Deloitte Access Economics

Living with Parkinson's Disease – update

Parkinson's Australia

October 2011

Deloitte.

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Glossary

ABS	Australian Bureau of Statistics
ADL	activity of daily living
AEM	Access Economics Macroeconomic Model
AIHW	Australian Institute of Health and Welfare
ATO	Australian Taxation Office
BEACH	Bettering the Evaluation and Care of Health
BOD	Burden of Disease
CACP	Community Aged Care Program
CPI	Consumer Price Index
DBS	Deep Brain Stimulation
DALY	disability-adjusted life year
DCIS	Disease Costs and Impact Study
DAE	Deloitte Access Economics
DAE DEM	Deloitte Access Economics Demographic Model
DOHA	Department of Health and Ageing
DSP	disability support pension
DWL	deadweight loss
EACH	Extended Aged Care Program
GP	General Practitioner
HACC	Home and Community Care Program
HSE	Health and Safety Executive
MRI	magnetic resonance imaging
NHPAC	National Health Priority Action Council
NINDS	National Institute of Neurological Disorders and Stroke
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
FAHCSIA	Department of Families, Housing, Community Services and Indigenous Affairs
PWP	People with Parkinson's disease
VHC	Veterans Home Care Program
VSLY	value of a statistical life year
YLD	years of healthy life lost due to disability
YLL	years of life lost due to premature death

Executive Summary

Parkinson's disease (PD) is the second most common neurological condition in Australia but remains one of the least understood in terms of its cause. There is a lack of awareness in the health and general community of the challenges and needs of those suffering from this complex and disabling condition, as well as community stigma and constraints in the delivery of health and social support services. As a result, Australia needs to develop a greater, more positive public awareness and understanding of PD among the general community.

Since the 2007 Access Economics report 'Living with Parkinson's disease: Challenges and positive steps for the future' was published, limited progress has been made in relation to the recommended 'positive steps'. This updated report highlights that a growing number of Australians are living with PD, and that PD will continue to be associated with significant and growing health system, lost productivity and other costs.

Key findings:

PD is a chronic, progressive, incurable, complex and disabling neurological condition. PD sufferers 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.

Incidence, prevalence and mortality

It is conservatively estimated that in 2011[1] over 64,000 Australians were living with PD, of which, 52% were male and 48% were female. This equates to 283 per 100,000 in the total Australian population, or 857 per 100,000 among the population aged over 50. Based on these estimates, approximately one in every 350 people in Australia lives with PD.

- The proportion of people with PD (PWP) is related to the size of the older population. As such, it is expected to grow with population ageing.
- Over 80% of PWP are aged over 65 years. However, people are diagnosed as young as 30 years. This report estimates that in 2011 there were over 2,000 PWP aged in their 30s and 40s.
- More than 12,000 Australians of working age (15-64) are estimated to be living with PD, comprising 19% of PWP.

[1] Throughout the report, '2011' refers to the financial year 2010-11 (i.e. June 2010 – June 2011.

- An estimated 10,500 new cases of PD were diagnosed in 2011, equivalent to nearly 30 new diagnoses every day.
- The median time from onset to death is 12.2 years, though many PWP live with the disease for well over 20 years.
- In 2011, an estimated 6,600 PWP are residing in aged care facilities, of which 188 are aged younger than 65 years (equal to 1.6% of all PWP aged younger than 65 years).
- PD is a surprisingly prevalent condition – in 2005, estimated prevalence was higher than a number of diseases and injuries considered National Health Priority Areas (NHPAs) including:
    - Some cancers, such as prostate cancer, lymphoma and leukaemia, kidney and bladder cancer, and uterine, cervical, and ovarian cancer (and breast cancer, colorectal, stomach, liver and pancreatic cancer for people aged over 55 years).
    - Injuries such as homicide and violence, suicide and self-inflicted injuries, fires, burns and scalds, and machinery accidents.

Compared to other neurological conditions, in 2005, PD had the second highest prevalence and number of deaths (exceeded only by dementia).

Costs

The total financial cost of PD per annum in 2011 was around $775.4 million.

In addition, there were $35.9 million of transfer payments – lost tax revenue and welfare payments. These payments change the distribution of who bears the costs, and are also associated with smaller real efficiency losses from reallocation of resources, called 'deadweight losses' (DWL).

Health system costs were by far the largest component of the financial costs of PD ($478.5 million, 62%). 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 (Temlett and Thompson, 2006).

Deadweight losses represented the next greatest cost ($121.3 million, 16%), followed by costs relating to lost productivity for PWP ($107.3 million, 14%). Productivity costs were higher for males aged 50-59 (largely reflecting their higher earnings profile).

The estimated cost of informal care provided to PWP more than doubled between 2005 and 2011 ($11.2 million vs. $5.4 million). This measures income in a formal work environment foregone by carers. The growth reflects the additional PWP and higher average earnings in the workforce.

The average financial cost per PWP in 2011 was around $12,000, an increase of 48% since 2005. However, financial costs in relation to PD are incurred for many years. Although the median years lived with PD is 12.2 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 $144,000, which is on par with the lifetime cost of cancer ($165,000[2]).**

[2] Based on 2007 cost of $114,500 from Access Economics (2007b)

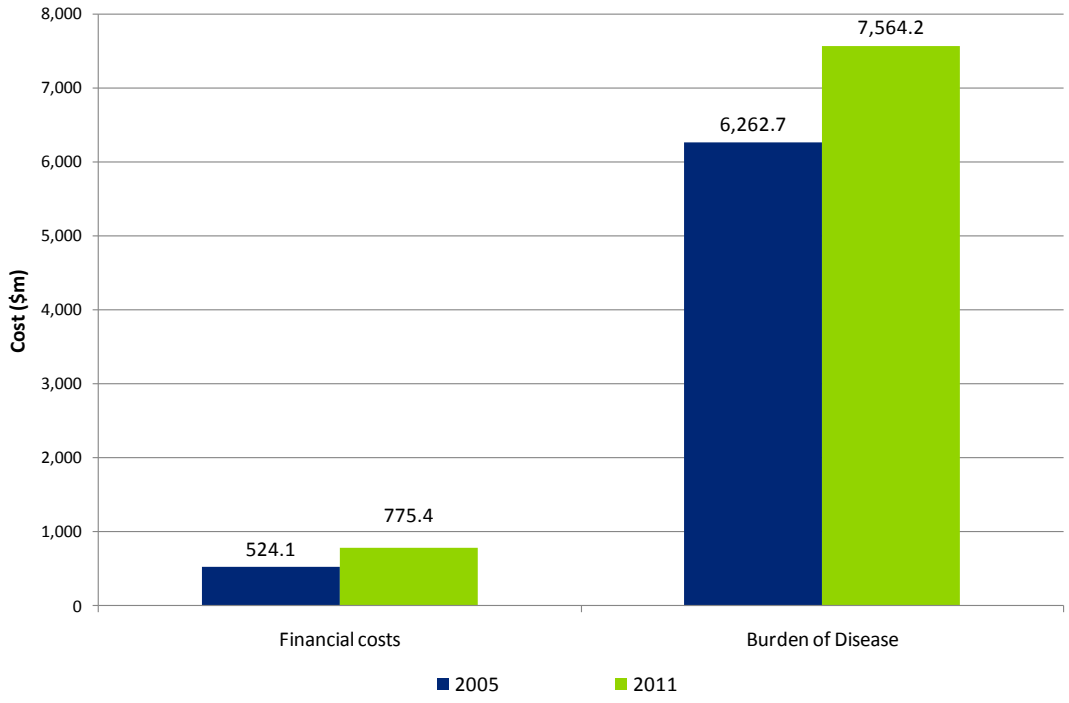
In addition to financial costs, the burden of disease – the suffering and premature death experienced by people with PD – is estimated to cost an additional 46,069 Disability Adjusted Life Years (DALYs) (years of healthy life lost), with 76% due to disability and the remaining 24% due to premature death. **The net value of the burden of disease was $7.6 billion in 2011.**

The total economic cost[3] of PD in 2011 was $8.3 billion.

Growth in prevalence and costs

- It is estimated that by 2031 there will be 115,300 PWP, equating to average growth in prevalence of 4% per annum over the next 20 years.
- There were an additional 9,300 PWP in 2011 compared to 2005, equating to growth of 17% over the 6-year period.
- The incidence of PD (i.e. the number of new cases each year) increased at an average rate of 3% per year over the 6-years to 2011.
- The financial cost of PD increased by 48% since 2005, largely due to the growth in health system costs and productivity costs.
- The estimated value of the burden of disease increased by 21% from the 2005 estimate.
- Overall, the total economic cost of PD per annum has increased by 23% since 2005.

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



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

Positive steps – progress since 2007 and the way forward

Overall, there has been limited progress regarding government actions and policies relating to PD and the "Positive Steps" identified in the 2007 report. Some positive developments include:

- the development of an online education program for GPs which is widely used;
- approval of some new medications; and
- the establishment of a Neurological Alliance.

A major challenge facing advancement in reducing the burden of PD is the lack of government funding for services focussed specifically on PD. PD is not formally recognised as a chronic disease under the Australian Government National Chronic Disease Strategy, and is therefore not able to access funding under that Strategy. Over a lifetime, PWP experience greater disability than people with any of the conditions that are recognised as chronic (including cancer, diabetes, heart disease, stroke and vascular disease).

There remains a lack of awareness in the general community and in many parts of the health services community, of the challenges and needs of PWP, their families and carers. This often results in sub-optimal care, amplifying suffering and leading to higher associated costs. This is exacerbated for people with early onset PD, who often have additional needs (e.g. forming relationships, children and financial planning), and for whom dedicated services are currently very limited.

A lack of synthesis in the approach to tackling PD has resulted in many effective treatments being too expensive. For example, a medication may be listed on the Pharmaceutical Benefits Scheme (PBS), but the consumables required to administer it may not be.

A key positive step for the future relates to funding for the education of specialist Parkinson's nurses. In Australia in 2011, there are 33 specialist Parkinson's nurses, compared with 264 in the UK, none of whom are funded by the Australian Government (based on advice from the Movement Disorders Faculty of the Royal College of Nursing). Based on evaluation undertaken in the UK, a single Parkinson's nurse can save approximately $60,000 in consultant appointments, $105,000 in avoided hospital admissions and $194,000 in hospital bed days per annum (Parkinson's UK, 2011). The potential benefits are stark in the context of growing numbers of PWP and significant and growing health system and other financial costs in Australia going forward.

Deloitte Access Economics
October 2011

1 Background

The purpose of this report is to provide an update to the 2007 report, 'Living with Parkinson's Disease'. It is not the intention to replace that report, rather, to update information where necessary.

The report is structured as follows:

- In chapter 2, there is a description of PD, its impact on the individual, and treatment pathways, covering major recent advances from research since the original Access Economics report was released.
- Prevalence and mortality of PD in Australia, with twenty years of projections (2011-2031) are presented in chapter 3. This includes analysis of prevalence by disease stage, the number of people with PD residing in aged care facilities and deaths due to PD. The updates are based on current demographic data. A literature scan was undertaken to search for any new epidemiological data, and this is described in chapter 3.
- Estimates are presented of the economic impacts of PD over a twenty-year forecast period (2011-2031) on:
    - health system costs in chapter 5;
    - productivity in chapter 6;
    - informal care costs and other financial costs in chapter 7; and
    - efficiency losses from transfers (income support and taxation foregone) in chapter 8.
- The burden of disease is presented in chapter 9.
- The total economic impact of PD in Australia is summarised in chapter 10.
- Sensitivity analysis is presented in chapter 11.
- Conclusions, highlighting progress in policy and programs are outlined in chapter 12.

2 PD in Australia

2.1 What is PD?

PD is a disease of the central nervous system, affecting in particular the autonomic nervous system. Degeneration of nerve cells, or neurons, that normally produce dopamine impairs the transmission of signals within the brain resulting in a reduced ability to control muscle activity. For details on different types of PD, see Access Economics (2007a).

2.2 What causes PD?

The cause of PD is essentially unknown. Many risk factors have been proposed, however, scientific evidence has not been found to support a large effect. Possible causes identified include (NINDS, 2005:

- **Accelerated ageing** — PD may be an acceleration of the normal, age-related deterioration of neurons.
- **Oxidative damage** – Free radicals are unstable and potentially damaging molecules generated through normal chemical reactions in the body.
- **Environmental toxins** – an external or internal toxin which destroys the neurons.
- **Genetic predisposition** – 15% to 20% of PWP have a close relative who has also experienced PD symptoms.

Further details of these factors and other potential risks are described in Access Economics (2007a).

2.3 Symptoms of PD

Symptoms of PD are varied, however, the four major symptoms of PD are (NINDS, April 2005b):

- **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.
- **Akinesia and Bradykinesia** – slowness or loss of spontaneous movement that is 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.

Further information on other symptoms can be found in Access Economics (2007a).

2.4 Prognosis

PD is a chronic and progressive disease with substantial disability. The stages of PD were described in Access Economics (2007a). The majority of PWP 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. PWP do not necessarily progress from one stage to the next, but can drop down a stage during treatment or experience accelerated progression. The median time from disease onset to death is 12.2 years.

2.5 Current treatment pathways

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. Sometimes people are given anti-PD drugs to see if they respond, or other tests may be performed, such as MRI and CAT scans, to rule out other disorders with similar symptoms. The presence of other diseases, such as dementia and general ageing can obscure PD symptoms and reduce the chance of an accurate diagnosis. Consequently, many PWP in Stage I are often under- or misdiagnosed and the time from disease onset to diagnosis can be substantial.

Currently there is no cure for PD. Figure 2.1 and Figure 2.2 show the current guidelines for treating PD. The main treatment for PD is a selection of drugs that attempt to temporarily replenish or mimic dopamine in the brain. Drug treatment regimes are complex, with continual and slight adjustments in dosages, timing and combinations of drugs to reduce symptoms. Consequently adequate medication management is an important contributor towards reducing unnecessary disease burden.

Commonly prescribed medication includes:

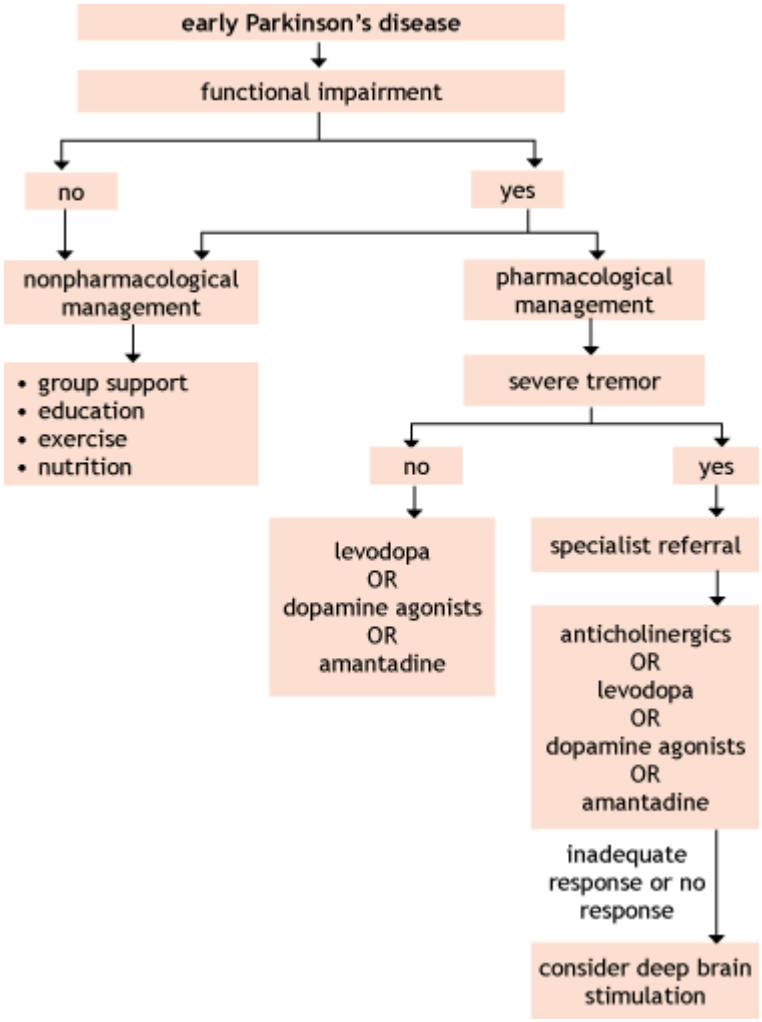
- **Dopaminergic or Related Therapies**
  - **Levodopa** is the main drug used to treat PD. Nerve cells can use this drug to produce additional dopamine (dopamine cannot be used directly as it does not cross the blood-brain barrier). However it can have significant side effects including nausea, vomiting, 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.
  - **Carbidopa or benserazide** is often added to levodopa to delay its conversion to dopamine until it reaches the brain thus improving its 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**, also known as deprenyl, inhibits the enzyme monoamine oxidase-B (MAO-B) which metabolises dopamine in the brain. This delays the need

for levodopa in the early stages of PD by 8 to 12 months (Rubenstein, 2001: 740) 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**
  - **Bromocriptine, pergolide, pramipexole, cabergoline and ropinirole** mimic dopamine in the brain and can be used as an alternative[4] (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. Alone these drugs are less effective than levodopa and their side effects include paranoia, hallucinations, confusion, dyskinesia, nightmares, nausea and vomiting. PBAC had recommended the listing of ropinirole on the PBS for PD in December 1997, but it was never listed as the sponsor decided not to proceed with the listing. In March 2006 PBAC rejected listing of ropinirole for the treatment of restless legs syndrome (Department of Health and Ageing 2006).
  - **Apomorphine**, given subcutaneously, is a very potent dopamine agonist (works within 3-20 minutes of injection), however it has a brief duration (half an hour to an hour) and must be taken with domperidone (an antiemetic) to counteract nausea (Chaudhuri, 1998). It is often used as a rescue drug for PWP who have found that the effectiveness of oral medications has reduced and their "on-off" fluctuations have increased, but 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. Studies have shown that they have allowed a reduction of total daily levodopa dosage by 30% and reduce motor fluctuations and the end of dose "wearing off" effect (Rubenstein, 2001: 743). Entacapone is now available in a single medication with levodopa and carbidopa. However tolcapone was de-registered with the TGA due to liver side-effects in 1999.
  - **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. Used in the early stages or to boost levodopa or anticholinergics. Side effects include mottled skin, oedema, confusion, blurred vision and depression (NINDS, April 2005b).

