estimated the prevalence of PD in Europe using pooled data from seven similar, community-focused studies, and then supplemented by estimates of prevalence of PD in people aged younger than 65 years from an earlier study (de Rijk, 1995).

In addition, Begg et al (2007) only defined PD as idiopathic (or primary) PD where the cause is unknown. The estimates of prevalence and burden do not extend to secondary PD (which may have been induced by drugs, environmental toxins, trauma, metabolic derangement, stroke and brain tumour) or Parkinson's-like conditions such as progressive supranuclear palsy and multiple system atrophy.

While secondary PD is not often listed as a cause of death on death certificates, the literature shows that secondary PD is more common than cause of death data suggests. Stacy and Jankovic (1995) found that 8.2% of PWP have secondary PD. This number varies recently, with a range from 0.4% to 12% (Muangpaisan et al, 2011; Esper and Factor, 2008; Colosimo et al, 2010). A weighted average of these studies suggests 8.1% of PWP have secondary PD.

Although diagnosis, medical treatment and prognosis can be very different, both idiopathic and secondary PD have similar impacts on the individual. Consequently both groups should be included, and Begg et al (2007) prevalence estimates are scaled up by 8.1% to ensure secondary PD is included.

### Summary of prevalence estimates in the low case

Table 12.1 outlines the estimates of prevalence of PD in Australia in 2014 using the Begg et al (2007) prevalence rates. As the estimates are based on a two-phase investigation method which ensures that under-diagnosis and misdiagnosis is kept to a minimum, no additional adjustment is made for under-diagnosis and misdiagnosis.

- **Prevalence:** It was estimated that there were around 66,827 PWP in 2014 in the low case.
  - 61,803 PWP had idiopathic PD and 5,024 had secondary PD.
  - 33,435 were male and 33,392 were female.
  - 53,095 were in the initial stages of PD, 9,366 PWP in the intermediate stage, and 4,366 PWP in the end stage of PD.
- **Projections:** Prevalence is expected to increase to 81,540 people (up 21%) by 2020 and to 125,046 people (up 87% from today) by 2034, in the low case.
  - This is equivalent to a growth rate of 4.4% per annum between 2014 and 2034.
  - 50.0% of PWP are female, which is projected to decline slightly to 49.0% in 2034.
  - 10.0% of PWP are of working age (15-64 years), which is projected to decline slightly to 6.9% in 2034.

**Table 12.1: Prevalence estimates, 2014 – low case**

| | Prevalence rates (%)* | | | Cases | | |
|---|---|---|---|---|---|---|
| **Age** | **Males** | **Females** | **Total** | **Males** | **Females** | **Total** |
| 0-4 | 0.00 | 0.00 | 0.00 | 0 | 0 | 0 |
| 5–14 | 0.00 | 0.00 | 0.00 | 0 | 0 | 0 |
| 15–24 | 0.00 | 0.00 | 0.00 | 0 | 0 | 0 |
| 25–34 | 0.00 | 0.00 | 0.00 | 0 | 0 | 0 |
| 35–44 | 0.00 | 0.00 | 0.00 | 15 | 2 | 18 |
| 45–54 | 0.04 | 0.01 | 0.03 | 691 | 139 | 830 |
| 55–64 | 0.28 | 0.15 | 0.22 | 3,733 | 2,088 | 5,821 |
| 65–74 | 0.93 | 0.90 | 0.92 | 8,895 | 8,828 | 17,723 |
| 75-84 | 2.84 | 2.37 | 2.58 | 13,749 | 13,592 | 27,340 |
| 85+ | 3.87 | 3.00 | 3.31 | 6,351 | 8,743 | 15,095 |
| **Total** | | | | **33,435** | **33,392** | **66,827** |

Note: Rows and columns may not sum due to rounding. * Prevalence rates have been adjusted to include secondary PD cases.

Source: Deloitte Access Economics' calculations.

### Summary of economic costs – low case

The following estimates of the economic costs of PD are based on the same methodology as contained in Section 4 through to Section 10, however using the estimated prevalence from Begg et al (2007). Table 12.2 presents the cost findings.

- **Health system costs**: The health system cost of PD was $571.9 million. This is higher than the base case as there are proportionately more PWP in older age groups (see Table 3.2 and Table 12.1) than in the base case, incurring higher per person costs.
  - $469.0 million were directly due to PD, while $102.9 million were additional health system costs due to comorbidities.
  - The average cost per PWP was $8,558, of which 17.8% was borne by individuals.
- **Productivity costs:** The total productivity cost of PD was $127.0 million.
  - The largest component was premature workforce separation ($77.8 million), followed by temporary absenteeism from work ($29.3 million), premature mortality ($19.8 million), and search, hiring and training costs ($0.1 million).
  - The average cost per PWP was $1,900, of which workers bore 51%, the government bore 36%, and employers bore 14%.
- **Informal care costs:** The total informal care cost of PD was $50.9 million.
  - There were 10,147 carers of PWP, of which 970 were of working age.
  - The average cost per PWP was $762, of which the household bore 64% and the government the remaining 36%.
- **Other financial costs:** The total other financial cost of PD was $62.3 million.
  - The largest component was aids and modifications ($41.5 million).
  - The average cost per PWP was $933, of which individuals bore 89%.
- **Transfers:** The total deadweight loss associated with transfers due to PD was $157.9 million.
  - The additional DSP payments paid to PWP was $33.3 million and carers of PWP received $55.4 million.
  - The total lost taxes were $63.7 million.

The total financial cost of PD was $970.0 million (9% lower than the base case methodology) and the average financial cost was $14,516 per PWP (6% lower than the base case methodology).

- **Burden of disease:** The net value of the burden of disease due to PD was $8.7 billion.
  - Using a prevalence methodology: PWP experienced 36,901 YLDs and 10,895 YLLs – totalling 47,796 DALYs. This is equivalent to 0.55 YLDs per

PWP, 0.16 YLLs per PWP (or 6.25 YLLs per death), and 0.72 DALYs per PWP.

**Table 12.2: Total cost of PD ($m) – low case**

| | PWP | Family /Friends | Federal Govt. | State Govt. | Employers | Society /Other | Total |
|---|---|---|---|---|---|---|---|
| Burden of disease | 8,698.9 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | **8,698.9** |
| Health system costs | 101.8 | 0.0 | 236.8 | 153.9 | 0.0 | 79.5 | **571.9** |
| Productivity costs | 64.3 | 0.0 | 45.5 | 0.0 | 17.2 | 0.0 | **127.0** |
| Carer costs | 0.0 | 32.7 | 18.2 | 0.0 | 0.0 | 0.0 | **50.9** |
| Other financial costs | 55.2 | 0.9 | 6.2 | 0.0 | 0.0 | 0.0 | **62.3** |
| Deadweight loss | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 157.9 | **157.9** |
| Transfers | -33.3 | -55.4 | 88.7 | 0.0 | 0.0 | 0.0 | **0.0** |
| **Total** | **8,886.9** | **-21.8** | **395.4** | **153.9** | **17.2** | **237.4** | **9,668.9** |

Source: Deloitte Access Economics' calculations.

The total economic cost of PD was $9.7 billion (2.7% lower than the base case methodology) and the average economic cost was $144,686 per PWP (0.7% higher than the base case methodology).[36]

## 12.2 Upper bound estimate of prevalence

The upper bound estimate of prevalence is based on the number of people receiving PD medications explicitly for PD (see Section 3.1.3) increased by the average rate of under-diagnosis. The rate of under-diagnosis of PD varies greatly by study and region – as low as 8% in Japan and as high as 70% in Australian studies (de Rijk et al 1997; Chan et al 2001; 2005; Zhang et al 2005; Yamakawi et al 2009; Osaki et al 2010; Seijo-Martinez et al 2011; Khedr et al 2012). The weighted average across these studies gives an under-diagnosis rate of 29.6%. Consequently, this rate is applied to give the upper bound estimate of prevalence. Underlying this methodology is the assumption that under-diagnosed PWP use the same level of economic resources and have the same level of burden of disease as diagnosed PWP.

[36] Per PWP costs are higher primarily due to total prevalence falling by relatively more than the fall in the total cost of the burden of disease.