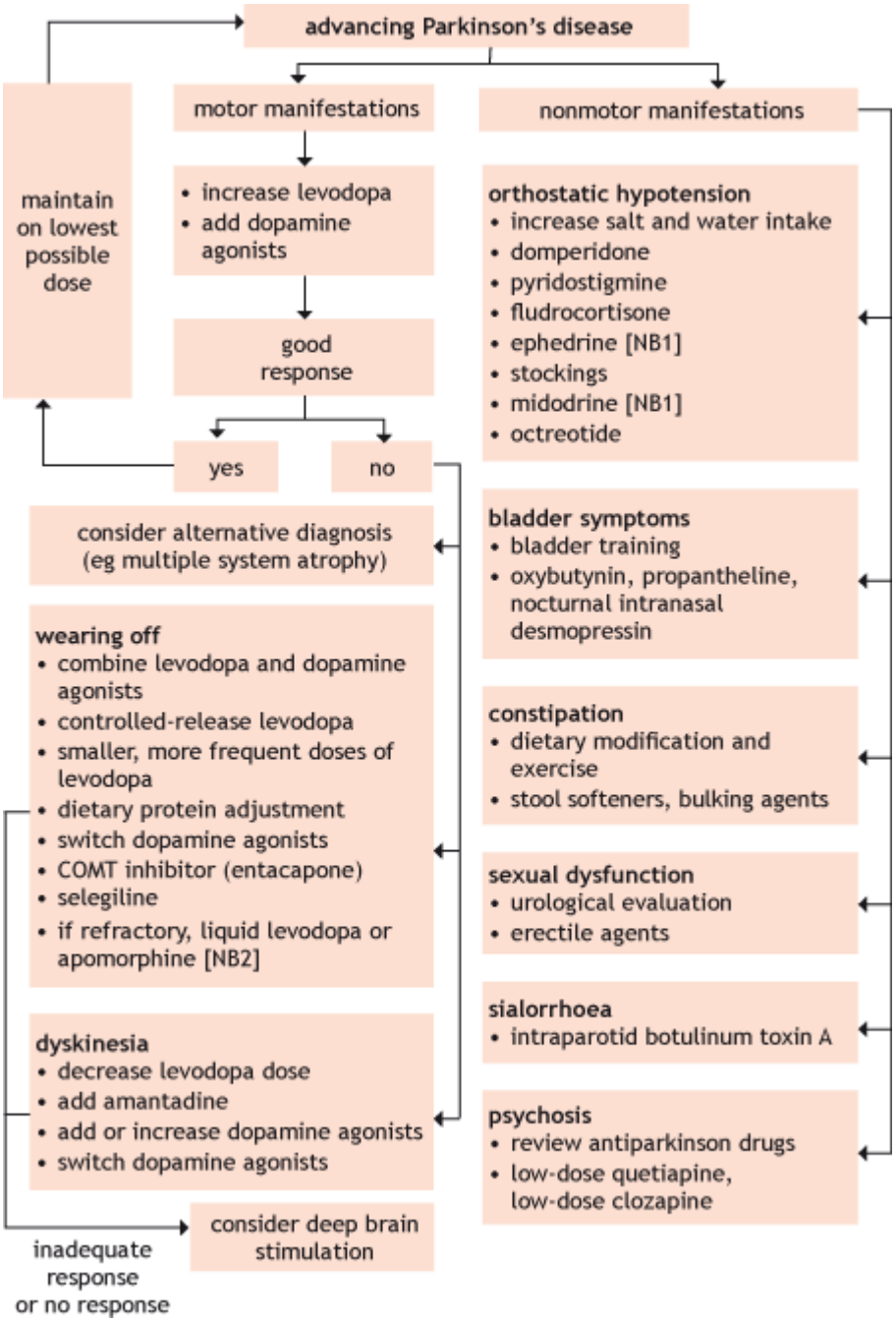
[4] Dopamine agonists can delay levodopa therapy by 2 to 3 years (Rubenstein 2001: 741).

Figure 2.1: Management of early Parkinson's disease



Source: Neurology Expert Group (Therapeutic Guidelines Limited) 2007.

Figure 2.2: Treatment of advancing Parkinson's disease and non-motor complications



Source: Neurology Expert Group (Therapeutic Guidelines Limited) 2007.

Other therapies for PD include:

- **Surgery** – 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).

- **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 (Deane, 2001a). Therapists can also provide careful assessment and diagnosis of swallowing problems (dysphagia) and advise on swallowing technique, exercise and may offer dietary alternatives and advise on food consistency to reduce the risks of ill health (such as an increased chance of pneumonia) and promote safety and comfort in swallowing (Deane, 2001b).
- **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, thus minimising the likelihood of injuries. Interventions may include support in organising the daily routine, learning new skills for alternative or adaptive ways to carry out activities, or providing and advising on specialist equipment or resources, for example, mobility aids, home or car modifications (Deane, 2001c).
- **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, such as learning to perform household chores or home/vehicle maintenance.

2.6 Recent medical advances

2.6.1 Deep brain stimulation

Deep brain stimulation involves implanting an electrode on the brain. This is used to deliver high frequency stimulation and block electrical signals targeted to areas of the brain that control movement blocking the abnormal nerve signals that cause tremor and PD symptoms. Generally, these targets are the ventrointermedialis nucleus of the thalamus (VIM), subthalamic nucleus (STN), and globus pallidus pars interna (GPi).

Before the procedure, a neurosurgeon uses an MRI, CAT scanning or microelectrode recording to identify and locate the exact target in the brain generating the PD symptoms.

The DBS 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, April 2005c).

DBS 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.

At present, this procedure is only available for PWP whose symptoms can no longer be managed medically. While most PWP still need to take medication after undergoing DBS, many PWP are able to greatly reduce the amount of medication taken.

In 2006, the Australian Government agreed to fund deep brain stimulation for Parkinson's disease (MSAC, 2006). In 2006-07, 91 DBS procedures were administered to PWP and in 2009-10 there were 224.

DBS can be administered to both sides of the brain (bilateral) or to one side of the brain (unilateral). Around 90% of the procedures administered in 2009-10 (199 procedures) were bilateral. The total cost to the government for all DBS procedures for PWP in 2009-10 was $792,428.

2.6.2 Improved diagnosis

Researchers from the Prince of Wales Medical Research Institute, the Royal North Shore Hospital, and the University of Würzburg, Germany, developed a new blood test with improved diagnostic accuracy for the early diagnosis of PD. 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 is currently being refined and a multicentre, international study is being conducted to determine the usefulness of the test to objectively and sensitively diagnose PD in clinical practice. Researchers from the Prince of Wales Medical Research Institute and the University of Saarland, Germany, are also examining the use of ultrasound imaging to improve the diagnostic accuracy of PD (POWMRI 2007).

Similar research is also being conducted by researchers from the Howard Florey Institute, The University of Melbourne and The Mental Health Research Institute of Victoria.

2.6.3 Improved drug delivery

Clinical trials of transdermal patches for the delivery of PD drugs (namely the dopamine agonist rotigotine) are currently underway. The continuous delivery may prove to be superior to oral delivery due to a reduced occurrence of the "on-off" effect (Moyer 2004).

2.6.4 Stem cell research

Stem cells are unspecialized cells that consistently have the ability to produce an identical copy of themselves when they divide and can be induced to become cells with special functions, such as dopamine producing cells.

Adult stem cells are derived from numerous sources, including the umbilical cord, placenta, bone marrow, nose, blood and other places in the human body. Most adult stem cells are *multipotent* and thus can develop only into closely related cells – for example, red and white blood cells). The main advantage of using adult stem cells from the same patient is that they do not carry the same risk of immune rejection and hence there is no need to use anti-rejection drugs.

Several studies have been successful in using adult stem cells to treat PD (Australian Government, 2005):

- **Pre-Clinical Trials:** differentiation of various adult stem cells to dopaminergic neurones and transplantation in mice/rats led to increased dopamine production.
- **Clinical Trials:** A phase 2 trial is in progress in the US with cultured retinal pigment epithelial cells (68 patients).

Embryonic are stem cells derived from the inner cell mass of a blastocyst (an early stage embryo approximately 4 to 5 days old). Embryonic stem cells are pluripotent and thus can develop into all or many of the different cells contained in the body (but not the whole organism).

3 Prevalence and mortality of PD

3.1 Introduction

This chapter reviews the prevalence and mortality estimates for PD in Australia from the 2007 Access Economics study. Projections for cases of PD are provided over a twenty year time horizon, 2011 to 2031. The analysis is therefore based on epidemiological estimates from the 2007 study, updated to reflect current demographic data and population projections.[5] PubMed/Medline[6] was scanned for updated prevalence and mortality literature and relevant information is included in the discussion. Section 3.2 provides updated projections of PD prevalence by disease stage and the number of people with PD residing in aged care facilities, while Section 3.5 focuses on updating projections of mortality related to PD.

3.2 Prevalence of PD

3.2.1 2007 Summary

There is (and was in 2007) no data for confirmed PD diagnosis that may be used to estimate prevalence. This is because there is no definitive test to confirm diagnosis of PD, which results in a potential for under-diagnosis and misdiagnosis. The approach adopted in the 2007 Access Economics study to estimate PD prevalence was derived from analysis of Pharmaceutical Benefits Scheme (PBS) data. That is, data for prescriptions commonly involved in the treatment of PD.[7] A full discussion of the methodology was provided in Section 3 of the 2007 Access Economics study.

The 2007 Access Economics study found that PD was a, "Surprisingly prevalent condition – with higher prevalence than a number of diseases and injuries considered National Health Priority Areas". It was, "conservatively estimated that in 2005 over 54,700 Australians had

[5] Definitions used in this report are the same as in the 2007 AE study – i.e. *"a broad definition of PD is used that incorporates both primary and secondary PD as all these people experience similar symptoms and treatments"* (p. 15).

[6] US National Library of Medicine, National Institutes of Health, http://www.ncbi.nlm.nih.gov/pubmed/ (accessed 5 July 2011).

[7] The risks with this approach were identified as follows:

- *"**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:*
  - *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."* (p. 16).

PD". Approximately 8,900 new cases were estimated to have occurred in 2005 (p. i). The estimates by disease stage and demographic segment are set out in Table 3.1. PD prevalence estimates increased considerably with age – ranging from 290 per 100,000 people aged 55-64, up to 2,940 per 100,000 for people aged over 85 years. In terms of the whole Australian population, this equated to approximately 270 PWP per 100,000 in 2005.

Table 3.1: Estimated prevalence of PD in Australia, 2005

	Prevalence rates (% of population)			Cases, 2005			Cases per 100,000 population, 2005		
Age	M	F	Total	M	F	Total	M	F	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	244	0	244	17	0	9
35-44	0.03	0.01	0.02	477	173	651	32	11	22
45-54	0.14	0.06	0.10	1,957	805	2,762	141	57	99
55-64	0.34	0.25	0.29	3,712	2,695	6,407	337	248	293
65-74	1.22	0.99	1.10	8,335	7,096	15,431	1,223	992	1,105
75-84	2.33	1.92	2.10	9,621	10,374	19,994	2,328	1,924	2,099
85+	3.69	2.59	2.94	3,738	5,497	9,234	3,691	2,587	2,944
Total	**0.28**	**0.26**	**0.27**	**28,100**	**26,600**	**54,700**	**278**	**260**	**269**

Note: Rows and columns may not sum due to rounding.
Source: Access Economics, 2007, p. 20.

3.2.2 New information from the literature since the 2007 Access Economics study

PubMed/Medline[8] was scanned for literature published since the 2007 Access Economics study. The focus was on PD prevalence in Australia and other developed countries. A number of studies were identified, including one from Australia. Different methodologies for estimating prevalence make comparisons difficult. International comparisons are further complicated by differences in methodologies, diagnosis rates, healthcare services and survival rates between countries. Where relevant new information was identified, it is reviewed in this section.

Mehta et al, (2007) used cross-sectional and longitudinal data on PD as part of a comprehensive survey of an older Australian community. The study focused on individuals aged 49 and over, estimating prevalence rates by age group, and utilised detailed examination by specialist medical practitioners to assess and confirm PD diagnosis[9]. Ten-

[8] US National Library of Medicine, National Institutes of Health, http://www.ncbi.nlm.nih.gov/pubmed/ (accessed 5 July 2011).

[9] The baseline survey of non-institutionalised permanent residents aged 49 or over in the Blue Mountains area of Sydney was conducted over 1992-94, with follow-up in 1997-99 (5 years) and 2002-04 (10 years). The initial survey included 3,654 participants (82.4% of those eligible). 2,335 of these were re-examined after 5 years and a further 1,378 individuals were identified as eligible – 1,174 of these participated. After 10 years, only

year incidence was estimated at 0.84% among those aged 49 and over (projecting 38,000 additional cases in Australia by 2011). The overall prevalence estimated, **for primary PD only**, was 362 per 100,000 people (0.46%, 95% confidence interval 183-541) among Australians aged 50 and over in 2001 (104 per 100,000 among all Australians). This is not directly comparable to the result of the 2007 Access Economics study, which also included secondary PD (without breaking down results by primary and secondary), estimating prevalence of approximately 800 per 100,000 people aged 50 and over in 2005.

The different methodological approaches utilised in the two studies (in addition to definition of PD) further complicates comparisons[10]. The Mehta et al, study examined 3,654 initial participants, 16 of whom were identified as having PD (none aged under 60), in two post code areas in the Blue Mountains[11]. The 2007 Access Economics study looked at Pharmaceutical Benefits Scheme data for all of Australia.

Three other Australian studies were noted in the Mehta et al, study. One in Sydney (Chan et al, 2005) estimated prevalence of PD at approximately 780 per 100,000, using a broader definition than Mehta et al, including, "subjects with features suggestive of parkinsonism". Two Queensland studies (McCann et al, 1998 and Peters et al, 2006), estimated a prevalence of between 146 and 415 per 100,000 people. This highlights the degree of variation between estimates.

A number of international studies were published since the 2007 Access Economics study, using different approaches to estimate PD prevalence. Relevant examples, summarised by approach, include:

- **Population surveys** – ranging from once-off, door to door surveys (see Seijo-Martinez et al, 2011, Yamawaki et al, 2009, and Wada-Isoe et al, 2009) to the longitudinal approach of Mehta et al, (2007), described above. Medical records for individuals identified as having PD were frequently confirmed by a neurologist.
- **Service-based epidemiological studies** – ranging from surveys of local health services (see Walker et al, 2010, Lix et al, 2010, Wickremaratchi et al, 2009, Morgante et al, 2008) to more detailed studies, e.g. recruiting patients through health services to have PD diagnosis confirmed by a specialist neurologist (see Osaki et al, 2010).
- **Prescription database search for PD medications** – e.g. within primary care databases, combined with medical record review to confirm PD diagnosis (see Newman et al, 2009a).
- In many cases, more than one of these approaches was used to confirm results (see Wermuth et al, 2008).

Some further insights were provided in the following studies, summarised below:

- Lix et al, (2010) found a greater burden of PD in low-income areas in Manitoba, Canada.

participants from the original cohort were re-examined – 1,952 of these participated (76.5% of survivors). Participants were screened for medications associated with PD, and if positive, their medical practitioners were contacted to confirm PD diagnosis (GP and neurologist).

[10] Mehta et al. was also based on 2001 data, whereas the AE 2007 study was on 2005 data, however this is unlikely to affect the prevalence rate significantly.

[11] Mehta et al. conceded that prevalence may have been underestimated, as institutionalised people were not included in the study.

- Newman et al, (2009b) found that, *"*At least 1 in every 20 patients taking medication for PD is misdiagnosed*"* (p. 2379).
- Yamawaki et al, (2009) studied, 'Changes in prevalence and incidence of PD in Japan during a quarter of a century', finding, *"*The prevalence of PD had increased, primarily because the population had aged*"* (p. 263).

The 2007 Access Economics study also considered rates of misdiagnosis and under-diagnosis. It was assumed that these would offset each other. There is no evidence in the recent literature to contradict this assumption.

> The wide range of methodological approaches to estimating prevalence of PD makes comparisons between studies difficult. A number of studies have been published since the 2007 Access Economics study, however these do not provide sufficient rationale to adjust prevalence estimates in this updated report.

3.2.3 Prevalence of PD in 2011

Table 3.2 summarises the prevalence rates estimated for the previous Access Economics report,[12] and — based on these prevalence rates — the numbers of PD cases in Australia in 2011, updated to reflect population growth since 2005. This shows a 17% overall increase in the number of PD cases since 2005 (approximately 10,000 additional cases). The increase reflects the ageing of the Australian population.

> There were an estimated 64,044 PWP in 2011, approximately 9,300 more than in 2005. This equates to 283 per 100,000 in the total Australian population, or 857 per 100,000 among the population aged over 50.

[12] The derivation of prevalence rates and methodology are described in Section 3 of the 2007 Access Economics study.

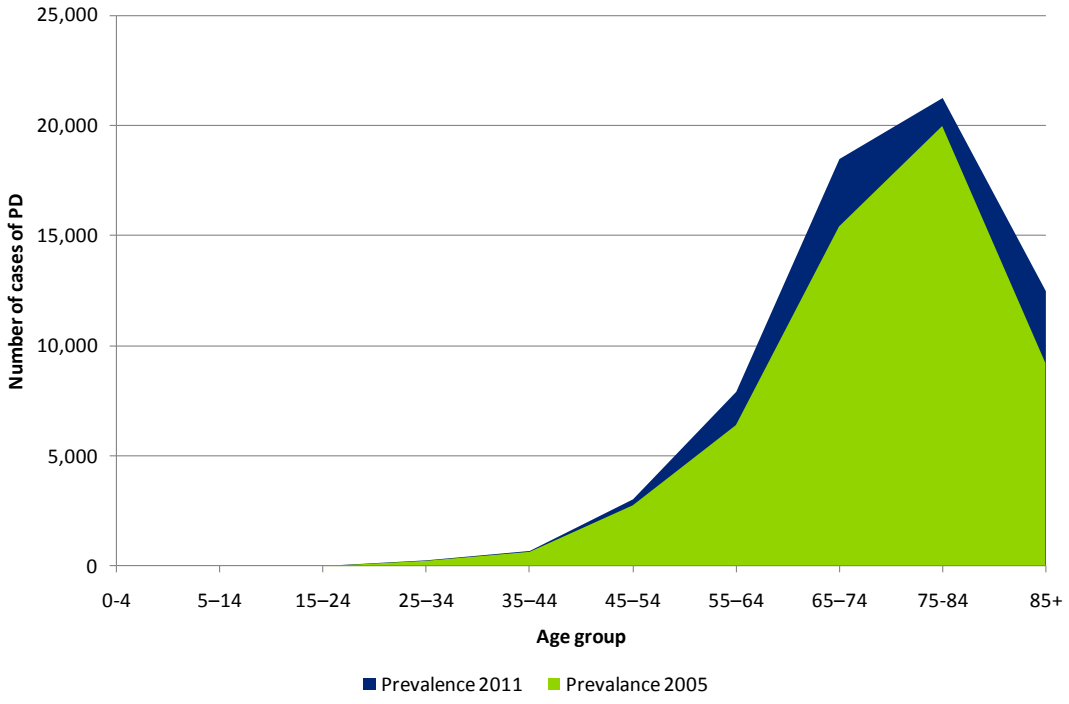
Table 3.2: Estimated prevalence rates and cases of PD, 2011

Age	Prevalence rates (%)			Cases, 2011			Additional cases, 2005-11		
	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	256	0	256	12	0	12
35–44	0.03	0.01	0.02	501	180	681	24	7	30
45–54	0.14	0.06	0.10	2,139	886	3,025	182	81	263
55–64	0.36	0.25	0.30	4,586	3,318	7,903	874	623	1,496
65–74	1.22	0.98	1.10	10,043	8,428	18,470	1,708	1,332	3,039
75-84	2.32	1.93	2.11	10,569	10,670	21,239	948	296	1,245
85+	3.69	2.59	2.97	5,422	7,048	12,470	1,684	1,551	3,236
Total				**33,515**	**30,529**	**64,044**	**5,415**	**3,929**	**9,344**

Source: Access Economics, 2007. Note: Rows and columns may not sum due to rounding.

Chart 3.1 shows prevalence of PD by age group in 2005 and 2011. Just over half (52%) of PWP were males, broadly unchanged since 2005. The prevalence of PD increased substantially with age. People of working age (15-64 years) comprised 19% of PWP in 2011, although this group represented approximately 67% of the total population.

Chart 3.1: Prevalence of PD by age, 2005 & 2011



3.3 Incidence of PD

Incidence refers to the number of new cases of PD. The 2007 Access Economics study estimated the incidence in 2005 using a similar methodology to Begg et al, (2007), based on estimated prevalence rates, remission rates (assumed to be zero) and the relative risk of mortality. The 2007 Access Economics study estimated approximately 8,900 new cases of PD in 2005. Applying 2011 demographic data to the incidence rates estimated in the 2007 report yields an estimated incidence of PD in 2010-11 of approximately 10,500. This is summarised in Table 3.3.

Table 3.3: Incidence of PD, 2011

Age	Incidence rates (%)			New cases, 2011		
	Males	Females	Total	Males	Females	Total
0-4	0	0	0	0	0	0
5–14	0	0	0	0	0	0
15–24	0	0	0	0	0	0
25–34	0	0	0	0	0	0
35–44	0.01	0	0	158	0	158
45–54	0.01	0.01	0.01	151	155	306
55–64	0.05	0.04	0.05	643	524	1,297
65–74	0.16	0.12	0.14	1,322	1,028	2,357
75-84	0.42	0.25	0.32	1,912	1,381	3,225
85+	1.10	0.65	0.79	1,616	1,771	3,312
Total				**5,802**	**4,859**	**10,497**

Source: Access Economics, 2007. Note: Rows and columns may not sum due to rounding.

3.3.2 Prevalence by disease stage

The 2007 Access Economics study estimated the number of people in each disease stage by applying the proportion of time spent in each disease stage to the prevalence rates (reproduced in Table 3.2). It also assumed a median time from onset to death of 12.2 years (see section 2.4 of Access Economics, 2007).

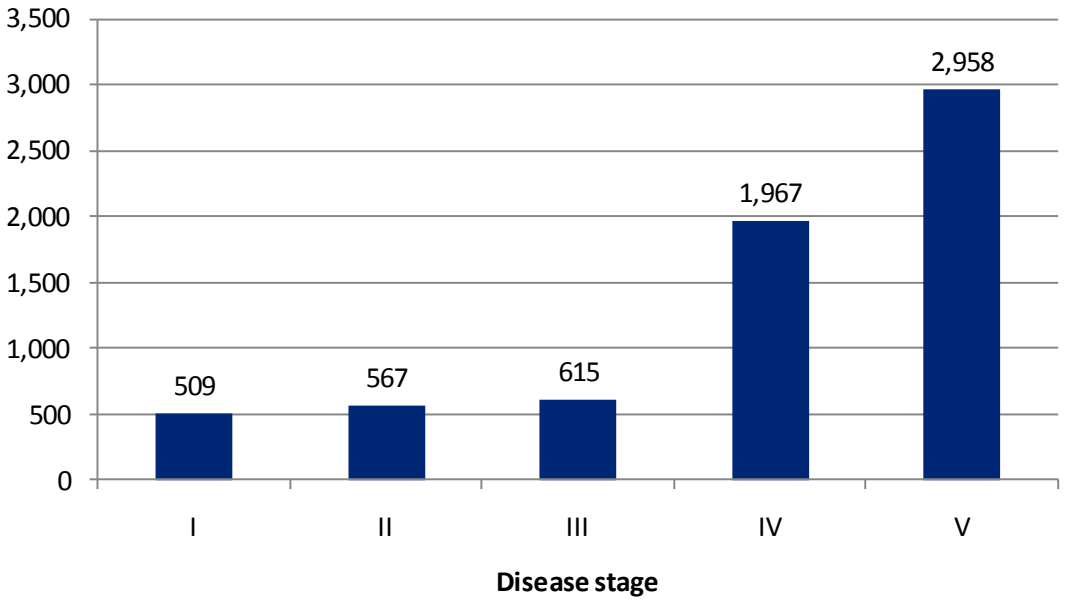
Applying this methodology to the updated demographic data, 2011 estimates are as follows:

- 51,723 PWP in the initial stages of PD (Stages I to III) – compared with 44,300 in 2005;
- 8,441 PWP in the intermediate of PD (Stage IV) – compared with 7,100 in 2005; and
- 3,880 PWP in the end stage of PD (Stage V) – compared with 3,300 in 2005.

3.4 PWP residing in aged care facilities

The number of PWP residing in aged care facilities was estimated using a similar methodology to that employed in the 2007 Access Economics study. Relative risk ratios of nursing home admission for Stages IV to V by age group were applied to the rate of admission in the general population (see Chart 3.2). In 2011, an estimated 6,600 PWP are residing in aged care facilities, of which 188 are aged younger than 65 years (equal to 1.6% of all PWP aged younger than 65 years). The majority of PWP aged younger than 65 years who are residing in aged care facilities are in Stages IV or V (this accounts for 12.9% of PWP aged younger than 65 years).

Chart 3.2: Estimated PWP in aged care facilities by disease stage, 2011

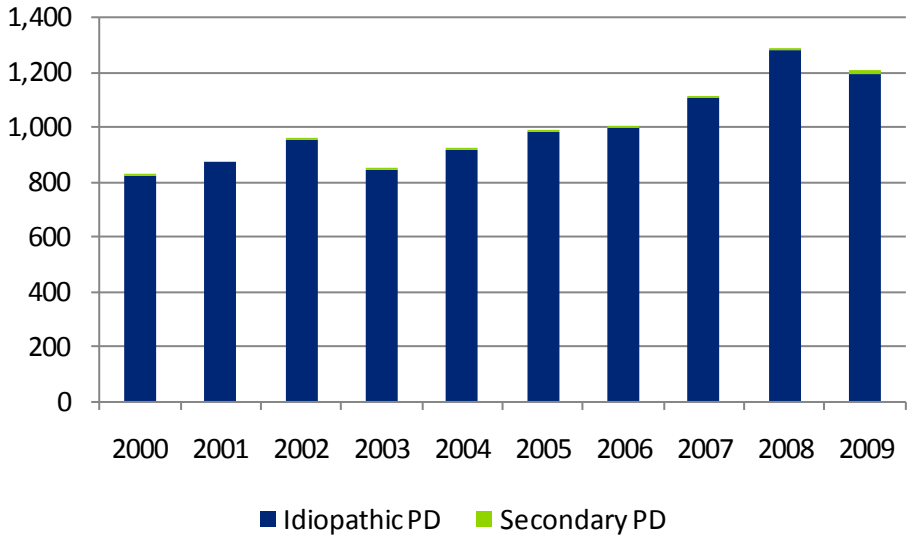


Source: Access Economics, 2007.

3.5 Deaths due to PD

Chart 3.3 shows ABS data on PD recorded as underlying cause of death over the period 2000 to 2009 (latest data available). In 2009, there were 1,194 people who died whose underlying cause of death was identified as idiopathic PD and 12 people who died whose underlying cause of death was secondary PD. The number fell from 2008, when 1,283 people who died had an underlying cause of idiopathic PD and 8 people secondary PD. The trend over the period 2000 to 2009 showed numbers of deaths with an underlying cause of death identified as idiopathic or secondary PD increasing at 5% per year on average.

Chart 3.3: Underlying cause of death idiopathic PD and secondary PD, 2000 to 2009



Source: ABS 2011.

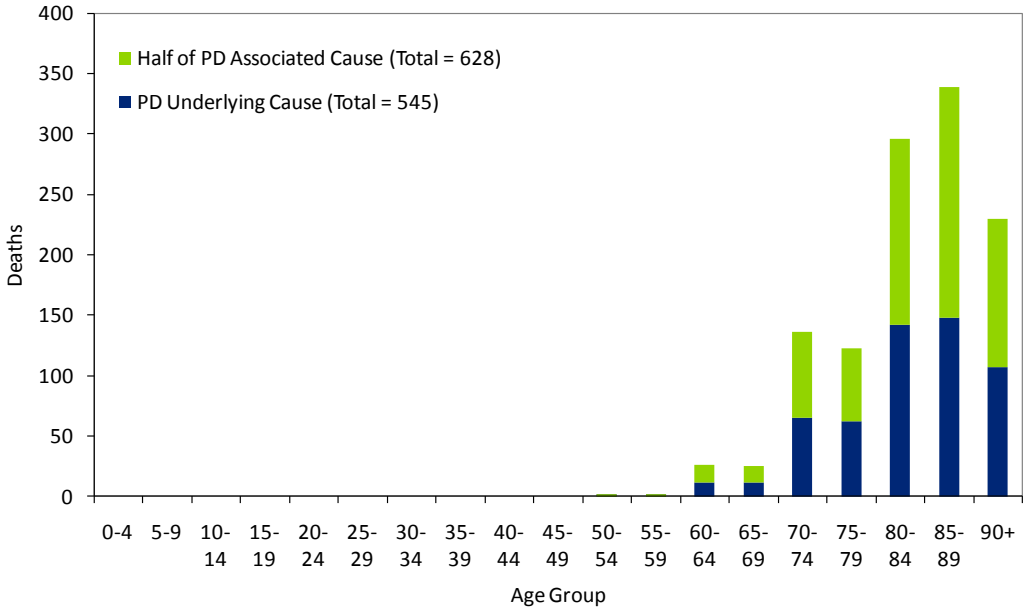
The 2007 Access Economics study found that ABS data for underlying cause of death was likely to understate actual deaths, because a death may be attributed to another cause on the death certificate (excluding PD). The 2007 Access Economics study addressed this issue by deriving age-sex specific mortality rates, from an analysis of associated causes of death from the literature and specially requested ABS data. This calculation, marked "associated cause" in Chart 3.4 to Chart 3.7, represents the upper bound of the estimate. The updated 2011 estimate is 1,692. The lower bound estimate of 1,299 reflects revised mortality rates, in line with the latest (2009) ABS cause of death data. This is marked "underlying cause" in the Chart 3.4 to Chart 3.7. It was assumed that the same proportions of deaths in each age/sex group applied as in 2004[13], as disaggregated down data was not available for 2009.

In 2011, deaths due to PD were estimated at between 1,299 and 1,692.

Chart 3.5 and Chart 3.4 show the updated estimates of deaths due to PD in 2011 for males and females. The differences in these estimates compared to the 2005 estimates are shown in Chart 3.6 and Chart 3.7. Of particular note is the higher number of estimated deaths among both males and females aged 80-84 and 85-90. This is attributed to population growth in those age groups.

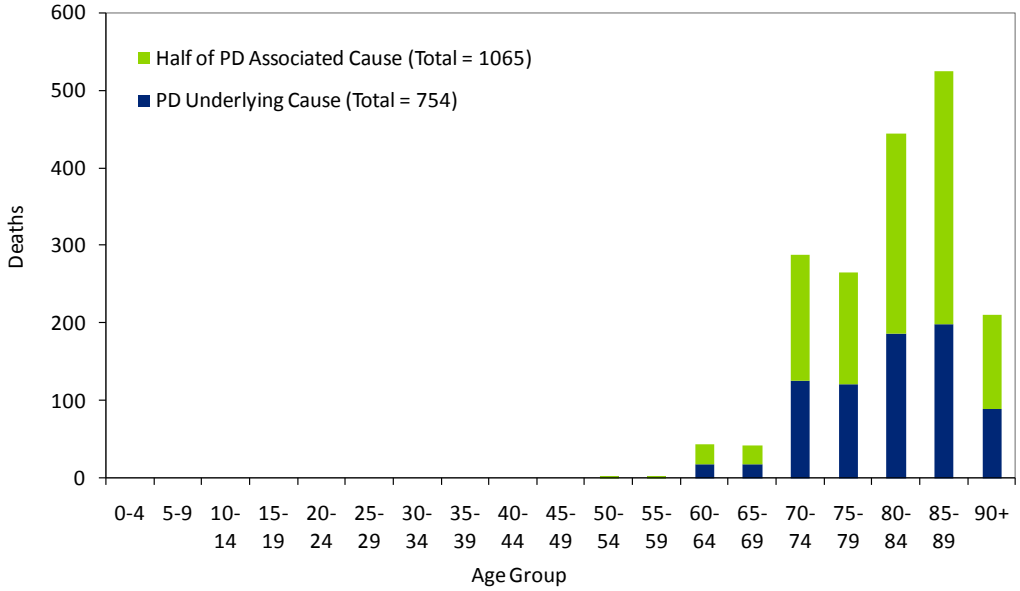
[13] 2004 was the latest data available for the 2007 Access Economics study.

Chart 3.4: PD Deaths, Females, 2011



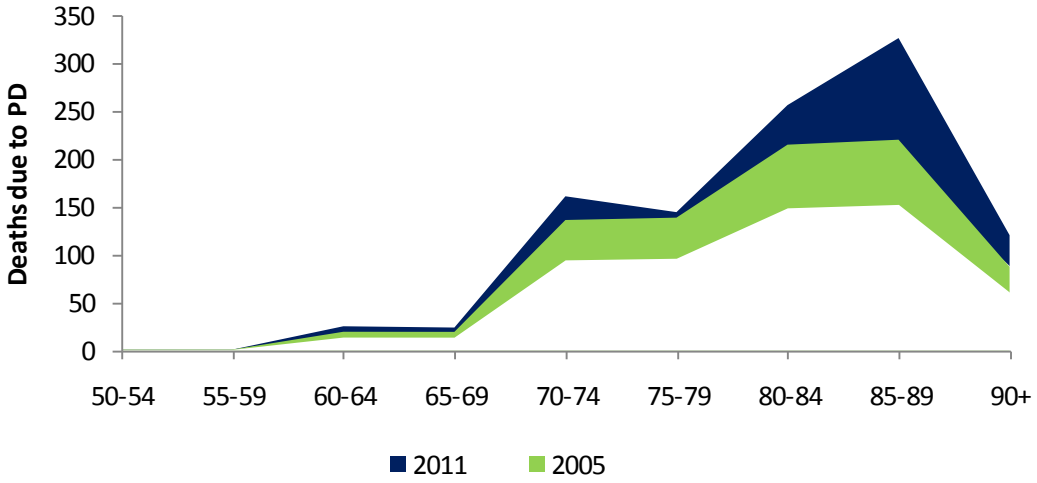
Source: Access Economics, 2007. Estimated "Associated Cause" deaths are halved due to evidence from the literature – see explanation in 2007 Access Economics study.

Chart 3.5: PD Deaths, Males, 2011



Source: Access Economics, 2007. Estimated "Associated Cause" deaths are halved due to evidence from the literature – see explanation in 2007 Access Economics study.

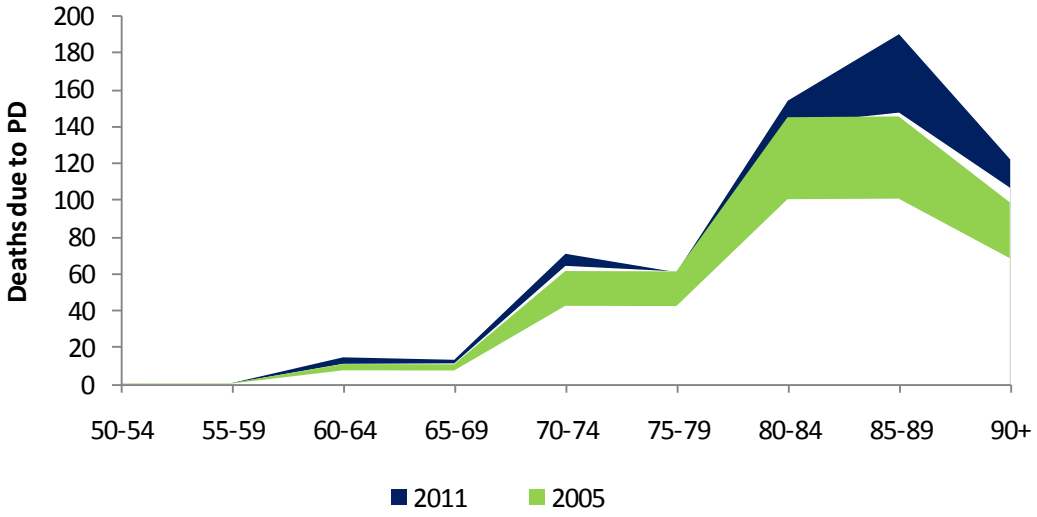
Chart 3.6: Estimated deaths due to PD, 2011 vs. 2005, males (a)



(a) The shaded areas reflect upper (associated cause) and lower (underlying cause) bounds.

Source: Access Economics, 2007.

Chart 3.7: Estimated deaths due to PD, 2011 vs. 2005, females (a)



(a) The shaded areas reflect upper (associated cause) and lower (underlying cause) bounds.

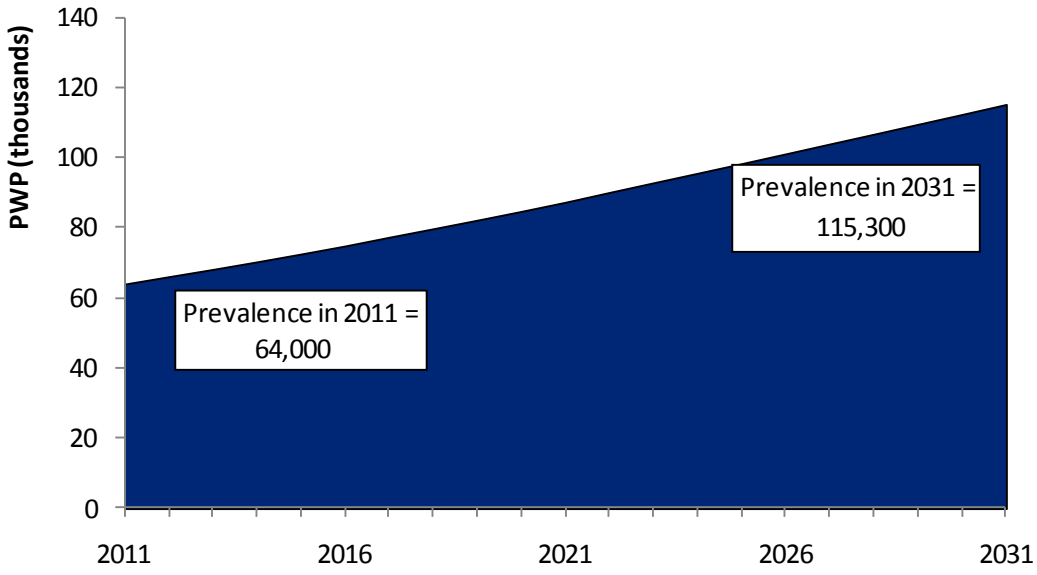
Source: Access Economics, 2007

3.6 Projections

Updated projections of PD prevalence and deaths due to PD for the period 2011 to 2031 are shown in Chart 3.8 and Chart 3.9. As in the 2007 Access Economics study, these are made on the basis of age-sex specific prevalence and mortality rates, updated to reflect current demographic data and projections from Deloitte Access Economics Demographic Model (DAE-DEM). Updates are described in Sections 3.2 and 3.5. The 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.

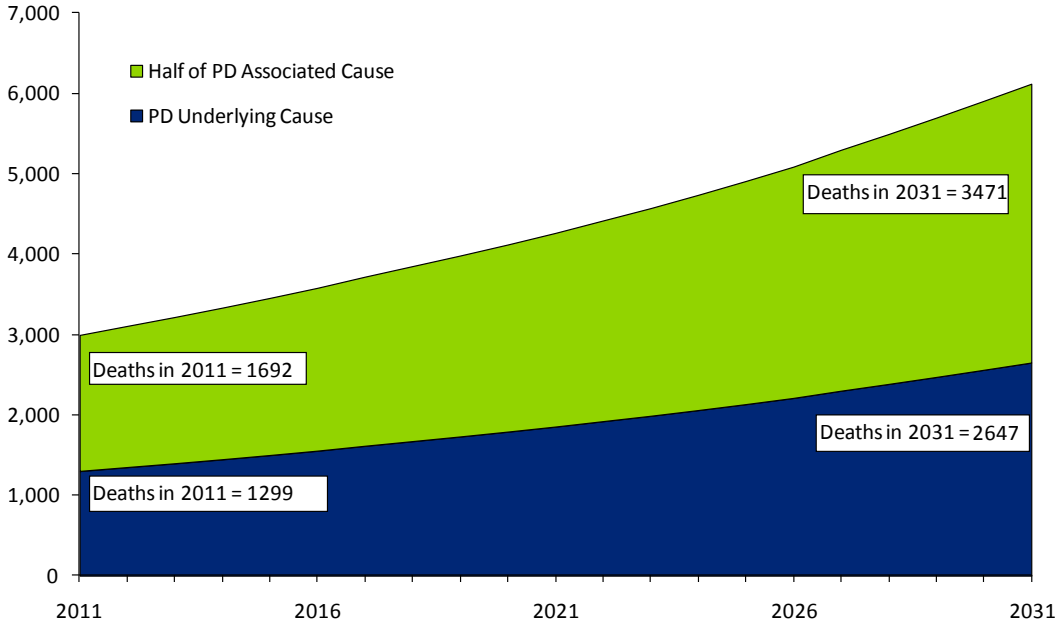
An estimated 64,000 PWP in 2011 is projected to grow to 115,300 by 2031 (an 80% increase). This is equivalent to annual growth of 4% per annum between 2011 and 2031. Females represent approximately 48% of PWP. People of working age (15-64 years) comprise 19% of PWP in 2011, which is projected to decline to 13% by 2031.

Chart 3.8: Projected PD prevalence, 2011-2031



There are estimated to be between 1,299 and 1,692 deaths from PD in 2011, doubling to between 2,639 and 3,471 deaths in 2031. Females comprise 42% of estimated deaths in 2011, falling slightly to 39% in 2031. People of working age comprise 2.4% of deaths in 2011, which is projected to fall to 1.5% in 2031, as a result of population ageing.