## Summary of prevalence estimates and economic costs – high case

- **Prevalence:** It is estimated that there were around 89,722 PWP in 2014.
  - 47,351 were male and 42,371 were female.
  - 72,500 were in the initial stages of the disease, 11,801 were in the intermediates stage, and 5,421 were in the final stage.
- **Health system costs**: The total health system cost of PD was $705.4 million.
  - $602.5 million were directly due to PD, while $102.9 million were additional health system costs due to comorbidities.
  - The average cost per PWP was $7,862, of which 17.8% was borne by individuals.
- **Productivity costs:** The total productivity cost of PD was $230.6 million.
  - The largest component was premature workforce separation ($148.3 million), followed by temporary absenteeism from work ($62.4 million), premature mortality ($19.8 million), and search, hiring and training costs ($0.1 million).
  - The average cost per PWP was $2,570, of which workers bore 48%, the government bore 36%, and employers bore 16%. The cost per person is lower than the base case as the costs associated with premature mortality do not change, but prevalence is higher.
- **Informal care costs:** The total informal care cost of PD was $78.2 million.[37]
  - There were 10,147 carers of PWP, of which 1,558 were of working age.
  - The average cost per PWP was $871, of which the household bore 64% and the government the remaining 36%.
- **Other financial costs:** The total other financial cost of PD was $79.0 million.
  - The largest component was aids and modifications ($54.6 million).
  - The average cost per PWP was $880, of which individuals bore 91%.
- **Transfers:** The total deadweight loss associated with transfers due to PD was $210.6 million.
  - The additional DSP payments paid to PWP was $78.7 million and carers of PWP received $55.4 million.
  - The total lost taxes were $110.6 million.

[37] The cost of care does not increase in the high case as the total is taken from SDAC and then redistributed by age and gender groups. In the low case, however, the distribution changes as the prevalence rates are from a difference source. This is why the carer costs falls in the low case but does not rise in the high case.

The total financial cost of PD was $1,303.8 million (22% higher than the base case methodology) and the average financial $14,532 per PWP (6% lower than the base case methodology).

- **Burden of disease:** The net value of the burden of disease due to PD was $10.9 billion.
  - Using a prevalence methodology: PWP experienced 49,110 YLDs and 10,895 YLLs – totalling 60,005 DALYs. This is equivalent to 0.55 YLDs per PWP, 0.12 YLLs per PWP (or 6.25 YLLs per death), and 0.67 DALYs per PWP.

**Table 12.3: Total cost of PD ($m) – high case**

| | PWP | Family /Friends | Federal Govt. | State Govt. | Employers | Society /Other | Total |
|---|---|---|---|---|---|---|---|
| Burden of disease | 10,920.9 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | **10,920.9** |
| Health system costs | 125.6 | 0.0 | 292.0 | 189.8 | 0.0 | 98.1 | **705.4** |
| Productivity costs | 111.6 | 0.0 | 82.6 | 0.0 | 36.4 | 0.0 | **230.6** |
| Carer costs | 0.0 | 50.2 | 28.0 | 0.0 | 0.0 | 0.0 | **78.2** |
| Other financial costs | 71.8 | 0.9 | 6.2 | 0.0 | 0.0 | 0.0 | **79.0** |
| Deadweight loss | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 210.6 | **210.6** |
| Transfers | -78.7 | -55.4 | 134.1 | 0.0 | 0.0 | 0.0 | **0.0** |
| **Total** | **11,151.2** | **-4.3** | **542.9** | **189.8** | **36.4** | **308.7** | **12,224.7** |

Source: Deloitte Access Economics' calculations.

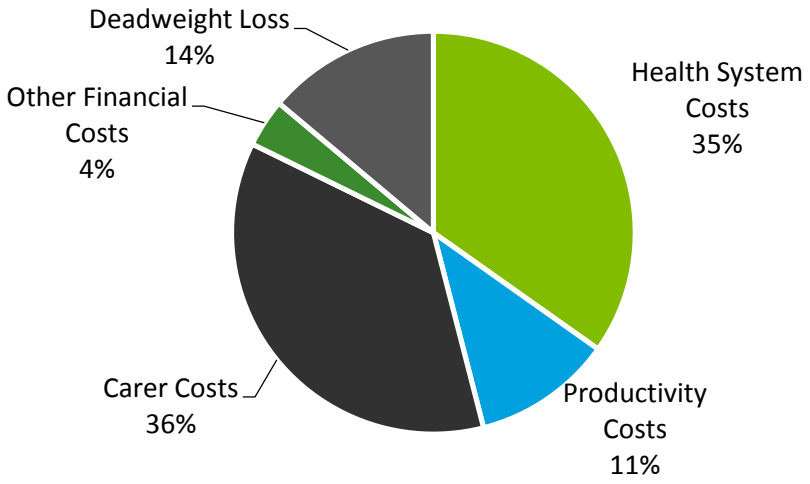
The total economic cost of PD was $12.2 billion (23% higher than the base case methodology) and the average economic cost was $136,251 per PWP (5% lower than the base case methodology).

## 12.3 Replacement value of informal care

The estimate of the replacement value of informal community care is sensitive to changes in the estimate of the wage parameter for alternate formal sector care. In this analysis, the unit cost used has been based on the wage of moderately skilled formal sector carers (supervised employees). The unit cost for formal sector carers in Access Economics (2010) was $31.04. The replacement value of informal care is calculated by assuming that the hours of care provided remains the same as the base case and is provided entirely by formal sector carers, with each hour of care valued at $31.04.

Using the replacement valuation for informal care increases carer costs by $565.9 million compared to the base case. Subsequently, financial costs also increase by $565.9 million to $1,630.7 million (53.1% higher than the base case), increasing carer costs from 7% to 36% of the financial costs of PD (Chart 12.1).

**Chart 12.1: Financial costs by type, replacement value of informal care, 2014**




Source: Deloitte Access Economics' calculations.

This large impact on the financial costs is unsurprising since informal carers provide so many hours of care to PWP. However, as so many informal carers are older they also have a lower probability of working which forces down the opportunity cost of their time. If informal carers were unable to care, then many PWP would require care from other sources such as HACC or Home Care Packages programs.

## 12.4 Summary of sensitivity analysis

Overall, the financial costs of PD range from $970.0 million to $1,630.7 million, while the total costs of PD (including the value of the burden of disease) range from $9.7 billion to $12.2 billion. The base case estimate of the costs of PD lies at the conservative side of the spectrum.

**Table 12.4: Sensitivity analysis**

| | Impact on value of burden of disease | | Impact on financial cost | | Impact on total economic cost | |
|---|---|---|---|---|---|---|
| **Variable** | **$m** | **%** | **$m** | **%** | **$m** | **%** |
| Upper Prevalence | +2,043.5 | 23.0 | +239.0 | 22.4 | +2,282.5 | 22.9 |
| Lower Prevalence | -178.5 | -2.0 | -94.8 | -8.9 | -273.3 | -2.7 |
| Replacement valuation of informal care | 0.0 | 0.0 | 565.9 | 52.8 | 565.9 | 5.7 |

Source: Deloitte Access Economics' calculations.

# 13 Comparisons

This chapter presents comparisons of the prevalence and deaths, health system and financial costs, and the burden of disease associated with PD and other conditions and diseases in Australia in 2014.

**Key findings:**

- PD is a surprisingly prevalent condition – with higher prevalence than a number of diseases and injuries considered National Health Priority Areas (NHPAs) including cancers such as breast cancer, lymphoma and leukaemia, kidney and bladder cancer, and uterine, cervical, and ovarian cancer.
- Health expenditure on PD per PWP per year is relatively higher than many other diseases and injuries including prostate cancer and breast cancer, in part due to the higher use of residential aged care.
- PWP experience more DALYs per person over their lifetime compared to many other diseases and injuries, especially since PWP live with the disease for a relatively long time.

## 13.1 Prevalence of PD and deaths due to PD

**PD is a surprisingly prevalent condition** – with higher prevalence than a number of diseases and injuries considered National Health Priority Areas (NHPAs) (see Chart 13.1), including:

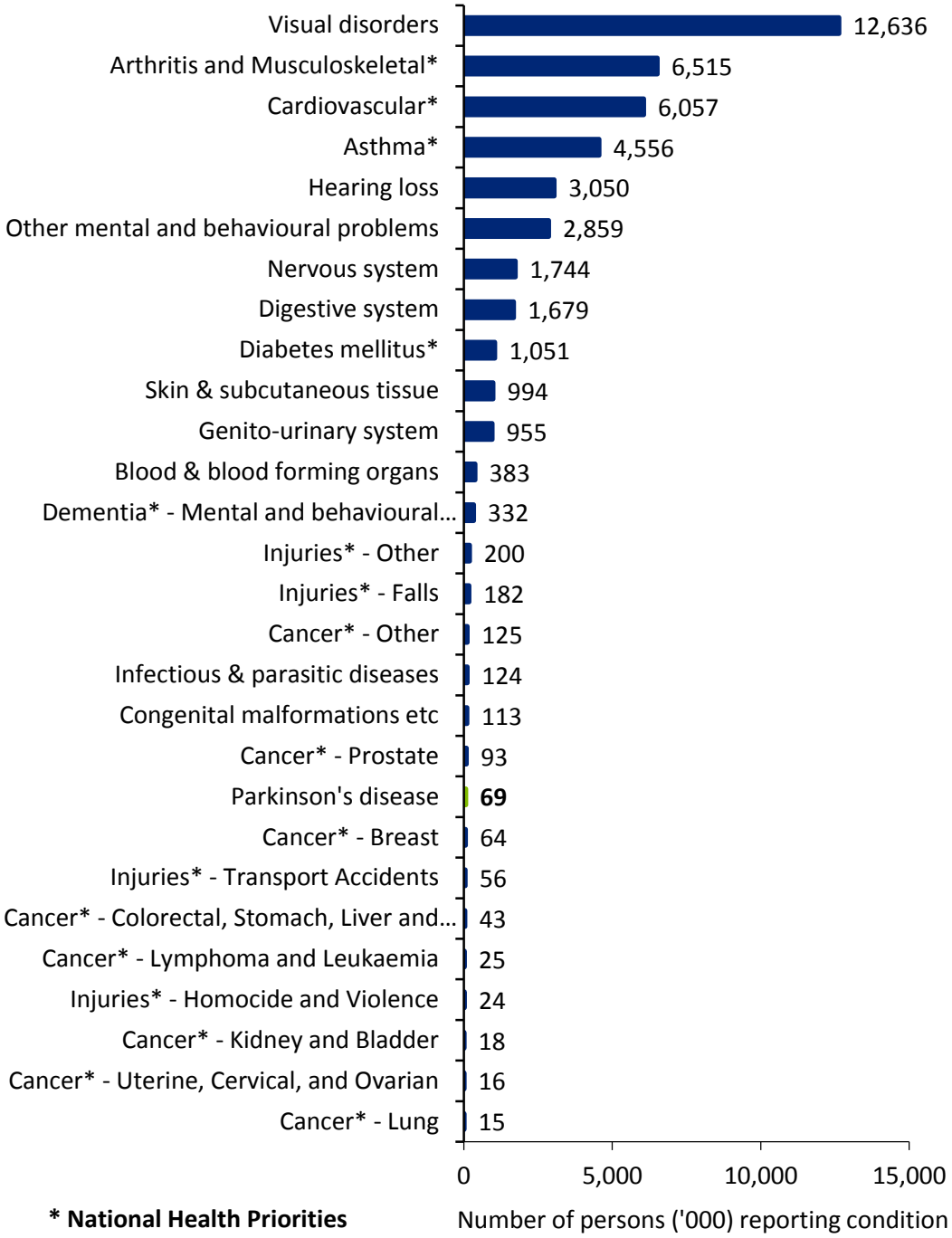
- Cancers such as breast cancer, lymphoma and leukaemia, kidney and bladder cancer, and uterine, cervical, and ovarian cancer.
- Hospitalised injuries such as transport accidents and homicide and violence.

For people aged over 55 years, the prevalence of PD is also higher than infectious diseases such as intestinal infectious diseases, bacterial diseases, viral infections characterised by skin and mucous membrane lesions and other viral diseases combined (see Chart 13.2).

Similarly the **number of deaths due to PD** is similar to deaths due to uterine, cervical, and ovarian cancer combined together, and higher than transport accidents (both NHPAs) (see Chart 13.3).

**Compared to other neurological conditions**, PD has the second highest prevalence and number of deaths (exceeded only by dementia) (see Chart 13.4 and Chart 13.5). However Mathers et al (1999) and Begg et al (2007) largely ignore many of the other PD-like diseases such as progressive supranuclear palsy and multiple system atrophy. While rarer, many of these diseases would have a similar financial impact and disease burden compared to PD.

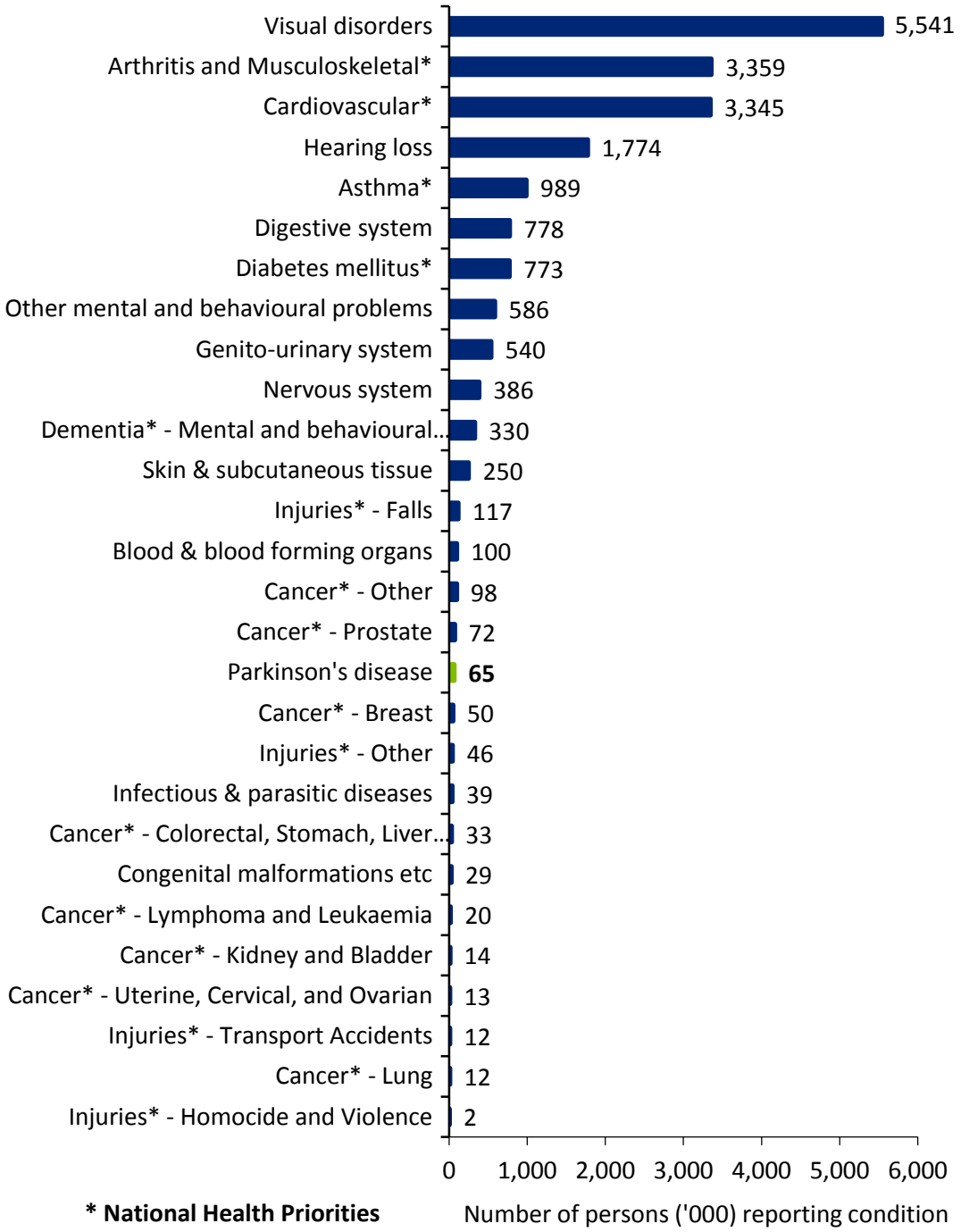
**Chart 13.1: Prevalence of diseases and injuries, 2013-14**




Note: since 2008, obesity is also considered a NHPA, however, most of the economic burden associated with obesity would be due to complications rather than obesity itself, and so it has been excluded from this chart. Prevalence of injuries refers to hospitalised cases only. 'Dementia* - Mental and…' is Dementia* - Mental and behavioural disorders, and 'Cancer* - Colorectal, Stomach, Liver…' is Cancer* - Colorectal, Stomach, Liver and Pancreatic.