Chart 3.9: Projected deaths due to PD, 2011-2031



Estimated "Associated Cause" deaths are halved due to evidence from the literature – see explanation in 2007 Access Economics study.

4 Updating economic costs

Current demographic data were used to update the cost estimates from the 2007 report. However, based on the findings outlined in chapter 3, no changes were made to prevalence and mortality rates. Parameters were updated using the most recent (or relevant) data sources, and costs were indexed using the appropriate inflators (such as the CPI or health cost inflation).

The following costs associated with PD are updated in this report:

- **Direct financial costs to the Australian health system** include the costs of running hospitals and nursing homes (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 diseases 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. Table 4.1 below outlines the schema used for cost classifications for this (and the 2007) report.

Table 4.1: Schema for cost classification

Conceptual group	Subgroups	Bearers of Cost	Comments
Pain/suffering and premature mortality	Burden of disease (YLLs, YLDs, DALYs) – incidence approach.	PWP*	
Health system costs	Costs by type of service (and prevalence in 2001)	PWP*, governments and society (private health insurers, workers' compensation)	
Productivity costs			
	Lost productivity from temporary absenteeism	PWP, employer and government#	
	Lost management productivity	Employer and government#	
	Long-term lower employment rates	PWP and government#	Includes premature retirement
	Premature death	PWP and government#	Loss of productive capacity
	Additional search and hiring replacement	Employer	Incurred when prematurely leave job
	Lost informal carer productivity	Friends and family, and employer#	Includes both paid and unpaid work
Other financial costs			
	Respite/palliative care services	Governments, PWP, and society	
	Out-of-pocket expenses	PWP	Formal care, aids, equipment, modifications, travel, accommodation.
	Funeral costs brought forward	Friends and family	
Transfer costs	Deadweight loss	Society	Relate to transfers from taxation, welfare etc

* Friends/family may also bear loss of wellbeing, health costs and lower living standards as a result of PD; however, care is needed to assess the extent to which these are measurable, additional (to avoid double counting) and not follow-on impacts. For example, a spouse may pay a medical bill and children may share in lower household income when the PWP's work hours are reduced – but as this is simply redistribution within family income it is not measured here. Moreover, if a family carer develops depression or a musculoskeletal disorder, it would be necessary to estimate the aetiological fraction attributable to PD, allowing for other possible contributing factors.

Where earnings are lost, so is taxation revenue and frequently also there are other transfers, such as welfare payments for disability/sickness/caring etc, so Governments share the burden.

4.2 Incidence and prevalence approaches

In line with the 2007 report, this report uses the prevalence (annual costs) approach to estimating the cost of PD. An alternative approach is the incidence (lifetime costs) approach. The difference between the two is explained below.

- **Prevalence approaches** measure the number of people with a given condition in a base period and the costs associated with treating them as well as other financial and non-financial costs (productivity losses, loss of quality of life) in that year, due to the condition. Prevalence approaches can be more suitable for chronic conditions and for a snapshot of total economy-wide costs that will be borne in a given year.
- **Incidence approaches** measure the number of new cases of a given condition in a base period and the costs associated with treating them, as well as other financial and non-financial costs (e.g., productivity losses, loss of quality of life) over the person's lifetime, due to the condition. The total costs represent the net present value (NPV) of current and future costs incurred due to new cases in the year in question.

Consider three different cases of people with PD:

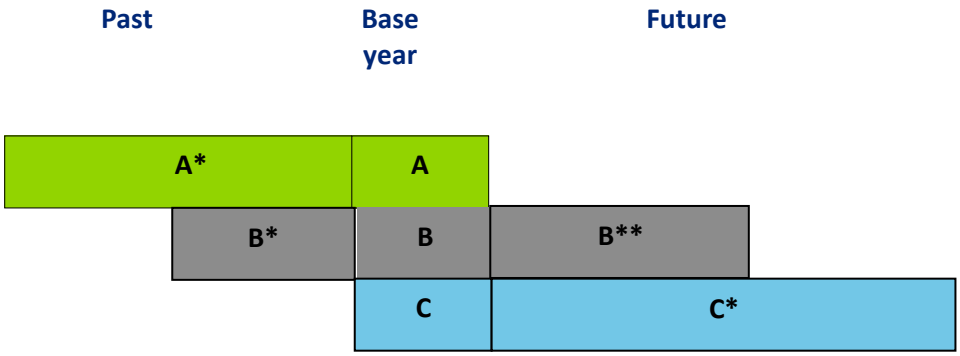
- *a*, who was diagnosed with PD in the past and has incurred the associated costs up to the year in question, with associated lifetime costs of A + A*, shaded in green;
- *b*, who was diagnosed with PD in the past and has incurred the associated costs in 2005 as well as in the past and future, with associated lifetime costs of B + B* + B**, shaded in grey; and
- *c*, who was diagnosed with PD in 2011, with lifetime costs of C + C*, shaded in blue.

All costs should be expressed as present values relative to 2011.

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 2011 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.

Figure 4.1: Incidence and Prevalence Approaches to Measurement of Annual Costs



Annual prevalence costs in the base year = Σ(A + B + C);

Annual incidence costs in the base year = Σ(C + present value of C*)

Note that 0 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*

4.3 Discount rates

Where future costs are ascribed to the year 2011 throughout the report the formula for calculating the NPV of those cost streams is:

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

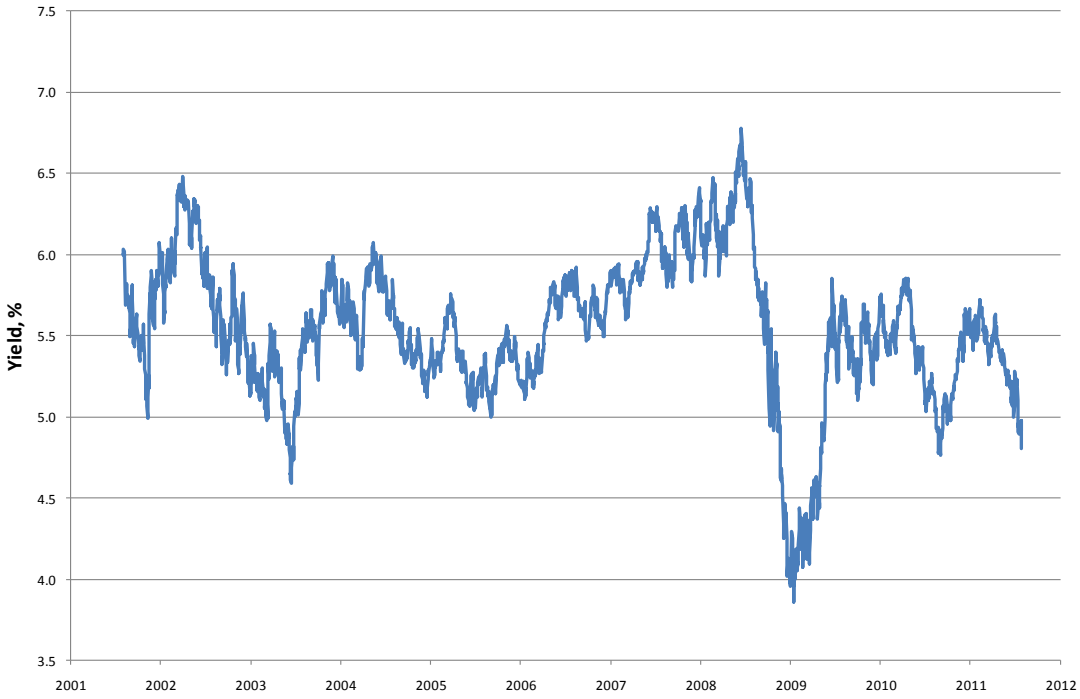
C_i = *cost in year i, n = years that costs are incurred and r = discount rate.*

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 needs to appropriately take into account risks, inflation and positive time preference.

Risk and positive time preference

A 'lower-bound' scenario for the discount rate would be to assume certainty with regard to future cash flows (i.e. assume the future flows are similar to the certain flows attached to a long-term Government bond). Over the past decade, the long-term nominal bond rate has averaged 5.5% per annum (Chart 4.1). This 'risk-free' rate compensates for inflation and positive time preference (if there were no positive time preference, people would be indifferent between having something now or a long way off in the future, which applies to all goods and services).

Chart 4.1: 10-year Australian Government bond yields, daily; %



Data is for 1 August 2001 – 29 July 2011
Source: RBA 2011

Inflation

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 an inflation rate in this range (2.5%) is used in arriving at the discount rate for healthy life below. It is important to allow for inflation in order to derive a real rather than nominal rate.

> In discounting healthy life and other costs in this report, a real discount rate of 3% (5.5 – 2.5) is used.

In the 2007 report, different discount rates were used to discount income streams of future earnings, health costs and other (healthy life) costs (page 35). Our preferred methodology now is to apply a single discount rate to all costs. This is consistent with international health studies.

5 Health system costs

Health expenditure data for PD was sourced by special request from the Australian Institute of Health and Welfare. The AIHW derive their 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. The 2000-01 data are the most recent available. These data use burden of disease categories based the Tenth Revision of the International Classification of Disease (ICD-10) published by the World Health Organisation and the International Classification of Primary Care Version 2 (ICPC2).

In this report, the 2000-01 data provided by the AIHW were used as the basis of the 2011 estimates. Two factors contribute to the extrapolation:

- health cost inflation — assumed to be 3.4% per year, which was the ten year annual average from 1997-1998 to 2007-08 (AIHW, 2010); and
- projected growth of the prevalence of PD based on DAE-DEM population growth for each age group.

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 was made for the unallocated component after presentation of the allocated components.

The health system cost estimates do not include the additional funding for health research announced in the 2006-07 Federal budget and other items that may have changed since 2000-01, such as greater utilisation rates for deep brain stimulation. Moreover, since 2000-01 several new drugs have been listed on the Pharmaceutical Benefits Scheme for PD and there have been changes to permitted use of some PD medications.

Table 5.1: Health system costs, 2000-01

Age	Males	Females	Total
	$m	*$m*	*$m*
0-4	0.03	0.07	0.10
5–14	0.01	0.00	0.02
15–24	0.03	0.20	0.23
25–34	0.21	0.04	0.26
35–44	0.67	0.66	1.33
45–54	1.59	3.35	4.94
55–64	12.72	5.92	18.64
65–74	34.85	18.31	53.17
75-84	46.29	34.87	81.16
85+	12.23	20.67	32.90
Total	**108.64**	**84.09**	**192.73**

Source: AIHW special data request.

Table 5.2: Health system costs, 2011

Age	Males		Females		Total	
	Total	per PWP	Total	per PWP	Total	per PWP
	$m	*$*	*$m*	*$*	*$m*	*$*
0-4	0.0	0	0.0	0	0.0	0
5–14	0.0	0	0.0	0	0.0	0
15–24	0.0	0	0.0	0	0.0	0
25–34	0.4	1,442	0.0	0	0.4	1,442
35–44	1.1	2,282	1.1	6,327	2.3	3,351
45–54	2.9	1,351	6.2	7,010	9.1	3,009
55–64	29.3	6,398	13.9	4,177	43.2	5,465
65–74	70.1	6,980	35.8	4,242	105.8	5,731
75-84	94.2	8,908	63.0	5,904	157.1	7,399
85+	35.0	6,459	49.0	6,957	84.0	6,740
Total	**233.0**	**6,952**	**169.0**	**5,540**	**402.0**	**6,277**

Source: Deloitte Access Economics' calculations.

Note: estimates for PWP aged under 35 shown as zeros due to rounding.

5.2 Cost components

Chart 5.1 shows the main health system cost components for PD in 2011[14].

- **Aged care ($236.0 million, $4,312 per PWP or $43,136 per PWP in an aged care facility)**: nursing home placement is often required, particularly in the later stages of PD

[14] These costs exclude the additional health system costs discussed in later chapters.

due to functional impairment, drug complications (such as hallucinations) and comorbidities associated with PD (such as dementia and incontinence).

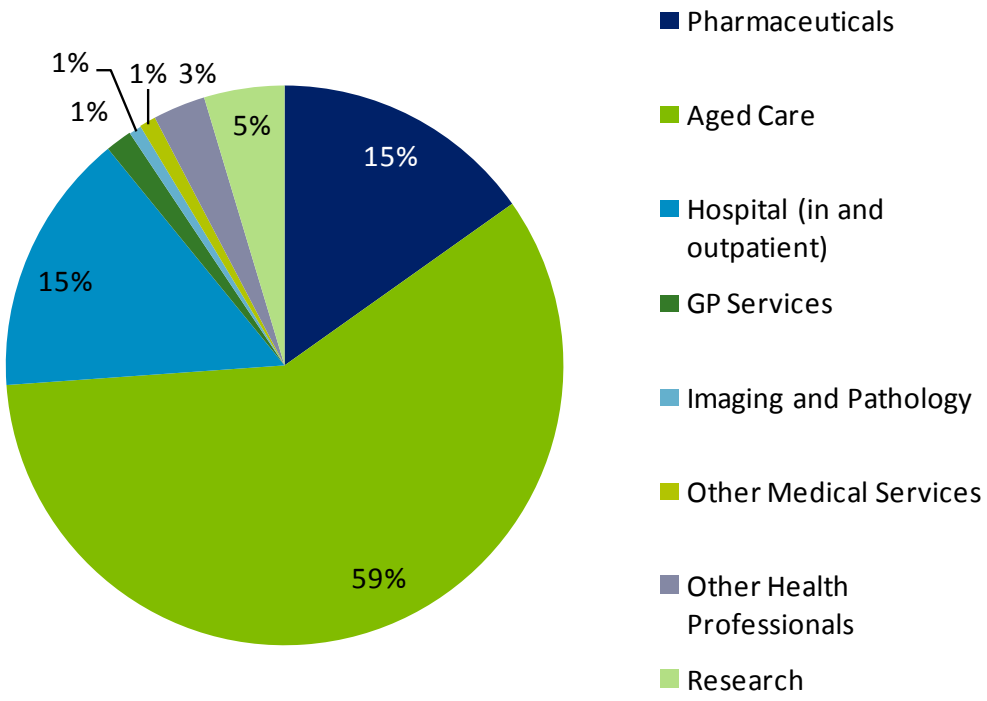
- **Pharmaceuticals ($61 million or $1,115 per PWP)**: drug treatments for PD — includes drugs listed on the PBS and RPBS (such as levodopa), non-subsidised prescription drugs (such as ropinirole) and over-the-counter drugs (such as paracetamol and vitamins).
- **Inpatient & outpatient hospital services ($61.3 million or $1,119 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, urinary disorders, arising from PD or PD medication.
- Other health system costs include:
    - **General practitioner (GP) services ($6.2 million or $112 per PWP)**[15]: on-going consultations with GPs are required to manage symptoms, prescribe drugs, and treat complications.
    - **Out-of-hospital specialists ($3.9 million or $70 per PWP)**[16]: neurologists are often consulted to diagnose PD and to advise on appropriate treatment pathways.
    - **Other health practitioners ($12.2 million or $223 per PWP)**: PWP may also be referred to physiotherapists, speech therapists, occupational therapists, clinical psychologists and specialist PD nurses.
    - **Imaging and pathology ($2.9 million or $53 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 ($18.7 million or $341 per PWP)**: ongoing epidemiological research into the causes of idiopathic PD, basic research (e.g. brain functions), applied research (e.g. synthesising large molecule 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).

[15] 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).

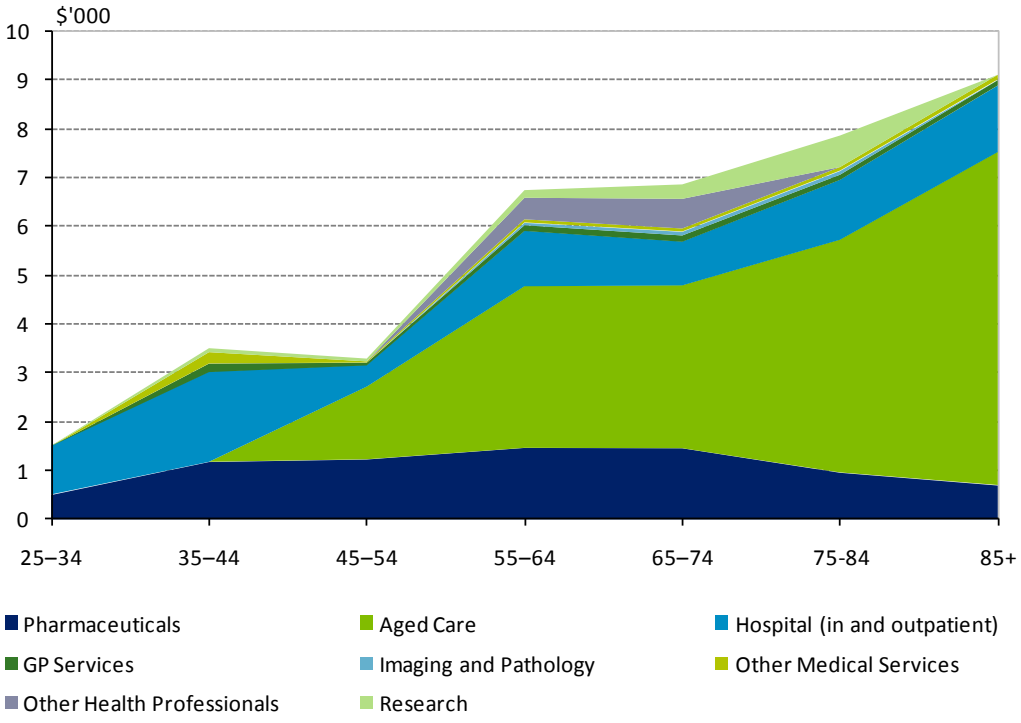
[16] The underlying source used by AIHW to measure the cost of GP services is the BEACH database 1999–00 to 2001–02. GP referral patterns were used to allocate total specialist expenditure (from AIHW). This may be an underestimate of total specialist costs associated with PD depending on the rates of GP referral to specialists for PD, compared to other diseases, and issues regarding identifying encounters for rarer diseases using BEACH (see Access Economics 2007).

Chart 5.1: Health system cost components, 2011



Source: Deloitte Access Economics' calculations.

Chart 5.2: Health system costs per person, component and age, 2011



Source: Deloitte Access Economics' calculations.

5.3 Health system costs by disease stage

The previous report identified estimated health costs by disease stage based on the results of Findley et al (2003) and Spottke et al (2005). For each study the average health system costs were estimated using the distribution of PWP by disease stage in Australia. The ratio of health system costs compared to this average was then estimated for each disease stage. The final results were adjusted so the total health expenditure by disease stage equals that in Table 5.2. Details of this calculation can be found in Access Economics (2007a). The average cost per PWP in 2011 was $6,277.

Table 5.3: Health system costs per PWP, by disease stage, 2011

Disease stage	Health system cost per PWP ($), 2011
I	4,059
II	4,057
III	7,527
IV	11,130
V	12,265
Total	**6,277**

Source: Deloitte Access Economics estimates.

5.4 Additional health system costs

The health system costs presented this far are 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: 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”.

Temlett and Thompson (2006) analysed admissions of PWP into the Royal Adelaide Hospital between 1999 and 2004. In the hospital each admission is coded according to the primary diagnosis (the reason for admission based on the acute problem treated), although additional information on secondary diagnoses is 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 5.4: Hospital admissions PWP

Diagnosis	Hospital Admissions	Ratio of Admissions: Primary to Secondary
PD primary diagnosis	**116**	
PD secondary diagnosis	**645**	**5.56**
Related to PD		
Accidental falls/fractures	81	0.70
Pneumonia	78	0.67
Dementia	22	0.19
Encephalopathy	45	0.39
Syncope[17]	26	0.22
Sub-total	251	2.16
Unrelated to PD:		
Genitourinary infections	71	0.61
Gastrointestinal	70	0.60
Cardiovascular	75	0.65
Stroke	23	0.20
Haematological	19	0.16
Neoplasms	46	0.40
Other	117	1.01
Sub-total	394	3.40
Total	**761**	

Note: Sub-totals do not add to total due to comorbidity in some cases.
Source: Temlett and Thompson (2006).

In 2009-10 there were 3,179 hospital admissions due PD (Table 5.5). From this it was estimated that there were around 2,220 hospital admissions for accidental falls that were a complication of PD, and 2,138 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 was at least $76.6 million in additional health system costs to treat the complications of PD (an additional 19% of the total health cost of PD).

[17] Temporary loss of consciousness or "fainting" due to postural hypotension (a fall in blood pressure when moving from lying to sitting, or from sitting to standing).

Table 5.5: Additional health system costs ($), 2011

	PD hospital admissions	Additional hospital admissions		Total health system costs per hospital admission		Additional health system costs ($m)
		Falls	Pneumonia	Falls ($)	Pneumonia ($)	
Males						
0-4	0	0	0	10,270	23,984	0.0
5–14	0	0	0	8,978	25,714	0.0
15–24	0	0	0	9,663	53,097	0.0
25–34	5	3	3	8,520	40,818	0.2
35–44	11	8	7	8,749	37,006	0.3
45–54	89	62	60	10,308	25,372	2.2
55–64	268	187	180	13,134	26,045	7.1
65–74	581	405	390	15,890	19,847	14.2
75-84	758	529	509	17,051	15,336	16.8
85+	270	188	181	17,734	13,894	5.9
Females						
0-4	0	0	0	9,388	23,102	0.0
5–14	0	0	0	14,152	25,817	0.0
15–24	1	1	1	9,267	63,237	0.0
25–34	1	1	1	9,764	36,794	0.0
35–44	10	7	7	11,522	38,254	0.3
45–54	40	28	27	14,671	36,205	1.4
55–64	144	101	97	12,809	28,176	4.0
65–74	338	236	227	16,545	26,393	9.9
75-84	494	345	332	13,335	18,480	10.7
85+	169	118	114	14,401	15,705	3.5
Total	**3,179**	**2,220**	**2,138**	**12,380**	**24,364**	**76.6**

Source: AIHW (2011b), Deloitte Access Economics' calculations.

Table 5.6: Additional health system costs per PWP 2011, by age and sex

Age	Male ($)	Female ($)	Total costs ($)
0-4	0	0	0
5–14	0	0	0
15–24	0	0	0
25–34	651	0	651
35–44	680	1,875	996
45–54	1,009	1,561	1,171
55–64	1,558	1,210	1,412
65–74	1,413	1,174	1,304
75-84	1,592	1,006	1,298
85+	1,081	494	749
Total	**1,393**	**978**	**1,195**

Source: Deloitte Access Economics' calculations.

Table 5.7: Additional health system costs per PWP, by disease stage, 2011

Disease stage	Cost per PWP ($)
I	826
II	795
III	1,421
IV	2,032
V	2,199
Total	**1,195**

Source: Deloitte Access Economics' estimates.

5.5 Deep brain stimulation

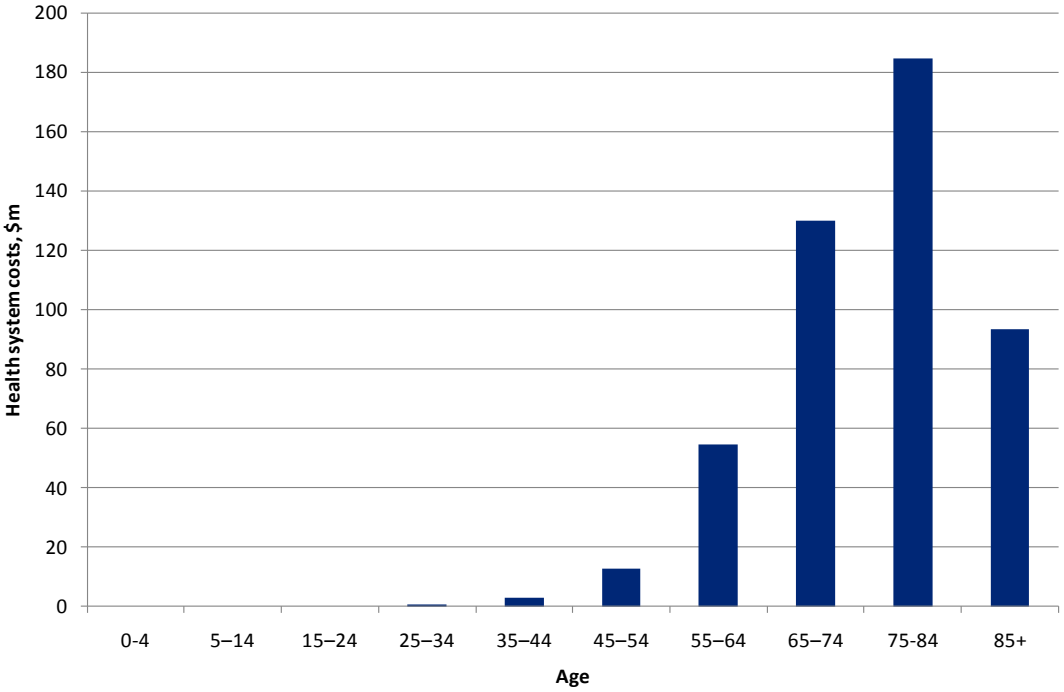
In 2009-10, Australian Government expenditure on deep brain stimulation for PWP was $792,428 (as discussed in section 2.6.1).

5.6 Summary of health costs

It is estimated that the **health costs of PD was $478.5 million in 2011**. Health system costs have increased by 39% since 2005.

- Of this expenditure, 42% was spent treating women with PD and 58% is spent treating men with PD.
- Of this expenditure, 15% was spent treating people aged less than 65 years (Chart 5.3).

Chart 5.3: Total health system costs by age ($m), 2011

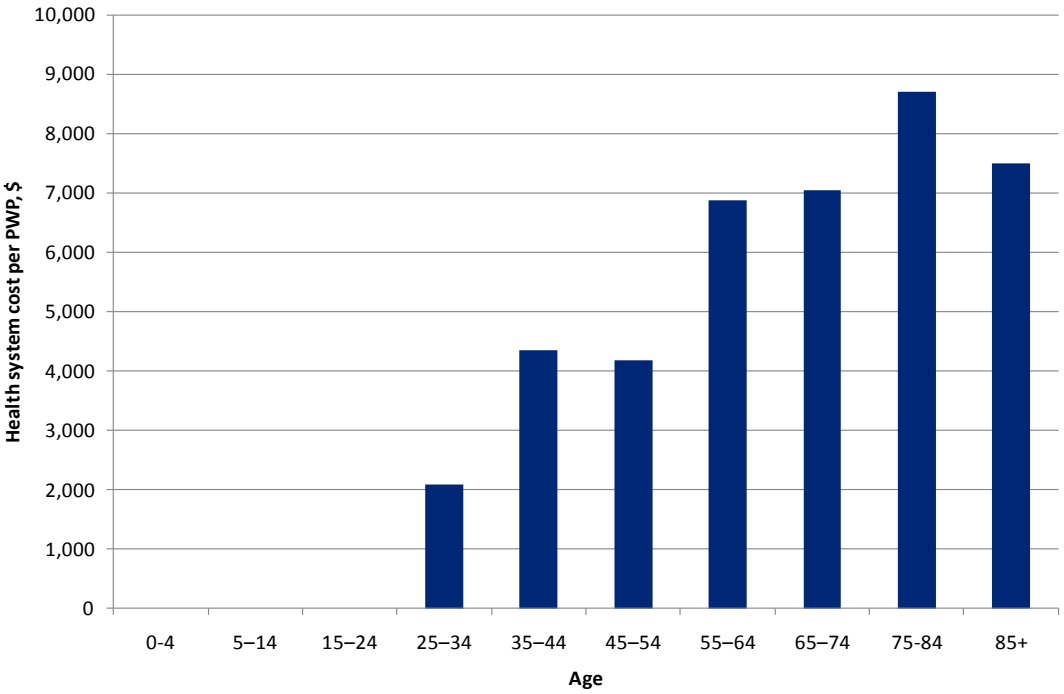


Source: Deloitte Access Economics' estimates.

The average total health system cost per person with PD was $7,599 per annum, around 19% higher than in 2005.

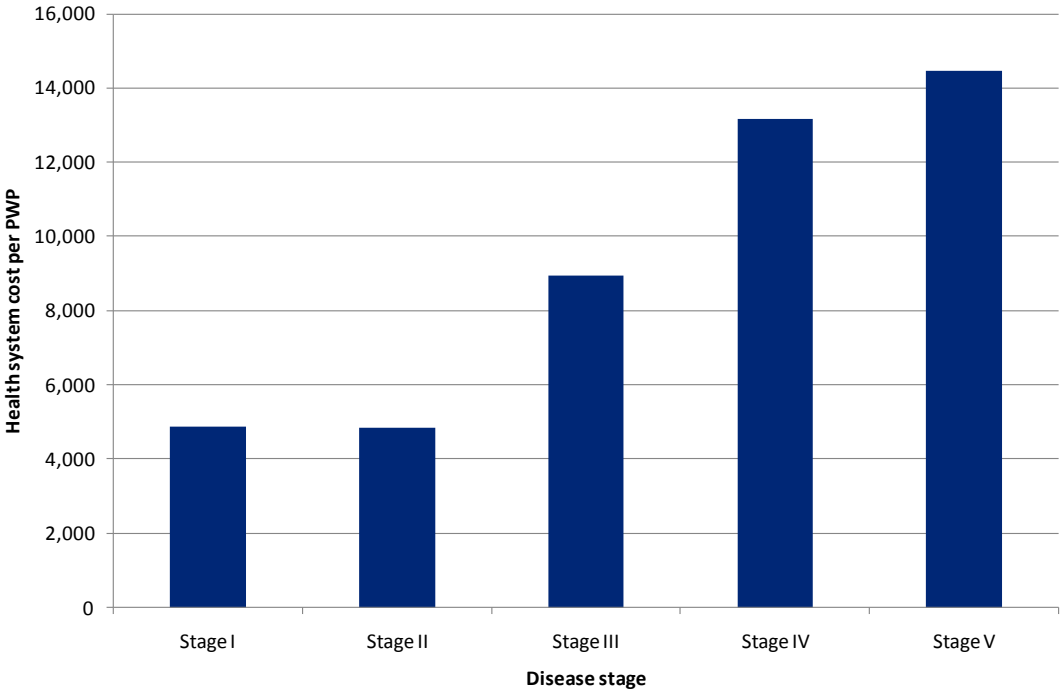
- Cost per PWP was lowest in the younger than 55 age-group, and highest in the 75 and over group, where residential care becomes the dominant cost element (see Chart 5.4)
- Cost per PWP increases with disease stage, where complications are more likely to occur and residential care becomes the dominant cost element (see Chart 5.5).

Chart 5.4: Total health system costs per PWP, by age, 2011



Source: Deloitte Access Economics' estimates.

Chart 5.5: Total health system costs per PWP, by disease stage, 2011

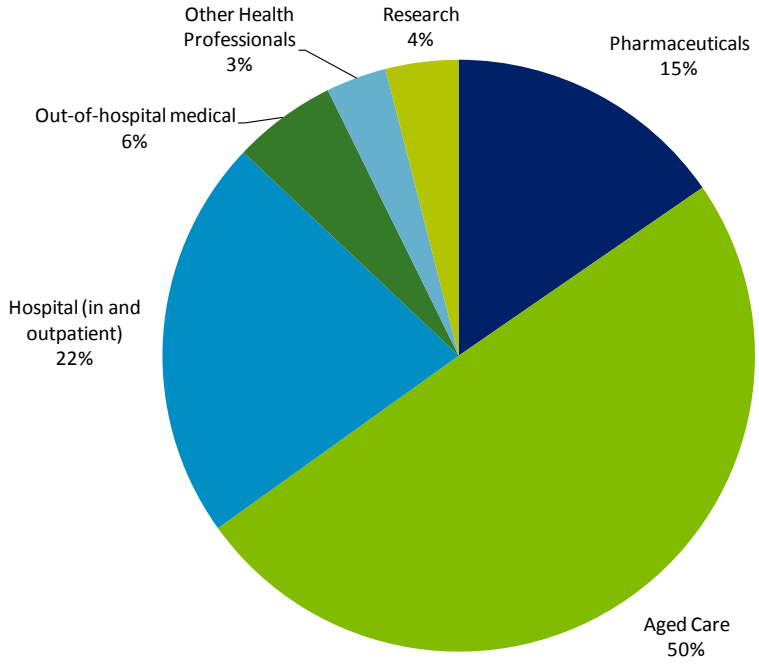


Source: Deloitte Access Economics' estimates.

The health cost profile for PD was dominated by high care residential accommodation or 'aged care' – $237.9 million (50%).

- The second largest cost component for PD was hospital costs (22% of total costs in 2011 or $105.1 million) while the third largest cost component for PD was pharmaceuticals (15.5% of total costs in 2011 or $70.6 million).
- Unreferred attendances (GPs), imaging and pathology costs and other out-of-hospital medical (specialists) were $27.1 million (5.7%); and other (allied) health practitioners $15.8 million (3.3%).
- Research into PD was estimated as $19 million in 2011 (4% of total health expenditure on PD). The average research share for all health conditions, of total allocated health expenditure, is lower at 2.6% (AIHW, 2010).

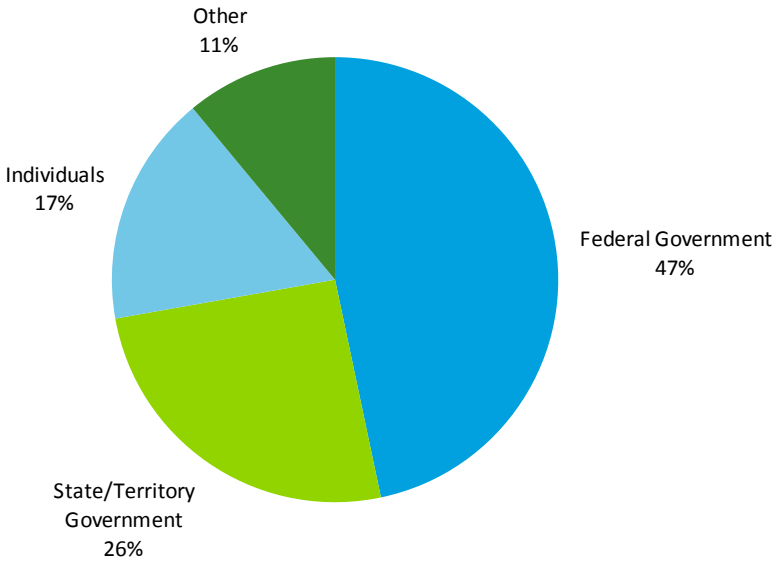
Chart 5.6: Health System Costs by Cost Component, 2011



Note: includes the additional health system costs due to accidental falls and pneumonia.
Source: Deloitte Access Economics' estimates.

Governments bore around two thirds of the health system costs (73%), while individuals bore another 17%, and other parties (private health insurance, charities) bore the remaining 11% (see Chart 5.7).

Chart 5.7: Health system costs, by who bears the cost, 2011



Source: Deloitte Access Economics' estimates.

6 Productivity costs

Productivity costs measure the losses to production resulting from PD. These include losses to the formal sector through reduced workforce participation of PWP and their carers; as well as losses to the unpaid sector such as house and yard work and voluntary work.

Productivity losses are broken down into short-run and long-run costs. Short-run costs are those associated with temporary absences from work due to PD (such as to attend medical appointments) and costs are incurred until production is restored to former levels. Long-run costs are those associated with permanent loss of the labour resource (through premature workforce separation or premature mortality). In addition to the direct productivity loss, the employer incurs administrative costs associated with both short-run and long-run costs (such as processing employees who take time off or searching, hiring and training replacement workers).

The 2007 report uses the **friction method** to measure short-run productivity costs and the **human capital method** to estimate long-run productivity costs.

- The **friction method** was developed by Koopmanschap et al (1995). This approach estimates production losses for the time period required to restore production to its pre-incident state. Based on neoclassical theory, wages and other marginal costs are assumed to be equal to the value of the marginal revenue generated by an additional worker under conditions of full employment (Berger and Murray, 2001). Lost production is thus the value of the wages (measured as average earnings) plus other inputs to production (capital, plant and equipment, land, enterprise etc) multiplied by the number of workdays missed.
- The **human capital method** estimates production losses based on the remaining expected lifetime earnings for the individual.

A review of the literature since the 2007 report identified no Australian studies or new useful datasets for estimating the impact of PD on productivity. As such, we used the methodology outlined on pages 49–52 of the original report to populate the parameters of these models and estimate productivity costs. This methodology draws largely on international studies such as Rubenstein (1997), Le Penn (1999) and Chrischilles (1998)

To update productivity costs from the 2005 estimates, we updated the following parameters:

- **earnings**, using current mean weekly earnings rates by age group from the Australian Bureau of Statistics (ABS, 2011b);
- the **probability of being employed** (and remaining in employment) at any given age using updated statistics on employment ratios by age group (ABS, 2011a & ABS, 2011f);
- employee **on-costs** using current ABS data (ABS, 2011c & ABS, 2011d);
- the **proportion of sick leave that is paid** (to divide costs of temporary absenteeism into those borne by the worker and those borne by employers) using the most recent ABS data on working arrangements (ABS, 2010).

The following parameters were left unchanged as they were based on research that is still the best available:

- temporary absenteeism from work (number of days) by disease stage (Le Penn (1999) and Chrischilles (1998));
- manager time lost per temporary absenteeism (HSE, 1999);
- employee turnover costs (including increased turnover rate) (Access Economics, 2004); and
- the overtime premium (Access Economics, 2004).

The estimated productivity cost of PD in 2011 was around $107.3 million. This is almost double the estimated cost in 2005 (Table 6.1).

Table 6.1: Summary of productivity costs in 2011 and 2005 (nominal), $m

Source of cost	Costs ($m)		Growth (%)
	2005	2011	
Temporary absenteeism from work (including management admin time)	15.3	28.0	83
Premature workforce separation	33.1	63.7	93
Premature mortality*	6.8	15.4	129
Search, hiring and training costs	0.02	0.1	339
Total	**55.2**	**107.3**	**95**

Although a higher prevalence of PD in 2011 compared to 2005 (see section 3.2.3) would no doubt be contributing to the increase in productivity costs, the average productivity cost per PWP has also increased significantly in real terms to $1,675 in 2011, up 66% from $1,000 in 2005.

The increase is largely due to growth in earnings, which, on average, increased by 37% in nominal terms and 14% in real terms (Table 6.2). Earnings are the major input in the calculation of productivity costs (see explanation on friction and human capital methods above), therefore any growth in earnings will have a discernable impact on overall productivity costs.