Sources: ABS (2014c), AIHW (2014a), AIHW (2013), AIHW (2012), and Deloitte Access Economics' calculations.

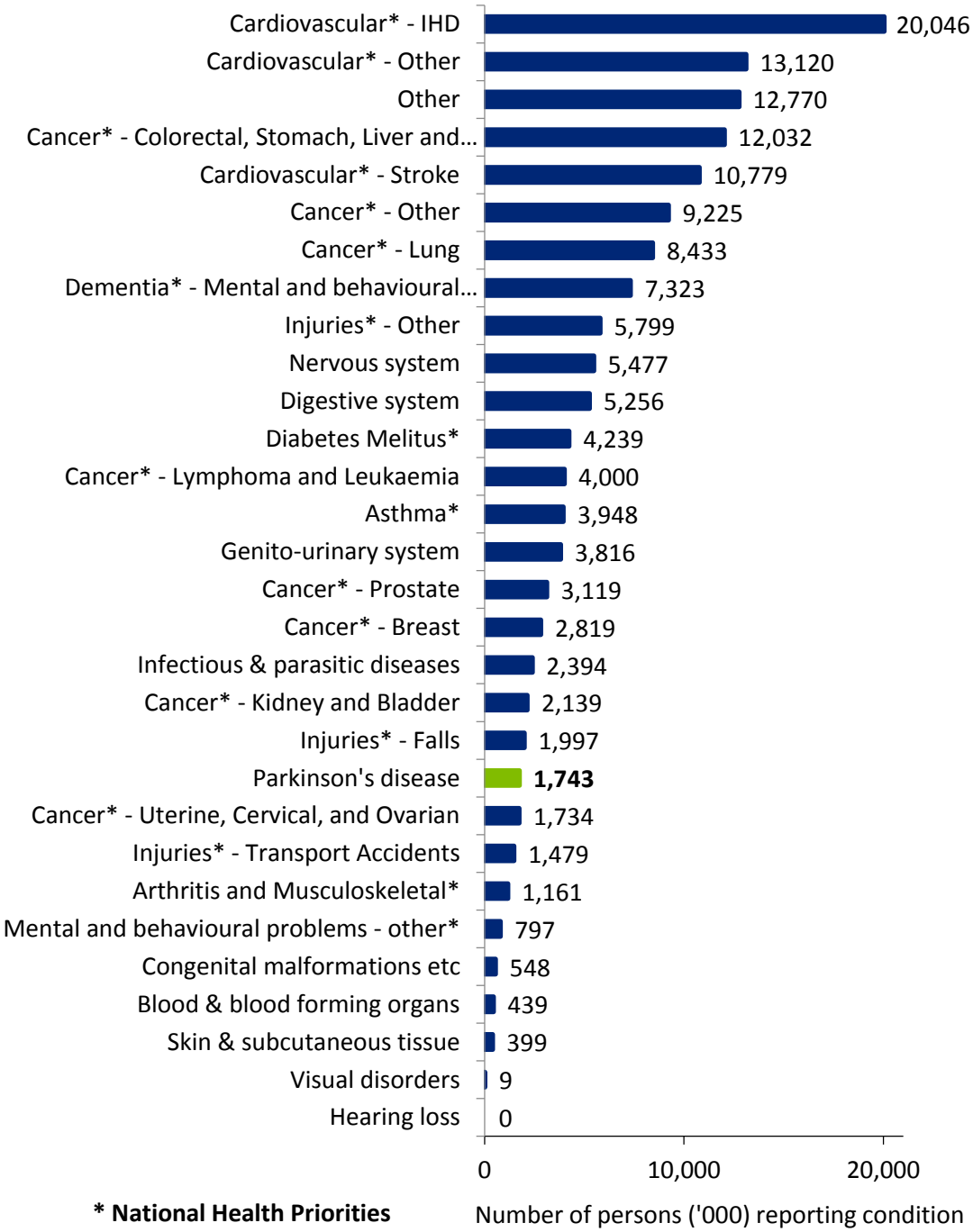
**Chart 13.2: Prevalence of disease and injuries, ages 55+, 2013-14**




Note: since 2008, obesity is also considered a NHPA, however, most of the economic burden associated with obesity would be due to complications rather than obesity itself, and so it has been excluded from this chart. Prevalence of injuries refers to hospitalised cases only. 'Dementia* - Mental and…' is Dementia* - Mental and behavioural disorders, and 'Cancer* - Colorectal, Stomach, Liver…' is Cancer* - Colorectal, Stomach, Liver and Pancreatic.

Sources: ABS (2014c), AIHW (2014), AIHW (2013), AIHW (2012), and Deloitte Access Economics' calculations.

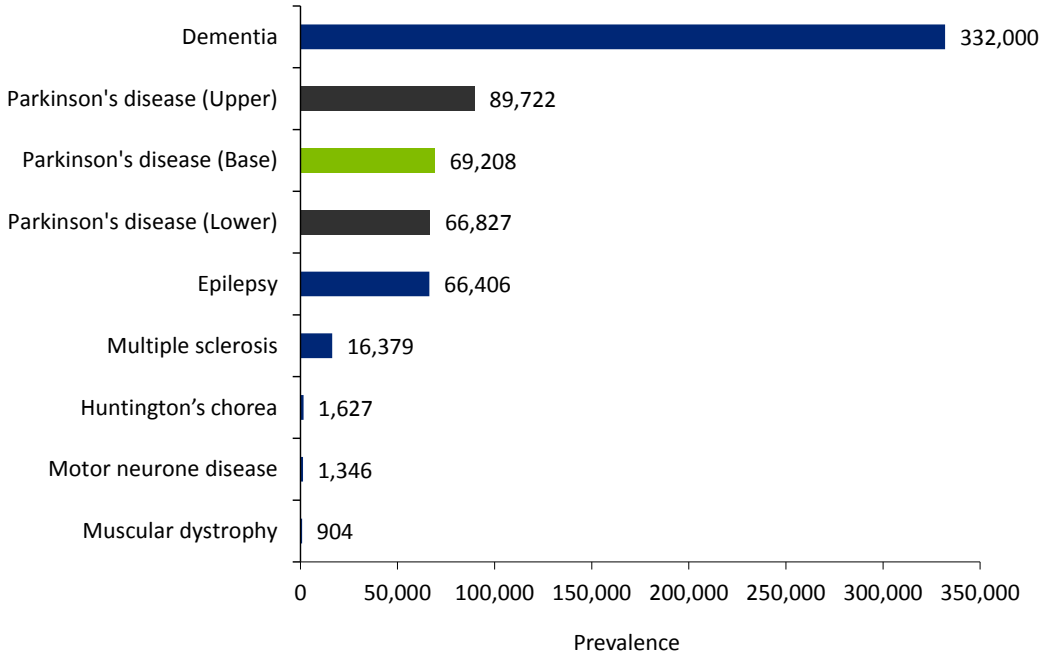
**Chart 13.3: Causes of death, 2012**




Note: 'Dementia* - Mental and behavioural…' is Dementia* - Mental and behavioural disorders, and 'Cancer* - Colorectal, Stomach, Liver and…' is Cancer* - Colorectal, Stomach, Liver and Pancreatic.