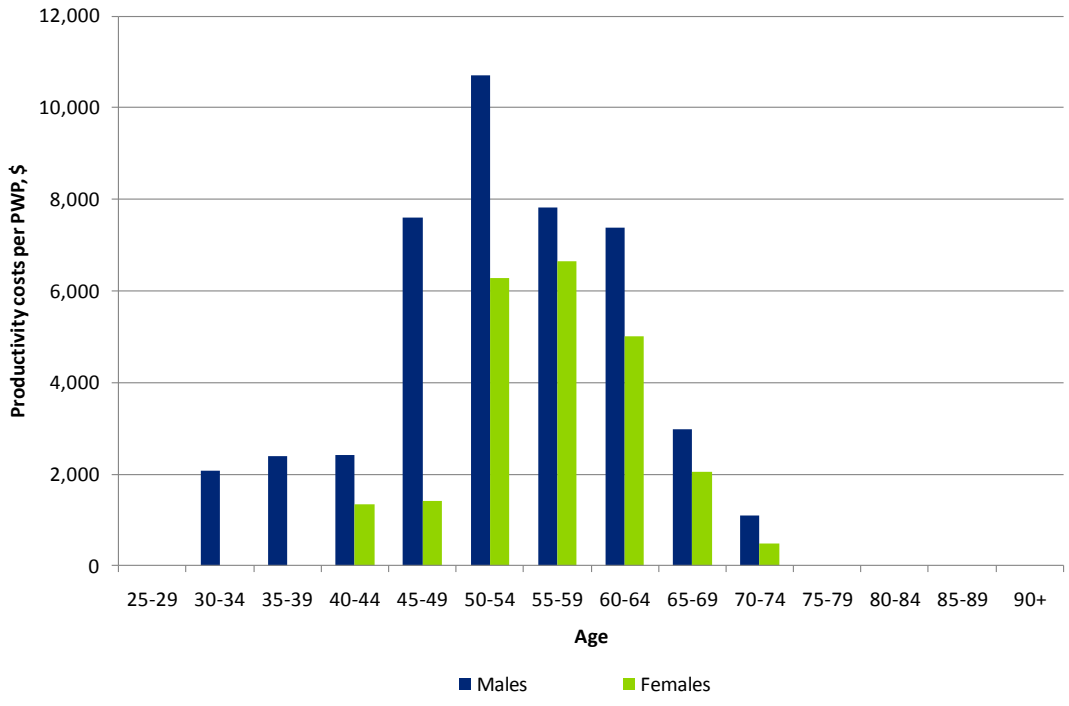
Table 6.2: Real and nominal earnings growth 2005-11, by age group

Age group	AWE distribution (average of males and females)		Total (nominal) growth (%)	Real growth* (%)
	2005	2011		
15-19	235	285	22	1
20-24	531	671	26	5
25-29	799	993	24	3
30-34	799	1,097	37	14
35-39	862	1,179	37	14
40-44	862	1,201	39	16
45-49	878	1,197	36	14
50-54	878	1,152	31	9
55-59	836	1,144	37	14
60-64	726	1,018	40	17
65+	484	847	75	46
Average	**717**	**980**	**37**	**14**

* Adjusted for 20% CPI inflation over the period

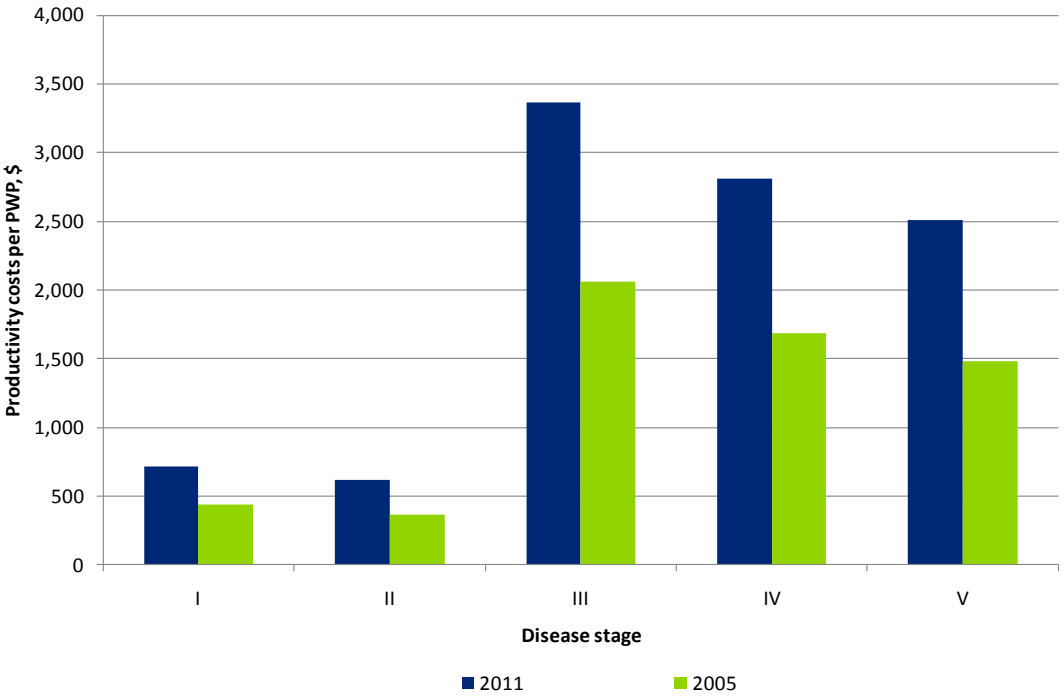
As was the case in 2005, costs per PWP differed significantly by age, sex and disease stage (Chart 6.1 and Chart 6.2). Costs were higher for males (largely reflecting their higher earnings profile) and peaked between the ages of 50–59 (when the intersection of the prevalence of PD and the probability of being employed is the highest).

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



Productivity costs are largest for stage III of the disease, reflecting the fact that PWP in stages IV and V are mostly above the working age (and their potential productive capacity is lower, regardless of PD).

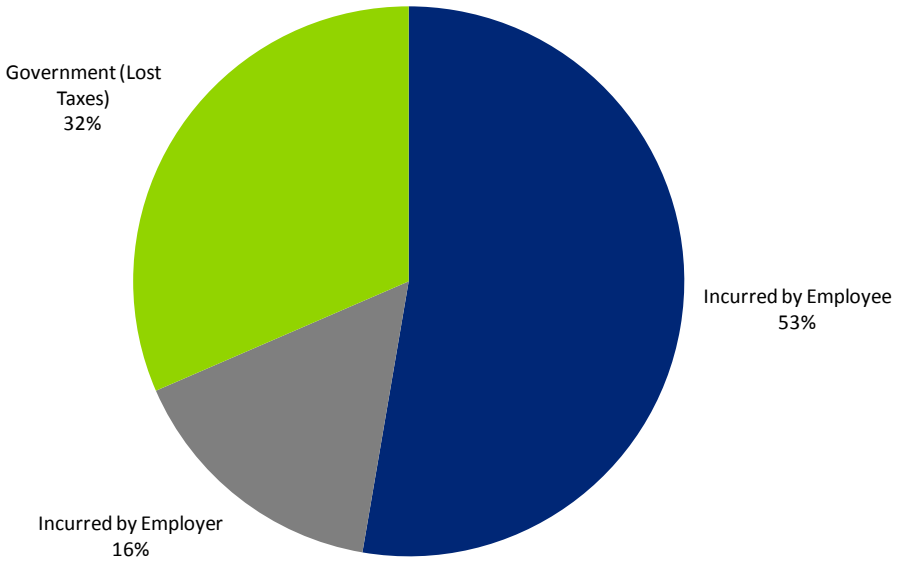
Chart 6.2: Productivity costs per PWP ($), by disease stage, 2005 & 2011 (nominal)



Productivity costs are shared between the worker, the employer and society (through lost taxation revenue) (Chart 6.3). Post tax:

- **Workers** bore 52% of the productivity cost of PD ($53 million or $900 per PWP).
- **Employers** bore around 16% of the productivity costs of PD (around $16 million or $300 per PWP). These costs largely reflect paid sick leave, overtime payments to workers who pick up the hours of the absent PWP, costs of replacing workers (search, hiring and training costs) and management administration time.
- **Governments** bore 32% of the productivity costs ($32 million or $500 per PWP) through lost taxation revenue.

Chart 6.3: Distribution of Productivity costs, 2011



Compared to 2005, some of the costs have shifted from the Government to the employee through lower average tax rates. Employers' share of costs is largely unchanged.

7 Informal care and other financial costs

7.1 Number of carers of PWP

Access Economics (2007a) estimated that there were around 7,300 carers of PWP in 2005. Based on growth in the prevalence of PWP between 2005 and 2011, we estimate that the **number of carers in 2011 is 8,501.**

The number of carers by age, sex and disease stage (which is required to estimate the opportunity cost of their time) was estimated using the methodology detailed on page 59 of the original report (Access Economics, 2007a). Overall, around 1,425 carers are of working age (compared to 1,200 in 2005).

7.2 Time spent caring for PWP

In line with Access Economics (2007a), the time spent caring for PWP is estimated using the average number of hours provided per week by Australian primary carers in general (30.5 hours (ABS, 2010b) down from 33.5 hours estimated in 2005).

In total, **informal carers provided around 13.5 million hours of care in 2011** – equivalent to around 211 hours per PWP. In 2005, carers provided around 231 hours of informal care per PWP.

7.3 Updating the cost of informal care

Applying the updated parameter estimates outlined in sections 7.2 and 7.3 above yields an estimate of the **cost of informal care provided to PWP in 2011 of $11.2 million, or $174 per PWP.**

In 2005, this cost was estimated as $5.4 million (or $100 per PWP), so the costs of informal care have more than doubled over the six years to 2011. The increase is almost entirely a result of the higher value placed on informal carers' time spent caring, which is measured using earnings data outlined in chapter 6[18]. The total number of informal care hours provided has only increased slightly (and has decreased per PWP). These findings are summarised in Table 7.1.

[18] The estimate of the cost of informal care is derived using the opportunity cost method, which places a dollar value on the time spent providing informal care by assigning the formal sector productivity losses associated with this time (i.e. it values the time devoted to caring as time that cannot be spent in the workforce).

Table 7.1: Estimating the cost of informal care, 2005 & 2011 (nominal)

	2005		2011	
	Total	Per PWP	Total	Per PWP
Number of carers	7,264	0.13	8,501	0.13
Time spent caring (hours)	12,654,091	231	13,483,241	211
Cost of informal care ($)	5,359,125	98	11,164,208	174

Informal care can also have other indirect costs on carers through impacts on their health and wellbeing, though these are not measured here. These costs include emotional detriment from the responsibility of caring, as well as physical injury often incurred from lifting or moving the recipient of care[19].

7.4 Out-of-pocket expenses

7.4.1 Use of aids and modifications

Access Economics (2007a) estimated the additional use of aids and modifications due to PD for each stage of the disease, and then calculated the cost of this additional usage by applying these weights to the average cost per year for the aid, which was sourced from Sun Medical Equipment Centre. These costs were updated for 2011 using the Consumer Price Index CPI and the additional usage rates are maintained from the previous report. The results are summarised in Table 7.2.

On average (across all aids and disease stages), the additional use of aids and modifications resulting from PD costs $802 per year per PWP. This is an increase of 20% on the average cost per year per PWP in 2005.

[19] For more information see pages 61 and 62 of the original report.

Table 7.2: Additional use of aids and modifications due to PD (by disease stage) and average cost of aids in 2011

Aid	Average cost in 2011 ($)	Additional use by disease stage, %				
		I	II	III	IV	V
Walker, cane or crutches	96	12	16	25	27	27
Wheelchair	1,201	12	17	26	28	28
Grab bars or railings	30	11	16	25	27	27
Shower seats or raised stools	52	12	17	26	28	28
Raised toilet	72	11	15	23	25	25
Incontinence Pads*	3,499	0	14	30	46	62
Wheelchair Maintenance	60	12	17	26	28	28
Average cost per year due to PD, per PWP ($)		**180**	**740**	**1,440**	**2,030**	**2,590**

* 2,912 units used per year at $1 each for 2005 and $1.20 each for 2011
Source: Access Economics (2007a)

However, these costs are only incurred by PWP who are not already receiving help in a high care residential setting. Applying the average cost per year per PWP to the number of PWP not in a nursing home yields a **total cost of aids and modifications of $51.4 million in 2011**. In 2005, this cost was estimated to be $36.5 million, thus the cost of aids and modifications has increased by around 41%.

7.4.2 Use of formal care, accommodation and travel costs

In line with the 2007 report, the cost of formal care, accommodation and travel are estimated as 6% of the total health system costs, which **in 2011 equates to an average of $45 per PWP**, up from $38 per PWP in 2005.

Again, these costs are assumed to only be incurred by PWP not in a nursing home, so applying this average cost as such yields a total cost of travel, accommodation and informal care in 2011 of around $1.8 million (up from $1.3 million in 2005). Since we have assumed that formal care costs have remained a constant proportion of total health system costs since 2005, the sole driver of the PWP cost increase is the increase in health system costs. A small increase in the number of PWP not residing in nursing homes has also added to the total cost.

7.5 Government programs

Palliative Care Programs:

Government expenditure on the Palliative Care and Community Assistance program in 2010-11 was budgeted to be $33.2 million (DoHA, 2011). The other two Palliative care programs listed in the 2007 report – under the Australian Health Care Agreements and the Local Palliative Care Grants program – did not extend to 2010-11. Instead, in 2010-11 additional funding for palliative care came under the 'sub-acute care' funding bucket. The 2010-11 Budget for sub-acute care was $731.8 million. However, the proportion of this funding relating to palliative care is not transparent.

Due to the difficulty in obtaining a comparable estimate for total palliative care funding in 2011, we (conservatively) assume that Federal government funding for palliative care has not changed since 2005. Total funding in 2005 of $59.8 is indexed to 2011 by applying health cost inflation of 3.3% per annum, yielding an estimate of total Federal Government expenditure on palliative care in 2011 of $73.0 million. This figure will underestimate the total funding for palliative care, as it does not include contributions from State and Territory governments or from private sources.

Using the same methodology as the 2007 report (see page 67) to allocate a proportion of palliative care funding to PD yields an estimate of total government expenditure on palliative care for PD of around $70,000 (compared to around $57,000 in 2005).

The 2007 report also includes the value of volunteer hours provided to palliative care. Maintaining this methodology, we indexed the value of volunteer hours provided to PWP in 2005 ($11,200) to 2011 using health cost inflation of 3.3% per annum, yielding an estimate of $13,700 per PWP in 2011.

Consequently, the total value of *community based* palliative care services for PD is around $83,000 (or $49 per death due to PD[20]).

The assumptions maintained from the 2007 report to arrive at this estimate are outlined in Table 7.3.

Table 7.3: Assumptions maintained from 2007 report

Statistic	Value	Source
% of people who died from PD receiving specialist palliative care	4.1%	McNamara et al (2004)
% of people receiving specialist palliative care with PD	0.1%	Access Economics (2007a)
Number of palliative care services	254	Register of Palliative Care Services - Palliative Care Australia
% of palliative care services reporting the use of volunteer services	78%	Palliative Care Australia 1998 Census
Number of volunteer hours received per week received by each service	35.7	Palliative Care Australia 1998 Census

National Respite for Carers Program (NRCP)

Funding for the NRCP was $200 million in 2009-10 (the most recent year available) (PC, 2010). Inflating this to 2011 by applying health cost inflation of 3.3% yields an equivalent funding of $206.6 million in 2010-11.

According to the Survey of Disability Ageing and Carers (SDAC) (ABS, 2003), in 2003 there were 474,600 primary carers, of which 6,900 were carers of PWP (1.45%) (Access

[20] Using the upper bound estimates for deaths (see section 3.5)

Economics, 2007a). Assuming that the proportion of primary carers caring for PWP has remained unchanged and assuming that carers of PWP accessed respite services at the same rate and same intensity as other carers, the **total expenditure in 2010-11 on respite for PWP is $3.0 million or $353 per carer.** In 2005, total expenditure on the NRCP for PWP was $2.0 million or $284 per PWP.

Community assistance programs:

The following community assistance programs are accessed by PWP:

- Home and Community Care (HACC) Program;
- Extended Aged Care at Home (EACH);
- Community Aged Care Packages (CACP); and
- Veterans Home Care (VHC) program.

The most recent report from the Productivity Commission on Government services (PC, 2011) details government expenditure on these programs in 2009-10 (Table 7.4).

Table 7.4: Government expenditure on selected community care programs (2009-10), $m

	HACC	CACP	EACH	VHC*	Total
Total expenditure in Australia ($m)	1,944.5	508.7	206.0	90.8	2,750

Source: PC, 2011

An additional 5.3 million for Community Care Grants and 109.6 million for DVA Community Nursing were provided by DoHA and the DVA respectively.

However, no information is available on the use of these programs by PWP, so in line with the 2007 methodology, they are excluded from our cost estimate.

Summary

In 2011, expenditure on PWP through government programs was at least $3.1 million, consisting of community based palliative care ($83,101) and respite ($3.0 million). This is a highly conservative estimate as expenditure on community care programs is excluded.

In 2005, this cost was estimated as $2.1 million, therefore growing by 40% over the 6-years to 2011.

7.6 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 $4,763 per person in 2011 (inflated using the CPI).

7.7 Summary

Overall, other financial costs due to PD were around $57.1 million in 2011. In 2005, this cost was around $40.5 million, equating to growth of around 40% over the period (Table 7.5). The cost of aids and modifications continues to constitute the majority of these costs.

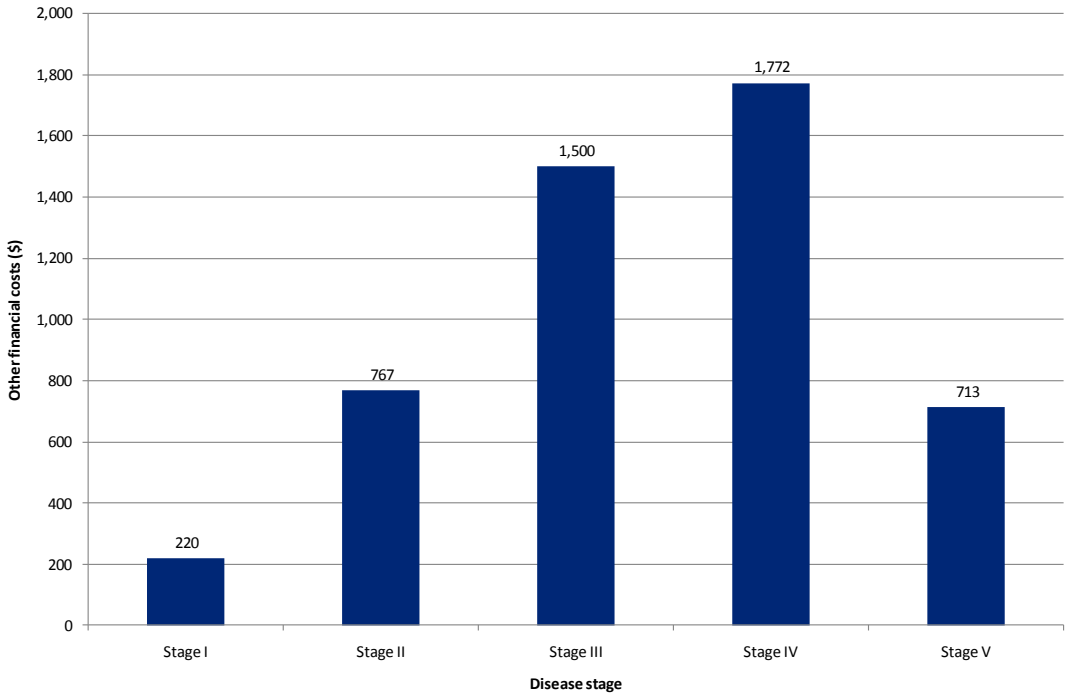
Table 7.5: Other financial costs of PD ($m), 2005 and 2011 (nominal)

Cost category	Cost ($m)		Growth (%)
	2005	2011	
Aids and modifications	36.5	51.4	41
Formal care	1.3	1.8	38
Palliative care	0.07	0.08	22
Respite	2.1	3.0	46
Funeral costs	0.6	0.8	32
Total	**40.5**	**57.1**	**41**

Around half of this growth was due to the increase in the prevalence of PD, but on average, the cost per PWP still increased substantially to $887 (up 20% from $741 in 2005). The remainder of the cost increase was largely due to CPI inflation over the period.

The distribution of costs over the stages of PD were largely unchanged, with costs peaking in stage IV before many people were admitted to nursing homes (Chart 7.1).

Chart 7.1: Indirect costs per PWP ($), by disease stage



8 Transfers

Transfer payments are financial flows that impact on who bears the cost, but not on the overall level of costs. However, the act of taxation and redistribution creates distortions and inefficiencies which result in real costs, known as deadweight losses.

As well as being necessary to calculate DWLs, 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.

The following transfers relate to PD:

- financial support for PWP (transfer from society to PWP)
- financial support for carers of PWP (transfer from society to carers)
- lost taxation revenue on foregone earnings through early workforce separation and/or temporary absenteeism due to PD (transfer from society to PWP)

8.1 Financial support for PWP

The main source of income support for PWP is the Disability Support Pension (DSP). This is payable to people aged less than 65 years. People aged 65+ are eligible for the age pension, but following the method in the 2007 report, this section will focus only on people aged less than 65 who would be receiving the DSP.

Drawing on findings from the 1999 'Living with Parkinson's Disease in the Central West NSW Study', the 2007 report assumed that 56% of PWP aged 55–64 years received income support. Maintaining this assumption, we estimate that **6,592 PWP aged less than 65 years received income support in 2011** (up from 5,591 in 2005).

At June 2010 (the most recent period with data available), 792,581 people in Australia were receiving the Disability Support Pension (FaHCSIA, 2011). DSP payments cost the Government around 0.9% of GDP per annum (Commonwealth of Australia, 2010), thus for 2011, the total cost of DSP payments was around $2.9 billion, or $3,683 per person (compared with $3,545 per person in 2005). Applying this per person cost to the number of PWP receiving income support in 2011 estimated above provides an estimate of the **total expenditure on DSP payments to PWP in 2011 of $24.3 million.** This expenditure has grown by around 23% from $19.8 million in 2005, mainly a result of an increase in the number of PWP receiving income support (payment per PWP has only increased slightly).

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. In line with the 2007 report, we do this by drawing on a Melbourne University study (Tseng and Wilkins, 2002) about the 'reliance' of the general population (aged 15-64 years) on income support.

Table 8.1: Additional DSP payments to PWP, 2011

	Average reliance (%)		Additional payments, 2011 ($m)
	Males	Females	
Disability Support Pension	10.2	14.9	21.4

Source: Tseng and Wilkins (2002)

Thus, we assume that 10% of the DSP payments made to females with PD and 15% of the payments made to males with PD would have been made regardless of PD. This means that **around $21.4 million in additional welfare payments are paid to working age PWP** – or $1,800 per working age PWP.

8.2 Financial 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[21].
- **Carer Allowance** is a non-means tested income supplement for people who provide daily care to an adult or child with a severe and long-term disability or health condition.

In 2010-11 around $4.3 billion was paid to carers in the form of the Carer Payment and Carer Allowance (FaHCSIA, 2011b). Assuming that the number of hours provided per carer receiving each payment has not changed since the 2007 report, the cost per hour can be calculated

Table 8.2: Income support to carers, 2010-11

	2010-11 budget $m	Number of recipients at June 2010	Hours of care (millions)	Cost per hour $
Carer payment	2,730.7	168,913	1,754	1.56
Carer allowance	1,601.0	495,733	1,957	0.82
Total	**4,331.7**	**664,646**	**3,711**	

Sources: ABS, 2010b; FaHCSIA, 2011 & 2011b

Based on these estimates and the number of carers of PWP (outlined in section 7.1), we estimate that around **$14.5 million was provided to carers of PWP in 2010-11[22], or $230 per PWP.** The estimate of the PWP cost has declined by $10 since 2005, indicating that the funding for these payments has not increased proportionately with the aggregate level of care required by PWP in 2011.

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

[22] This assumes that carers of PWP receive the Carer Payment or allowance at the same rate as the general carer population for the period for which care is provided.

The government also paid an additional $452.9 million in Carer Supplements and $160.5 million in Child Disability Support Payments. However, there is no detailed information on the number of recipients of these payments, so they are excluded from our costing.

The 2007 report details some additional avenues of financial support for carers and PWP, such as Bereavement Allowances and Payments, payments from the DVA and early access to superannuation.

8.3 Lost 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. This lost value in wages and firm output was calculated in chapters 6 and 7. Pre-tax:

- PWP lost $82.5 million in wage income due to long-term lost earnings and premature death;
- Carers lost $11.2 million in wage income due to caring for PWP;
- Employers lost $24.8 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.

In 2005, these losses were $42.1 million, $5.4 million and $13.1 million respectively.

In line with the methodology in the 2007 report, employer losses are treated as lost company revenue, and the remainder are treated as lost personal income. The average personal income tax rate is 18.9% and the average indirect tax rate is 12.6%, based on the Access Economics Macroeconomic model (AEM). 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 (Access Economics, 2007a).

Together these calculations generate a **total loss of tax revenue of $37.3 million in 2011,** up 68% from $22.2 million in 2005. The increase is entirely a result of there being more foregone income due to PD, with both average tax rates actually declining since 2005.

8.4 Deadweight losses

In line with the 2007 report, 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 (ATO) 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).

In 2011, the **total deadweight loss relating to PWP was around $116 million** (Table 8.3). In 2005, this cost was $82.3 million, thus DWL have increased by around 41% over the 6 years to 2011 (entirely due to the increase in transfers).

Table 8.3: Summary of transfers and deadweight losses, 2011

Transfer	Amount in 2011 ($m)
Health system costs borne by the Government	345.5
Other costs borne by the Government	3.1
Lost taxes	37.3
Welfare payments	35.9
Total transfers	**421.8**
Resulting dead weight loss	121.3

9 Burden of disease

A substantial cost of PD is the loss of wellbeing and life expectancy that patients experience. As such, total economic costs of PD include a valuation of the burden of disease (BoD). The BoD is measured in terms of disability adjusted life years (DALYs), which is the sum of healthy years of life lost due to disability (YLD) and years of life lost due to premature death (YLL). The BoD is converted into a monetary equivalent using an imputed value of a statistical life year (VSLY), to enable comparison between the BoD and the financial costs of PD.

In the last report, a gross VSLY of $162,561 (in 2005 dollars) was estimated based on the value of a statistical life of $3.7 million. Since the 2007 report was completed, the Department of Finance has released a guidance note on VSLY in Australia (OBPR, 2008). The recommendation is that departments and agencies use the estimate of $3.5 million for the value of statistical life and $151 000 for the value of statistical life year (both of these are measured in 2007 dollars). Applying indexation, the VSLY in 2011 is $164,192. This VSLY translates to a value of a statistical life year of $3.9 million in 2011 (using a discount rate of 3% (see section 4.3) and an expected life span of 40 years).

The BoD is then estimated by applying the value of a statistical life year of $164,192 to the total Disability Adjusted Life Years (DALYs) calculated due to PD. This is done as follows, with the results by disease stage summarised in Table 9.1:

- Years of healthy life lost due to disability (YLDs) are calculated based on disability weights of PD used in Begg et al (2007), multiplied by the number of PWP as estimated in Section 3.2 (with no age weighting)[23].
- Years of life lost due to PD (YLLs) are calculated by comparing the number of deaths from PD by age (as estimated in Section 3.5) with the corresponding YLLs for that age of death in the Standard Life Expectancy Table (West Level 26).
- YLDs and YLLs are added together to estimate total DALYs.

Table 9.1: Estimating the burden of PD in 2011, by disease stage

Stage	YLDs	YLLs	DALYs	Value in 2011 ($m)
I	9,633	3,143	12,776	2,098
II	8,202	2,921	11,123	1,826
III	6,993	2,630	9,623	1,580
IV	6,668	1,572	8,241	1,353
V	3,570	737	4,307	707
Total all stages	**35,065**	**11,004**	**46,069**	**7,564**

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

In summary, the non-financial burden of PD resulting from loss of life and wellbeing in 2011 is estimated at around $7.6 billion.

In 2005, this cost was estimated to be around $6.3 billion, thus the estimated BoD has increased by around 21% over the 6-years to 2011.

PWP aged 75-85 years bear most of the total burden of PD (Chart 9.1), but this is because of the high prevalence in this age group. Per PWP, the burden increases consistently with age (Chart 9.2).

Similarly, although most of the total burden is borne by PWP in the initial stages of the disease (Chart 9.3), the burden per PWP increases with disease stage (Chart 9.4).

Chart 9.1: Total DALYs, by age, 2011

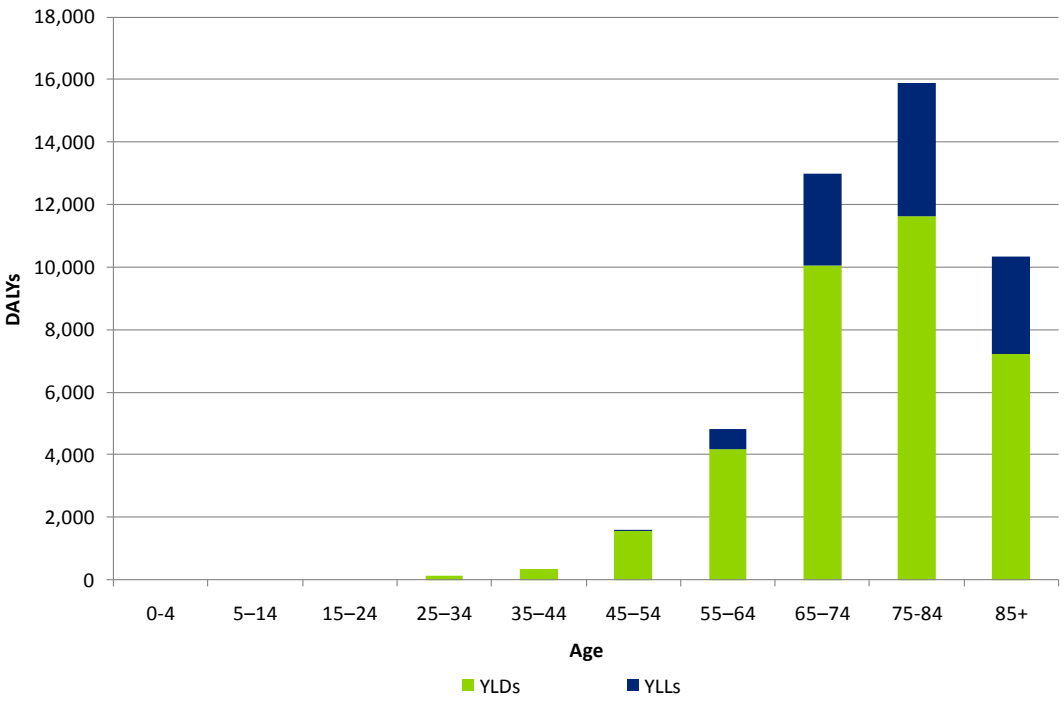


Chart 9.2: DALYs per PWP, by age, 2011

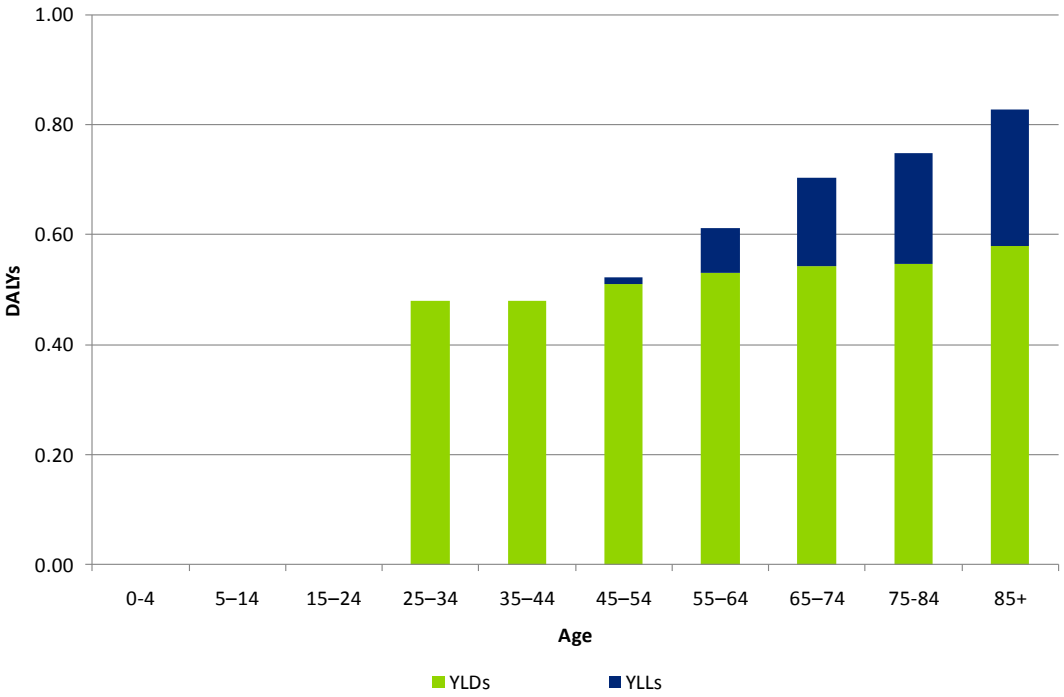


Chart 9.3: Total DALYs, by disease stage, 2011

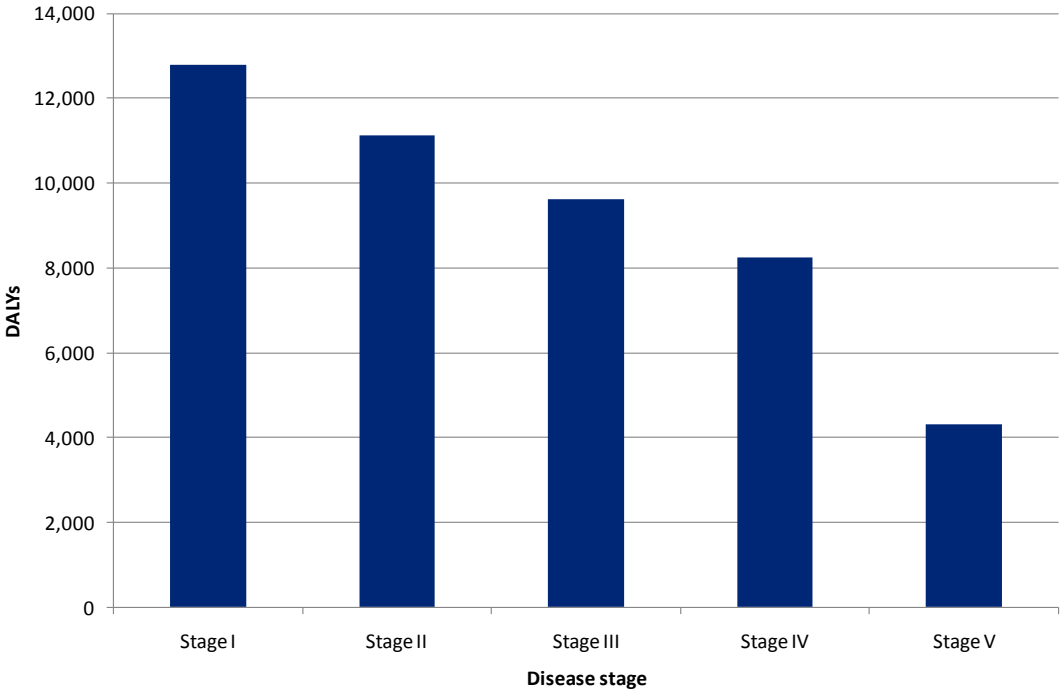
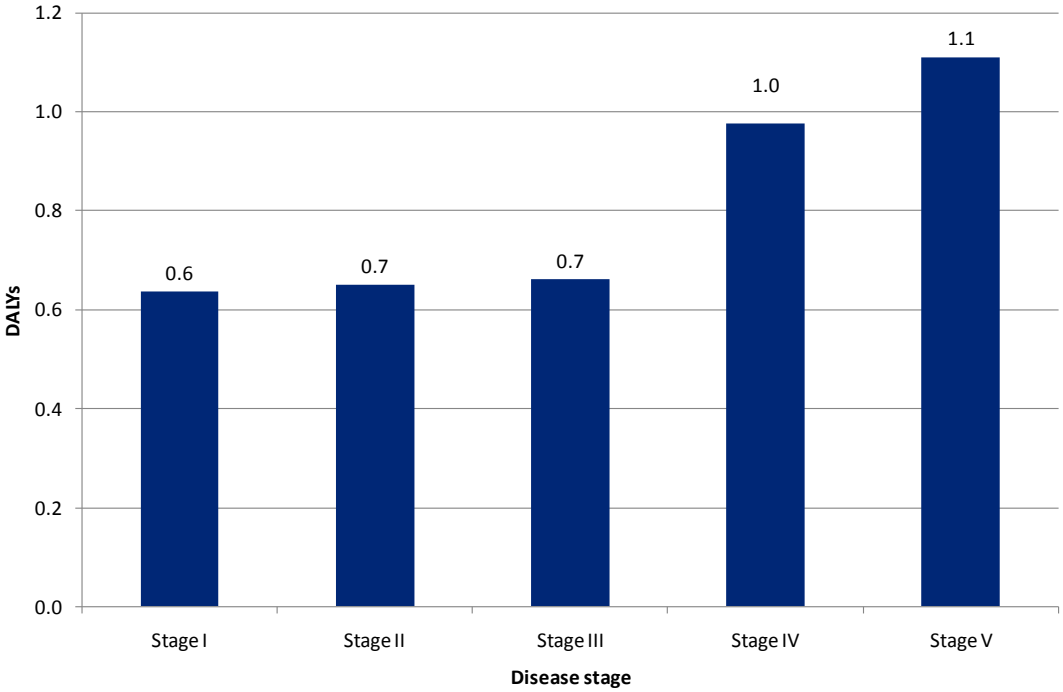


Chart 9.4: DALYs per PWP, by disease stage, 2011



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

10 Total economic cost of PD

In Australia in 2010-11 it is estimated that there were:

- 64,044 people living with PD;
- 10,497 new cases of PD; and
- between 1,299 and 1,692 deaths due to PD.

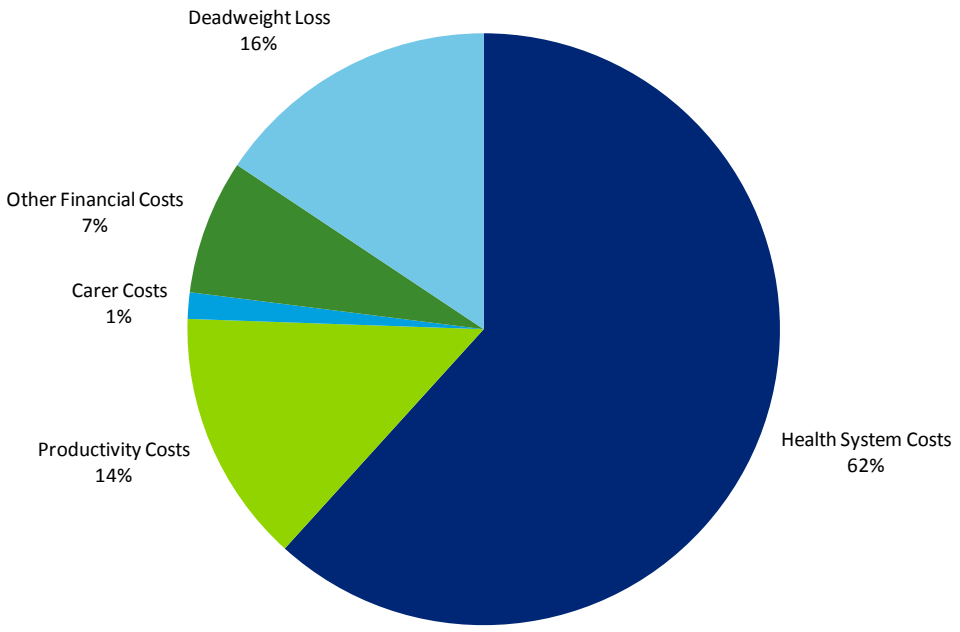
> The total financial cost of PD in the year 2011 was around $775.4 million.

The financial cost of PD has increased by 48% since 2005.

Costs placed on the health system were by far the largest component of the financial costs of PD (Figure 10.1). Moreover, growth in health system costs accounted for over half of the growth in financial costs since 2005.

- Health system costs were $478.5 million (62%).
- Deadweight losses were $121.3 million (16%).
- Productivity costs were $107.3 million (14%).
- Other financial costs were $57.1 million (7%).
- Carer costs were $11.2 million (1%).