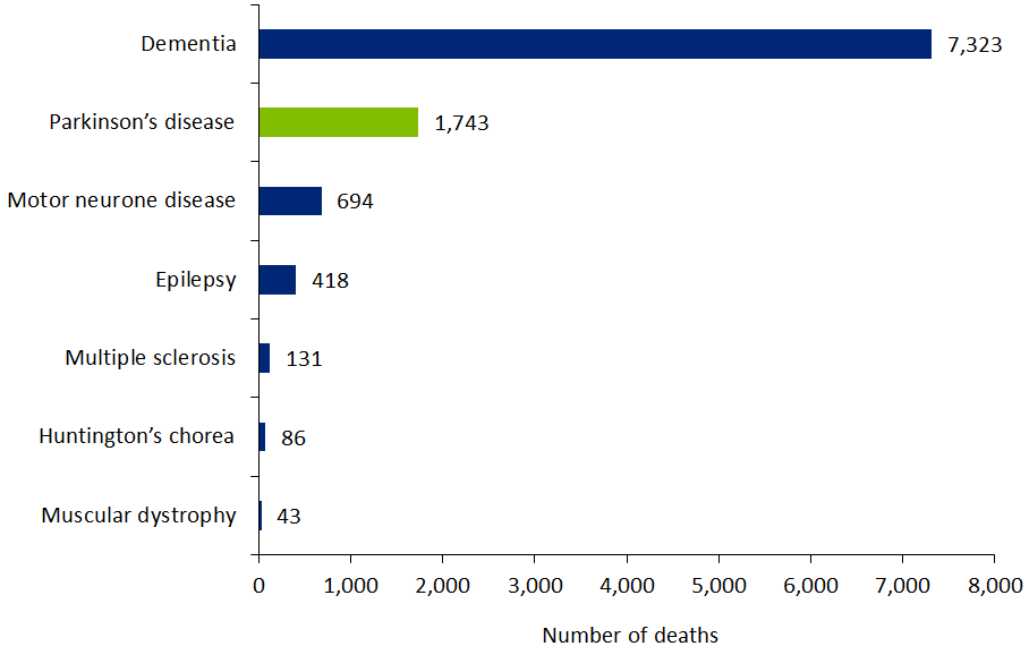
Source: ABS (2014) and Deloitte Access Economics' calculations.

### Chart 13.4: Prevalence of neurological conditions, 2014




Source: AIHW (2012), Begg et al (2007) and Deloitte Access Economics' calculations.

### Chart 13.5: Deaths due to neurological conditions, 2014

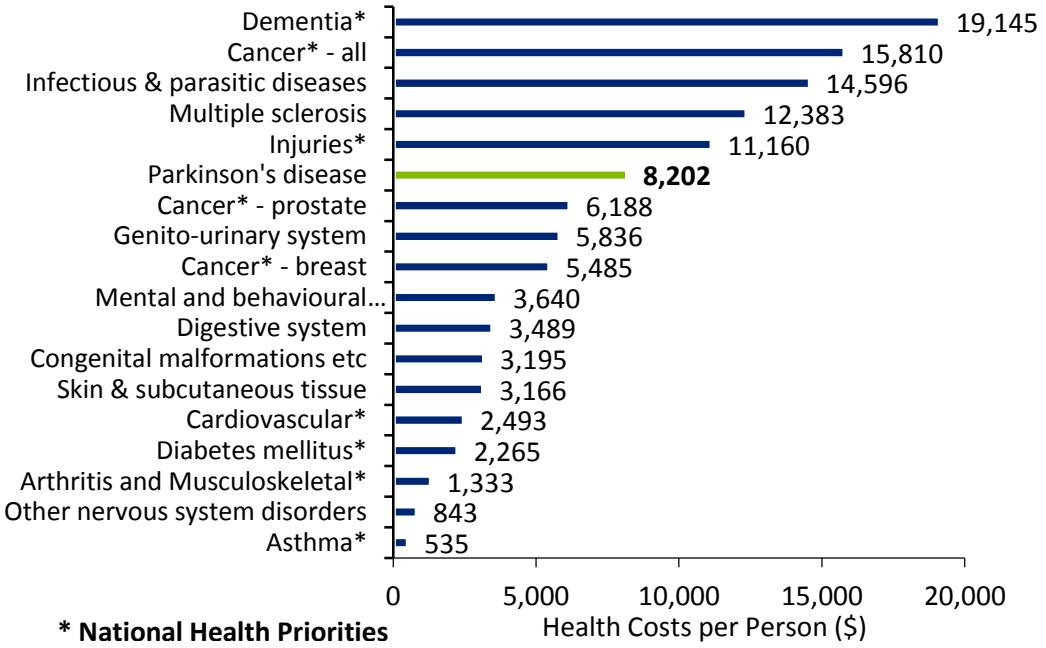



Source: ABS (2014), Begg et al (2007) and Deloitte Access Economics' calculations.

## 13.2 Health system and financial costs

Health expenditure on PD per PWP per year is relatively higher than many other diseases and injuries including prostate cancer and breast cancer, in part due to the higher use of residential aged care. However, expenditure per person is relatively lower than dementia, all cancers,[38] multiple sclerosis and infectious and parasitic diseases.

**Chart 13.6: Health system costs per person, 2014**




Note: For injuries, only data pertaining to hospitalised cases is available – as such, this represents the hospital costs per admitted patient, rather than the health system costs per person.

Source: AIHW (2005), AIHW (2010), AIHW (2012), AIHW (2013a) indexed to health inflation and growth in prevalent cases ABS (2006), ABS (2014c), AIHW (2014), Access Economics (2005), and Deloitte Access Economics' calculations.

The financial costs of PD are incurred over many years. **The lifetime financial cost of a PWP living with PD for 12 years (around $161,300) is on par with the average lifetime financial cost of cancer ($145,000).** While this is lower than many childhood cancers, it is significantly higher than prostate and breast cancer (both around $82,000).[39]

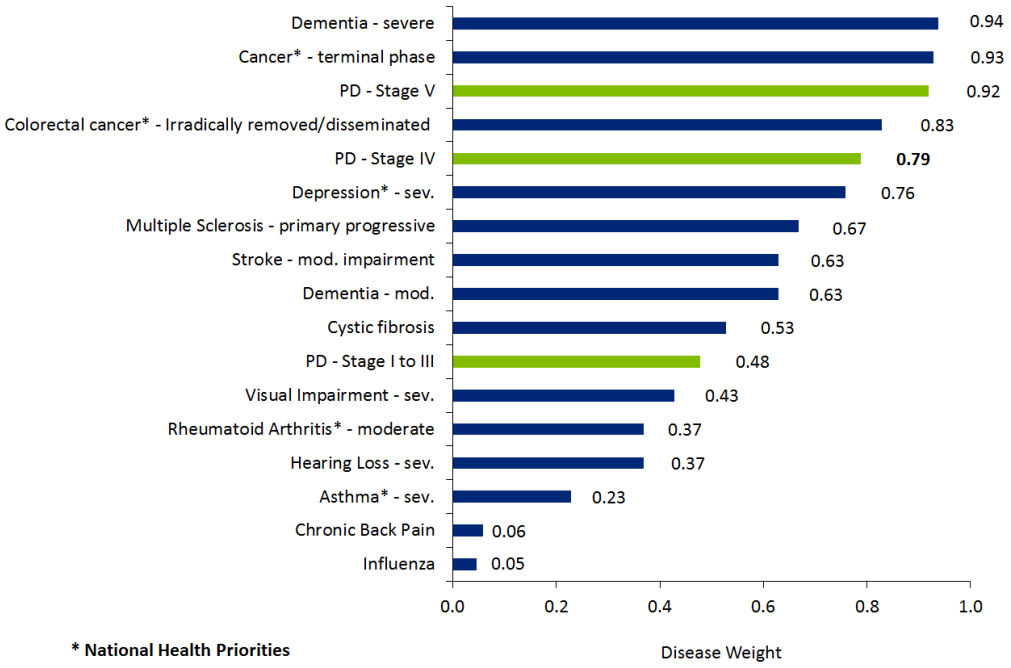
[38] All cancers per person costs are higher on average due to non-hodgkin lymphoma, leukaemia and other cancers, while colorectal cancer, breast cancer and prostate cancer are all below the average costs reported (AIHW, 2013a).

[39] Based on 2007 cost of $114,500 for all cancers, $64,800 for prostate cancer, and $64,300 for breast cancer from Access Economics (2007b), inflated to 2014.

## 13.3 Burden of disease

**PWP experience extremely high levels of disease burden.** Living with PD in the initial stages is considered more burdensome than blindness and deafness, living with PD in the intermediate stages is more burdensome than primary progressive multiple sclerosis and on-par with severe depression, and living with PD in the final stages is more burdensome than living with irradically removed or disseminated colorectal cancer, and on par with terminal stage cancer or severe dementia.

**Chart 13.7: Disability weights**




Source: Mathers et al (1998)

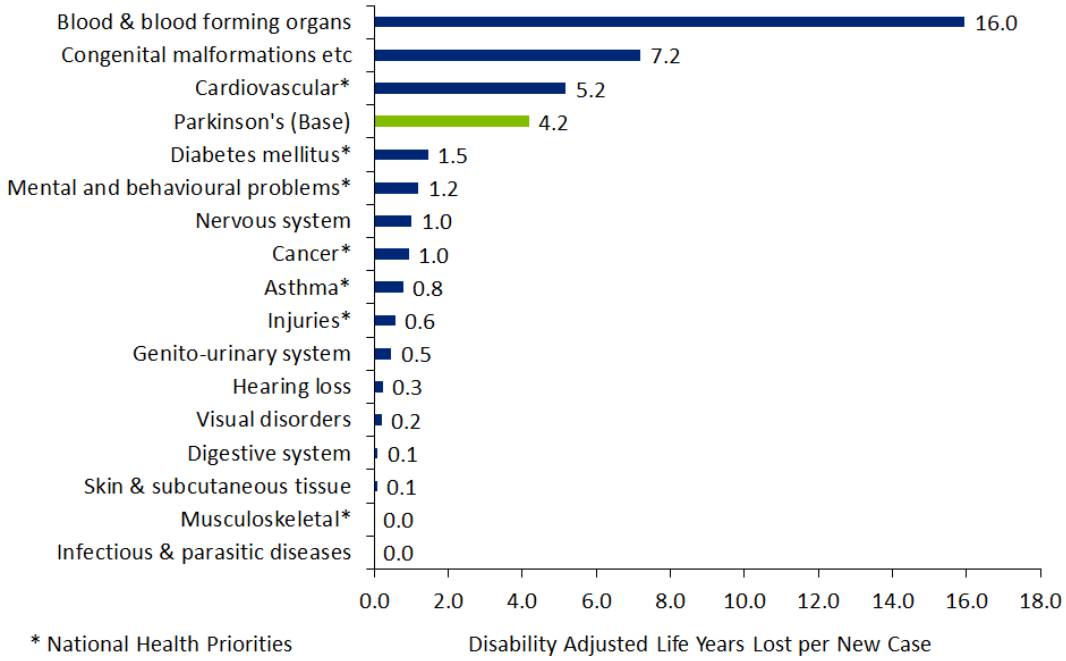
Consequently **PWP experience more DALYs per person over their lifetime compared to many other diseases and injuries**, especially as:

- PWP live with the disease for a relatively long time, compared to diseases such as cancer, and
- PWP are generally younger than people with dementia.

As in Section 10.2, the value of the burden of disease is estimated by applying the value of a statistical life year of $182,000 (OBPR, 2014) to the total DALYs due to PD. By adjusting the DALYs reported by Begg et al (2007) to 2014 in line with population demographic changes, an approximate comparison of the net value of burden of disease for conditions reported can be made. This assumes the underlying disease aetiology has remained the same since Begg et al was published and should be used with caution. However, **the net value of burden of disease of PD is similar to other**

**national health priorities such as visual impairment ($7.1 billion) and asthma ($13.2 billion).**

**Chart 13.8: Disability-adjusted life years (DALYs) per new case**




Source: Begg et al (2007), and Deloitte Access Economics' calculations.

# 13.4 Summary of comparisons

**PD is a surprisingly prevalent condition** – with higher prevalence than a number of diseases and injuries considered National Health Priority Areas (NHPAs), including:

- Cancers such as breast cancer, lymphoma and leukaemia, kidney and bladder cancer, and uterine, cervical, and ovarian cancer.
- Hospitalised injuries such as transport accidents and homicide and violence.

Health expenditure on PD per PWP per year is relatively higher than many other diseases and injuries including prostate cancer and breast cancer, in part due to the higher use of residential aged care. However, expenditure per person is lower than dementia, all cancers,[40] multiple sclerosis and infectious and parasitic diseases.

The average financial cost per PWP in 2014 was around $15,400, an increase of 61% since 2005. However, financial costs in relation to PD are incurred for many years. Although the median years lived with PD is 12.4 years, many people live with the

[40] All cancers per person costs are higher on average due to non-hodgkin lymphoma, leukaemia and other cancers, while colorectal cancer, breast cancer and prostate cancer are all below the average costs reported (AIHW, 2013a).

disease for well over 20 years. **For someone living with PD for 12 years, the average lifetime financial cost is around $161,300, which is on par with the average lifetime financial cost of cancer ($145,000).** While this is lower than many childhood cancers, it is significantly higher than prostate and breast cancer (both around $82,000).[41]

**PWP experience extremely high levels of disease burden.** Living with PD in the initial stages is considered more burdensome than blindness and deafness; living with PD in the intermediate stages is more burdensome than primary progressive multiple sclerosis and on-par with severe depression; and living with PD in the final stages is more burdensome than living with disseminated colorectal cancer, and on par with terminal stage cancer or severe dementia.

Consequently PWP experience more DALYs per person over their lifetime compared to many other diseases and injuries, especially since:

- PWP live with the disease for a relatively long time, compared to diseases such as cancer; and
- PWP are generally younger than people with dementia.

This means the net value of burden of disease of PD ($8.9 billion) is also relatively high compared to some national health priorities with higher prevalence such as visual impairment ($7.1 billion) and asthma ($13.2 billion).

[41] Based on 2007 cost of $114,500 for all cancers, $64,800 for prostate cancer, and $64,300 for breast cancer from Access Economics (2007b), inflated to 2014.

# 14 Positive steps

As discussed in Section 2, PD is a complex and disabling condition. The economic costs of PD as estimated in this report are large, with financial costs alone amounting to more than $1 billion. Including the value of the loss of wellbeing due to PD, this cost is estimated to be $9.9 billion for the year 2014.

The impact of PD is not only limited to PWP, but to their carers, friends, family and society as a whole. Carers for instance would be placed under tremendous pressure both emotionally and physically while providing quality informal care to their loved ones. It is therefore vital to consider effective policy options that not only aim at reducing the costs but the burden of PD as a whole.

**Key points:**

- PWP can face substantial out-of-pocket expenditure for medications and therapies. Improving access to appropriate treatments and therapies can improve outcomes for PWP and reduce the need to utilise other health system services, such as hospitals.
- There are large potential benefits associated with the provision of specialist services through a PD nurse specialist, including improved health outcomes for PWP and reduced emotional strain for their carers. The benefits found in the UK, such as reduction in unplanned hospital admissions and reduction in the number of bed days in hospitals, may potentially be achieved in Australia also.
- Young-onset PD continues to increase, with over 2,000 additional PWP younger than 65 in 2014 compared with 2005. Ensuring that PWP can continue to receive age appropriate support is important for improving outcomes for PWP. This includes ensuring a smooth transition from the NDIS into residential aged care.

## 14.1 Access to medications and therapies

As noted in Section 2, there is no standard treatment option for PD, and treatment may include drug therapy, physiotherapy, occupational therapy, speech therapy and surgery depending on the PWP.

### 14.1.1 Access to therapies

Access to some PD therapies is limited due to high out-of-pocket costs faced by PWP. For example, only certain items for deep brain stimulation surgery are covered by Medicare, where the average benefit paid for MBS services related to deep brain stimulation in 2014 was $239 (Department of Health, 2015). The discounted incremental costs for people receiving treatment were estimated to be

higher than $65,000 in 2006 (Medical Services Advisory Committee, 2006).[42] Consequently, most procedures are funded through private health insurance, and can require substantial additional out-of-pocket contributions, placing this treatment out of reach for people living with young onset PD.

Deep brain stimulation surgery often results in substantially reduced medication needs post-surgery, and has the potential to keep PWP in the workforce or out of residential aged care (Medical Services Advisory Committee, 2006), reducing reliance on government funded services and welfare payments.

Apomine injection therapy is a dopamine agonist treatment delivered subcutaneously. Currently, the medication is listed on the PBS and the consultations are covered by the MBS; however, the consumables used in the therapy are not supported by other funding schemes, and PWP on this therapy are required to purchase the consumables (Medical Technology Association of Australia, 2009). Purchasing consumables can impose a large financial burden on PWP, costing up to $300 per month for the necessary infusion sets and pump reservoirs (AIHW, 2012a).

### 14.1.2 Access to medications

Section 5.2 found that pharmaceuticals are the second highest health system cost, marginally higher than in-hospital and out-of-hospital costs associated with PD. Prescription medication continues to impose a large burden on household financials for many PWP. While older PWP generally qualify for subsidised PD related prescriptions, maybe younger PWP who are still working and self-funded retirees face significant out-of-pocket expenditure on prescriptions.

The general co-payment for PD related prescriptions is $36.90 until the general safety net threshold is reached – the threshold was $1,421.20 in 2014 (Department of Health, 2015a). Once PWP exceed the safety net, the co-payment is $6 for prescriptions. However, some PWP find that the cost of PD prescriptions imposes a substantial financial burden for the household. In addition to facing substantial out-of-pocket expenditure, PWP may be reducing work hours, or exiting the work-force entirely, which imposes a further financial burden.

Furthermore, some off label and non-PBS medications are beneficial in treating PD. Seroquel (quetiapine fumarate), Repreve (ropinerole) and Tasmar (tolcapone) are examples of off label and non-PBS medications that are used to treat PD.

[42] These costs included the implantable pulse generator, leads, the activator which allows patients to adjust the stimulation, bilateral implant insertions, replacement implantable pulse generators, and cost of inpatient stay associated with the procedure. The costs of the procedure are estimated in comparison to standard medical therapy, and occur over the patient's remaining life and are discounted back to current dollars, although the Medical Services Advisory Committee notes that the majority of these costs occur within the first 12 months following surgery.

Seroquel (quetiapine fumarate) is an atypical psychotic medication commonly used to manage non-motor aspects of PD such as hallucinations or delusions; however, it is only listed for use in treating symptoms associated with bipolar disorder and not PD (Department of Health, 2015a). This medication can reduce the need for PWP to enter residential aged care. Similarly, Repreve (ropinerole) is only listed for use in restless legs syndrome (Department of Health, 2015a), but is also a commonly used dopamine agonist for treating PD.

Tasmar (tolcapone) was listed on the PBS for use in treating PD, but was withdrawn due to suspected adverse reactions in 2006. Tasmar (tolcapone) is a COMT inhibitor which reduces motor fluctuations in PWP. Recent evidence has shown that tolcapone is safe and effective in treating PD (Eggert et al, 2014). PWP that use Tasmar (tolcapone) for treatment are required to import it, paying out-of-pocket. Reducing the costs faced by PWP for effective medications may be beneficial.

Currently, there is limited to no help available through private health insurance for both PBS listed medications and off label and non-PBS medications. Where private health insurance does cover these medications, it is generally limited and still requires large out-of-pocket expenditure by PWP.

### 14.1.3 Next steps

Access to some PD medications and therapies can be limited due to large out-of-pocket expenditure faced by PWP. Improving access to medications and therapies can help reduce the financial burden faced by PWP. Providing further and timely assistance to PWP to access proven therapies and medications would improve outcomes for PWP and may lead to lower financial costs elsewhere in the health sector, such as PD related hospital admissions.

## 14.2 Access to PD nurse specialists and multidisciplinary care: benefits and cost savings

The concept of Parkinson's disease nurse specialists (PDNS), first pioneered in the United Kingdom (UK) in the mid-1990, is described in this section.

### 14.2.1 The role that they play

According to the National Collaborating Centre for Chronic Conditions (2006), the PDNS's role is defined as a community based specialist practitioner with essential skills in:

- communication;
- patient and carer assessment;

- symptoms management;
- medicines supervision and monitoring;
- provision of ongoing support and advice;
- referral to other therapists; and
- education.

Specifically, in the UK, the keys roles and responsibilities of the PDNS are:

- making and receiving referrals directly to create an integrated and responsive service for PWP;
- admitting and discharging people for specified conditions and within agreed protocols;
- managing caseloads;
- providing information, education and support to PWP in their homes, in clinics and in hospitals;
- prescribing medicines and treatment and monitoring effectiveness of changes in medication and treatment;
- using later information technology (IT) to triage PWP to the most appropriate health professional; and
- using IT to identify people at risk and speed up responses to crises.

Similarly, in Australia, PDNS provide education and support for people and their families living with PD through projects such as the Shoalhaven Project (Section 14.2.3). A nursing assessment focused on PD will provide the basis for ongoing care with the PDNS providing support and advice throughout.

In Australia, the Shoalhaven Project started in 2010 in the Shoalhaven region, New South Wales, based on the successful UK model which has a network of more than 300 PDNS. The Project aimed to offer highly specialist clinical services to patients in their homes as part of a major objective within the Australian national health reform agenda, intended to provide effective early intervention that would lead to a reduction in acute hospitalisations or premature transition into residential aged care (Parkinson's NSW, 2010; Pereira et al, 2013).

### 14.2.2 Potential benefits that they bring

There is already increasing evidence that nurses can play a more significant role in supporting preventive activities and addressing the needs of an ageing population with chronic and complex conditions. Specialist nurses are already commonly used to manage other conditions, for instance, diabetes, with available literature on nurse-led diabetes clinics demonstrating high levels of patient satisfaction as well as good health outcomes (Parker and Parkinson, 2013).

In another example, the UK Multiple Sclerosis (MS) Society reported that its MS nurse specialists saved National Health Service (NHS) trusts £60,000 a year per trust

by treatment patients with symptoms of MS at home. In Australia, stroke nurse specialists played a key part in advising and educating stroke unit nursing staff on stroke management according to clinical guidelines and providing early identification of the needs of stroke patients (Christodoulou, 2012).

A number of key studies were discussed in the 2005 and 2011 reports. For instance, it was found that, by substituting some specialist care, PDNS can reduce follow up consultations with specialists and general practitioners and consequently free up time for initial assessment and diagnosis. Hobson et al (2003) estimated that the introduction of a PDNS saved the Conwy and Debighshire NHS trust around £100,000 of specialist consultant time with outpatients per year.

In another study, Hurwitz (2005) conducted a two year randomised controlled trial in 438 general practices in nine randomly selected health authority areas in England. Relative to patients receiving standard care (i.e. the control group), patients attended by nurse specialists scored better on global health questions that rated their general sense of wellbeing, without incurring additional healthcare costs. The finding was a positive development relative to an earlier study by Reynolds et al (2000), who found limited benefits from having a PDNS, which was likely due to a lack of a control group.

A comprehensive effort was made by Parkinson's UK in 2011 to collect and present evidence to show the value of PDNS in monetary and practical terms. This study remains the most up to date research on the potential cost savings due to the appointment of PDNS. On average, the appointment of a PDNS led to savings ranging from £10,000 to over £150,000 for each Primary Care Trust. Various factors contributed to this savings, such as a reduction in unplanned hospital admissions and in the number of days spent in hospital (Table 14.1).

**Table 14.1: Potential cost savings**

| Types | Who | Extent |
|---|---|---|
| Avoided consultant appointments | Western Cheshire Primary Care Trust | Between January 2009 and February 2010, 504 patients were seen by PDNS rather than by the consultant. Consequently, it saved on average £97,776 in avoided consultant appointments each year |
| | Doncaster Primary Care Trust | On average, in a four-week month, 56 patients were reviewed in secondary care clinics, and 20 patients in nurse-led clinics, by PDNS. This resulted in a cost saving of £114,912 over a 12-month period. |
| | Bury Primary Care Trust | Consultant follow-up appointments have been reduced by six appointment slots per week since a PDNS started in post, which translated to an annual cost reduction of £32,568 each year |

| Types | Who | Extent |
|---|---|---|
| | Derbyshire Primary Care Trust | For an average 12-month period, 206 patients were seen in a nurse-led clinic rather than by the consultant resulting in a saving of £25,421 in avoided consultant appointments. |
| | Suffolk Primary Care Trust | Between March 2006 and July 2007, 159 patients were seen in a nurse-led clinic rather than by the consultant resulting in a saving of £17,331 in avoided consultant appointments. |
| Reduce unplanned hospital admission | Pennine Acute Trust | Admission figures have reduced by 10% since a PDNS started in post. The trust calculated the fixed annual cost saving of this reduction at around £81,522 each year. |
| | Harlow Hospital | A reduction of hospital admission by 67% since a PDNS started in post translating to around £80,000 in savings. |
| Reduce admissions for specialist care | West Cheshire Primary Care Trust | The PDNS prevented three day-case admissions for people starting apomorphine injections and two people with Parkinson's were started on their apomorphine pumps in the community, avoiding the need for a hospital stay of up to five days each in a specialist unit. |
| | East Berkshire Primary Care Trust | PDNS was able to carry out apomorphine challenges in the day hospital and GP practice, rather than with people as inpatients resulting in cost savings of around £10,000 over 18 months. |
| | Bury Primary Care Trust | It was estimated that providing the apomorphine service in the community saved £3,235 per patient. |
| Reduce number of days spent in hospital | Pennine Acute Trust | It was estimated that the PDNS appointed in 2009 saved the Trust £190,218 each year by reducing the number of bed days for PWP. |
| | Harlow Primary Care Trust | The appointment of a PDNS resulted in a reduction of number of bed days leading to a saving of £173,396 a year. |
| | Derbyshire County Primary Care Trust | Appointment of a PDNS has resulted in a saving of £77,448 per year. |
| Avoiding readmissions | Bury Primary Care Trust | Readmission figures for PWP have been reduced by 30% since the appointment of a PDNS over a 12-month period. |

Source: Parkinson's UK (2011).

## Part of a multidisciplinary team

A nurse specialist can be part of a multidisciplinary team to deliver improved health outcomes to patients. For instance, there were several studies of multidisciplinary

care in PD comparing outcomes before and after the intervention. Outpatient multidisciplinary care programs have reported short term improvements in motor function, gait speed, stride length, speech, depression and health-related quality of life (Sitzia et al, 1998; Trend et al, 2002; Carne et al, 2005; Skelly et al, 2012).

Randomised controlled trials have also increasingly showed positive outcomes being achieved. For instance, Guo et al (2009) showed promising results with improvements in quality of life, motor function and ADL at eight weeks with a program of group education combined with personal rehabilitation. While studies have increasingly showed positive results in relation to a multidisciplinary team providing care to PWP, neither the membership nor the degree of team integration was consistent across published trials. However, this is changing.

A recent study by Gage et al (2014) conducted a randomised controlled trial on specialist rehabilitation for PWP in the community. It was a pragmatic three-parallel group randomised controlled trial with Groups A and B receiving specialist rehabilitation from a multidisciplinary team that specifically comprised PDNS, physiotherapists, occupational therapists and speech and language therapists. In addition to a multidisciplinary team, Group B received ongoing support from a care assistant for a further four month period. Participants in control Group C received care as usual (with no multidisciplinary team and ongoing support). Their findings showed that relative to the control Group C, participants in Groups A and B had reduced disability and improved non-motor symptoms and improved health-related quality of life. Their carers reported improved psychological wellbeing. It was reported the multidisciplinary teams costed around £833 per patient however the qualitative analysis by the authors indicated that patients and carers may benefit in a less tangible manner, including improved knowledge and understanding of PD, which may not be captured by typical measurable outcomes.

### 14.2.3 Shoalhaven Project

In Australia, the Shoalhaven Project started in 2010 in the Shoalhaven region, New South Wales, based on the successful UK model which has a network of more than 300 PDNS. The Project aimed to offer highly specialist clinical services to patients in their homes as part of a major objective within the Australian national health reform agenda, intended to provide effective early intervention that would lead to a reduction in acute hospitalisations or premature transition into residential aged care (Parkinson's NSW, 2010; Pereira et al, 2013).

According to Pereira et al (2013), preliminary findings showed that over 80% of all clinical attendances were conducted in the home environment. Over 60% of all clinical attendances were PWP in the most advanced stages of the condition, indicating that the service delivery was directed towards those cases with greatest clinical needs. There was no significant decline in patients' quality of life and their carers reported improved quality of life and mood ratings. An equally important

finding was that 90% of the healthcare professionals expressed confidence that the PDNS would help reduce hospitalisations and residential aged care transitions.

### 14.2.4 Next steps

Cost effective interventions have the ability to reduce the immediate burden of the disease, help PWP maintain their independence, and ultimately slow growth in the future costs of PD, and enhance the quality of life of PWP and their carers both in the immediate and longer term.

Increasingly, research has indicated the potential benefits associated with provision of specialist services through a PDNS. Patients have improved health outcomes and their carers report less emotional strain. The benefits found in the UK, such as reduction in unplanned hospital admissions and reduction in the number of bed days in the hospitals, can potentially be achieved in Australia also. Such savings – ranging from £10,000 to over £150,000 across Primary Care Trusts in the UK – if replicated in Australia could lead to a substantial reduction in the cost of PD to Australian society as a whole.

To achieve the benefits and cost savings as seen in the UK, policy makers should look into increasing access to PDNS to levels recommended by the National Institute for Health and Care Excellence in the UK.

## 14.3 Improving care in residential aged care

Currently, there are estimated to be 8,500 PWP, or 12.2% of all PWP, in residential aged care in Australia. PWP are often in residential aged care due to functional impairment, drug complications such as hallucinations, and comorbidities associated with PD such as dementia and incontinence. As noted in Section 3.4, PWP faced an increased chance of residing in residential aged care compared with the general population. Improving both access to residential aged care and the appropriateness of care received in residential aged care can improve outcomes for PWP, and also help to reduce the high costs associated with aged care (Section 5.2).

Up to the age of 65, PWP generally receive assistance through established support schemes such as the DSP for PWP or the Carer Payment and Carer Allowance for carers of PWP. In the future, many PWP under the age of 65 will access care through the NDIS. However, there is a gap when transitioning from the NDIS or DSP to residential aged care at 65. PWP who are aged over 65 years are ineligible under the current arrangement for NDIS services. PWP may need to be placed in residential aged care to continue to receive support that they require, which can potentially reduce their independence (Physical Disability Australia, 2012).

Young-onset PD continues to increase, with over 2,000 additional PWP younger than 65 in 2014 compared with 2005. Ensuring that PWP can continue to receive age appropriate support is important for improving outcomes for PWP. This

includes ensuring a smooth transition from the NDIS into residential aged care (Physical Disability Australia, 2012).

Furthermore, condition appropriate training for staff is important in supporting PWP in residential aged care. Parkinson's Australia now runs a nation-wide training program for residential aged care staff – '*caring for people with Parkinson's*' – which is designed to educate and inform staff to improve the quality of care provided for PWP in residential aged care facilities (Parkinson's SA, 2015). The program aims to:

- increase the awareness and knowledge of the signs, symptoms and treatments of PD;
- increase the understanding of the needs of someone living with PD; and
- increase the capacity of staff in providing care for someone living with PD.

Increasing access to this training program across all residential aged care facilities may help to improve outcomes for PWP in residential aged care.

## 14.4 Investment in research

The returns to investment in medical research are estimated to be as high as 2.4:1 in terms of the value of gains in healthy life (Access Economics, 2003). The establishment of the Medical Research Future Fund in 2015 is estimated to double government funding for medical research from 2022-23 (Commonwealth of Australia, 2014), which can assist with continued funding for PD and other degenerative neurological conditions. Ensuring that research funding will continue to be available and grow for PD and other degenerative neurological conditions is important. Research into PD continues to advance, and research is identifying ways of slowing or halting the progression of PD.

Research priorities should be directed towards:

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

Research should continue to be collaborative and multidisciplinary, including interacting with other degenerative neurological conditions.

## 14.5 Summary of positive steps

Access to some PD medications and therapies is sometimes limited and improving access to medications and therapies can help reduce the financial burden faced by PWP. Providing further and timely assistance to PWP to access proven therapies and medications would improve outcomes for PWP and may lead to lower financial costs elsewhere in the health sector, such as PD related hospital admissions.

Access to PD nurse specialists and multidisciplinary care is important for improving outcomes for PWP. Increasingly, research has indicated the potential benefits associated with provision of specialist services through a PDNS. Patients have improved health outcomes and their carers report less emotional strain. The benefits found in the UK, such as reduction in unplanned hospital admissions and reduction in the number of bed days in the hospitals, can potentially be achieved in Australia also and lead to substantial reduction in the cost of PD to Australian society as a whole.

Young-onset PD continues to increase, with over 2,000 additional PWP younger than 65 in 2014 compared with 2005. Ensuring that PWP can continue to receive age appropriate support is important for improving outcomes for PWP. This includes ensuring a smooth transition from the NDIS into residential aged care. Furthermore, care provided in residential aged care should continue to be evidence-based and increasing access to nation-wide training programs such as Parkinson's Australia's '*Caring for people with Parkinson's*' across all residential aged care facilities would help to improve outcomes for PWP.

Medical research can provide large returns to investment, and is expected to continue to be healthy with the establishment of the Medical Research Future Fund in 2015. PD related research should continue to be collaborative and multidisciplinary, including interacting with other degenerative neurological conditions.

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