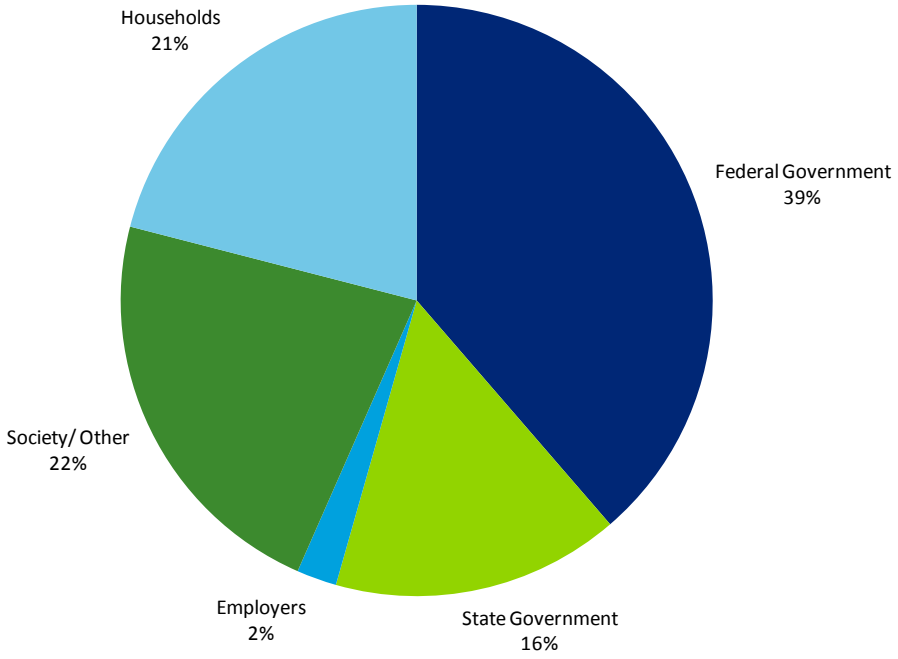
Figure 10.1: Financial costs of PD, by cost type, 2011



The proportion of total financial costs attributable to each component is largely unchanged since 2005. There was a slight shift from health system costs (-3 percentage points (%pts)) into productivity costs (+3 %pts).

The financial costs of PD are mainly borne by the Federal Government (39%), followed by society and other parties (such as private health insurers and charities) (22%), the household (PWP, their families and friends) (21%), State Governments (16%) and employers (2%) (Chart 10.2). Again, this distribution is largely unchanged since 2011.

Chart 10.2: Financial costs of PD, by bearer of cost, 2011



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 46,069 DALYs (years of healthy life lost), with 76% due to disability and the remaining 24% due to premature death. The net value of the burden of disease was $7.6 million in 2011 (an increase of 21% since 2005).

Thus, the total economic cost of PD per annum in 2011 was $8.3 billion.

Table 10.2: The total cost of PD by cost type and bearer of cost ($m), 2011

	Individuals	Family/ Friends	Australian Govt	State Govt	Employers	Society / Other	Total
Burden of Disease	7,564.2	0.0	0.0	0.0	0.0	0.0	**7,564**
Health System Costs	80.4	0.0	223.5	122.0	0.0	52.6	**478**
Productivity Costs	56.5	0.0	33.8	0.0	17.0	0.0	**107**
Carer Costs	0.0	7.6	3.5	0.0	0.0	0.0	**11**
Other Financial Costs	53.2	0.8	3.1			0.0	**57**
Deadweight Loss	0.0	0.0	0.0	0.0	0.0	121.3	**121**
Transfers	-21.4	-14.5	35.9	0.0	0.0	0.0	**0**
Total	**7,732.9**	**-6.1**	**299.8**	**122.0**	**17.0**	**173.9**	**8,339**

The economic cost of PD per PWP was around $130,000, of which the BoD component was around $118,000 per PWP (91%) while the financial cost was around $12,000 per PWP (9%).

The total economic cost per PWP increased by 5% over the 6-years to 2011, largely as a result of higher burden of disease and productivity costs (Chart 10.3Chart 10.4).

Chart 10.3: Financial cost of PD per PWP, by cost type, 2005 and 2011 (nominal)

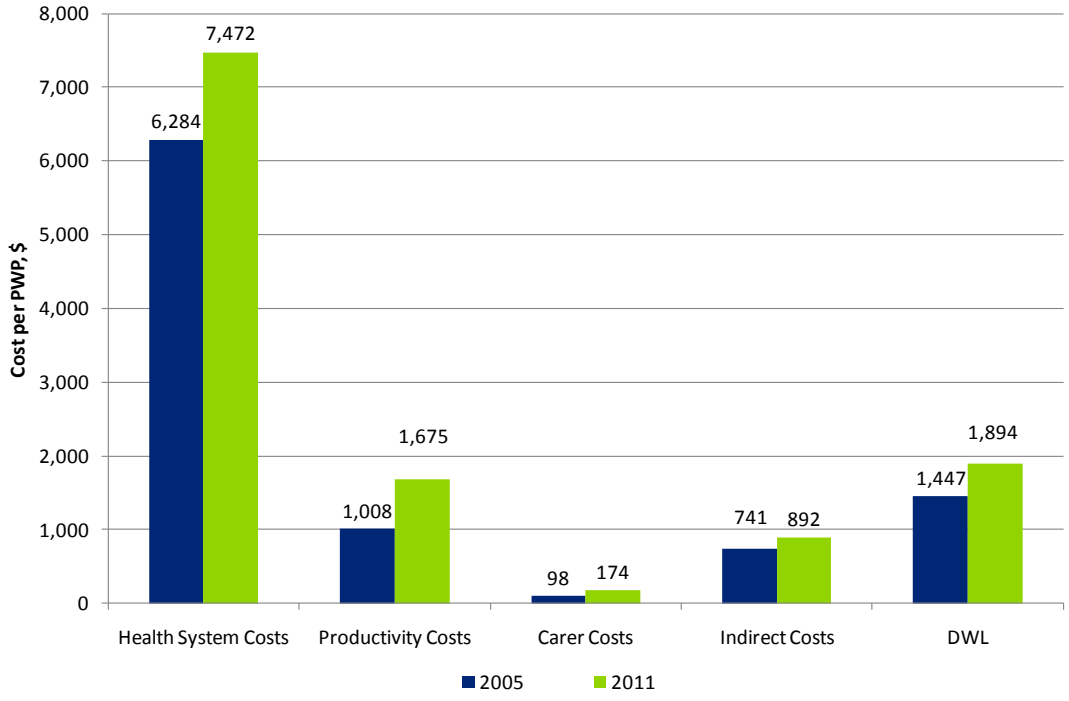
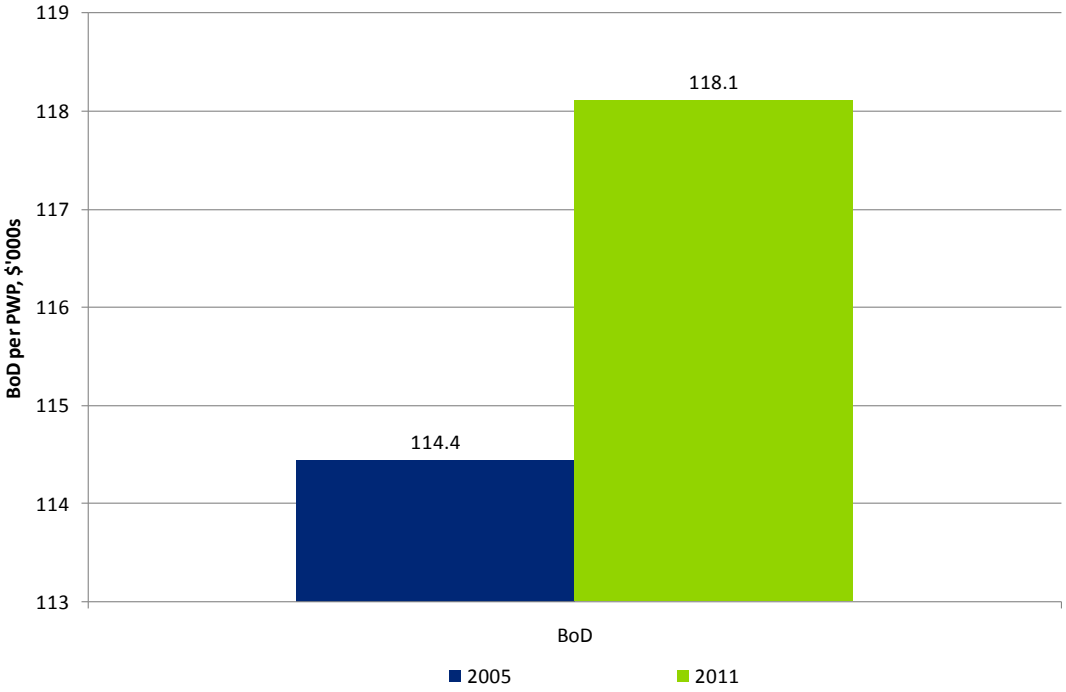


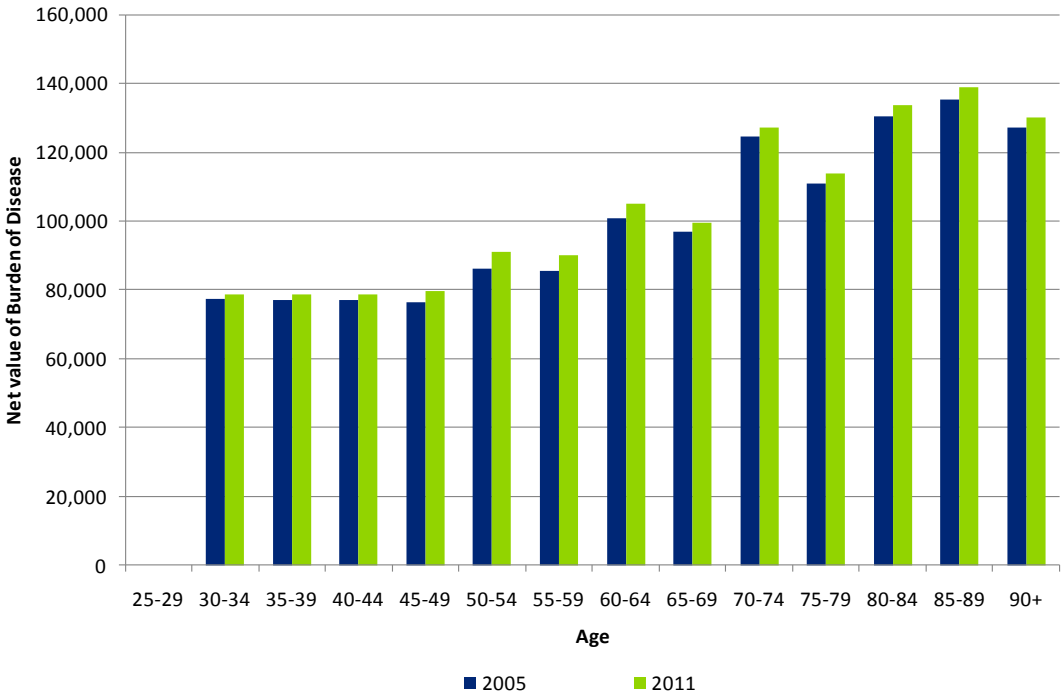
Chart 10.4: Burden of Disease per PWP, 2005 and 2011 (nominal)



While the BoD generally increases with age (Chart 10.5), the financial cost of PD is highest for people aged 50-65 years (Chart 10.6). This is largely due to the lost earnings due to premature mortality and workforce separation, with this effect dissipating from 65 years onwards.

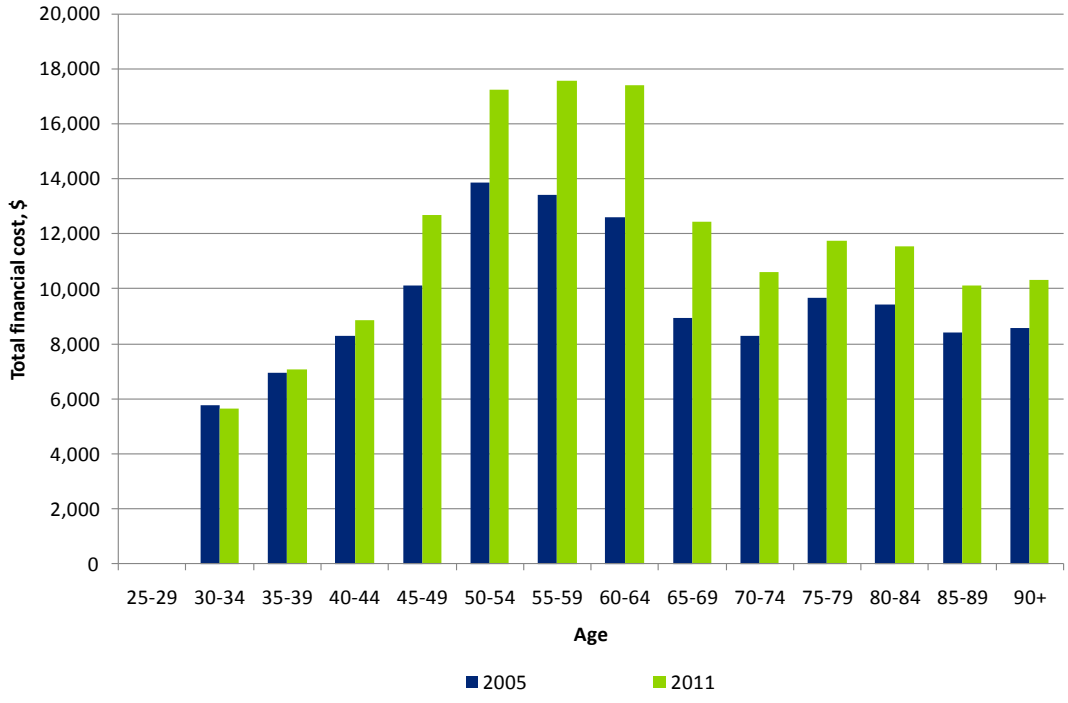
The total value of the BoD is largely unchanged since 2005, mainly because the methodology for the estimate of the VSLY differed from the previous report (chapter 9).

Chart 10.5: Net value of the burden of disease per PWP, by age ($), 2005 and 2011 (nominal)



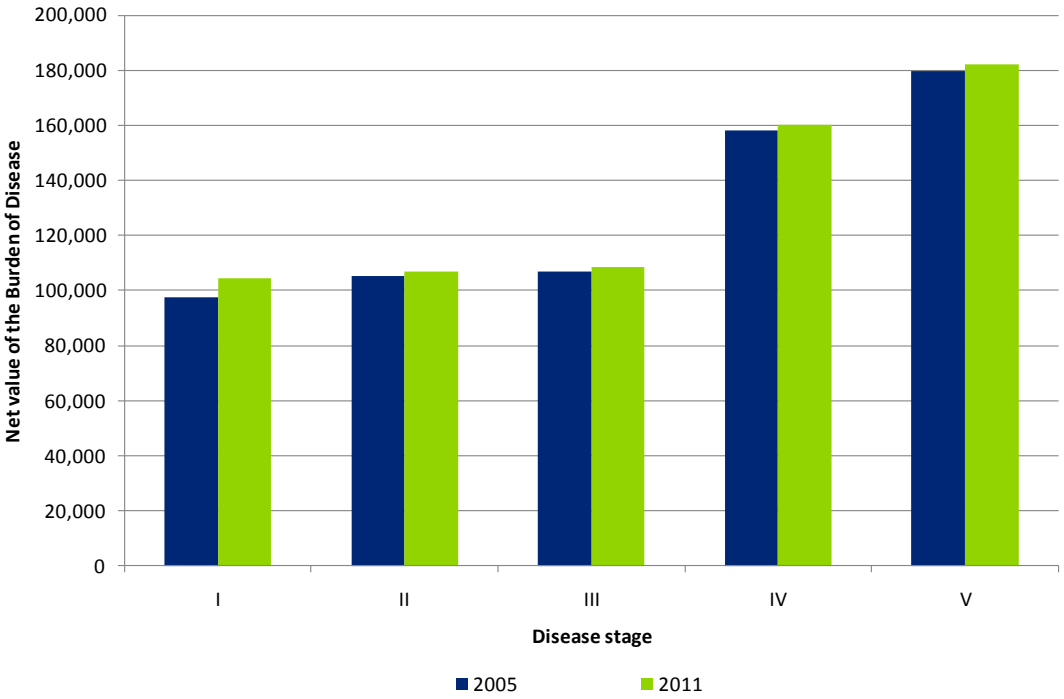
Financial costs increased across all age groups except those aged 30-34, but the distribution across age groups was largely unchanged.

Chart 10.6: Financial cost per PWP, by age ($), 2005 and 2011 (nominal)



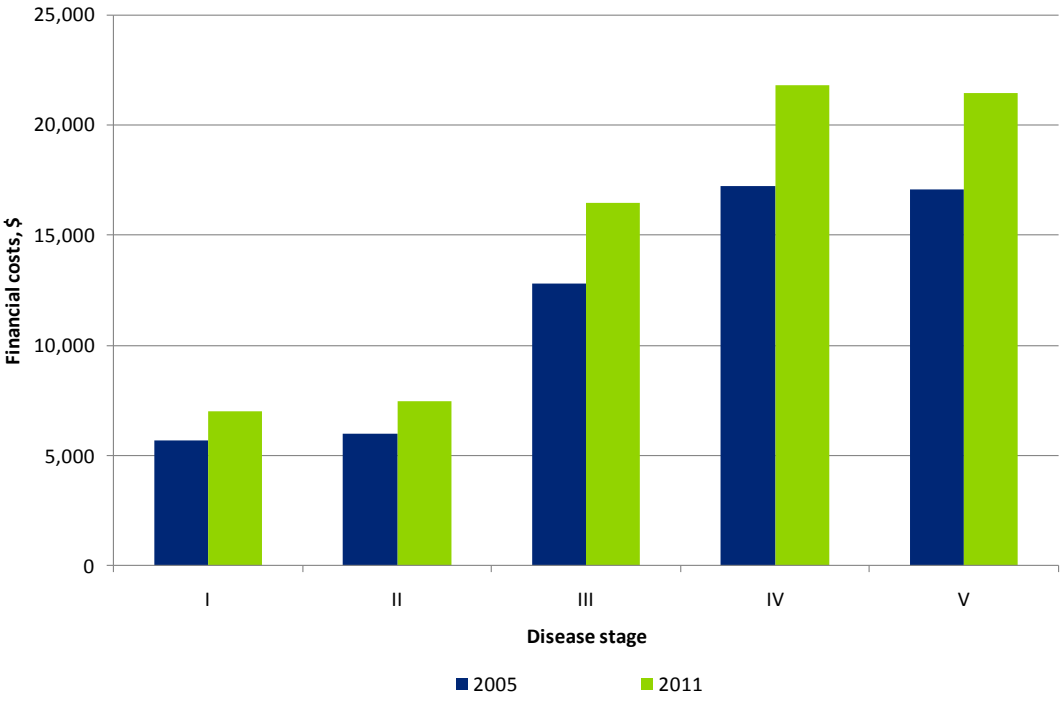
The value of the BoD increases with disease stage and again, is largely unchanged since 2005 (Chart 10.7)

Chart 10.7: Net value of the burden of disease per PWP, by disease stage ($), 2005 and 2011 (nominal)



Financial costs are highest in stage IV of PD (though stage V costs are basically equivalent) (Chart 10.8). Financial costs have increased for all stages since 2005.

Chart 10.8: Financial costs per PWP, by disease stage ($), 2005 and 2011 (nominal)



11 Sensitivity analyses

Although conservative assumptions have been used, almost every parameter is surrounded by some uncertainty. Performing a sensitivity analysis on every parameter would involve expending considerable effort for very little benefit (varying many of the parameters would have a negligible impact on the total cost). Consequently the sensitivity analysis focuses on a range of variables considered to be significant in this study. The choice of parameters reflects *either* their potential impact on an important individual cost category (for example parameters specific to productivity costs), or their pervasive impact on a number of cost categories (for example the discount rate).

11.1 Prevalence and incidence

The 2007 report details the method for calculating an upper and lower bound for prevalence and incidence of PD (pp 95-6). Following these methods yields the following results for 2011 (Table 11.1):

Table 11.1: Analysis using upper and lower bound prevalence estimates, 2011

	Base case	Lower bound*	Upper bound**
Prevalence	64,044	62,486	84,538
		(-2.4%)	(+32%)
Costs ($m):			
BoD	7,564	7,489	9,407
		(-1%)	(+24%)
Financial costs	775.4	711.9	826.1
		(-8%)	(+6.5%)
Total economic costs	8,339.5	8,200.8	10,232.6
		(-1.7%)	(+23%)

*Based on Begg et al (2007) scaled up 8.2% to include secondary PD.

** The upper bound estimate of prevalence is based on the number of people receiving medications explicitly for PD (i.e. the base case) increased by 32% to take into account the average rate of under-diagnosis of PD found by de Rijk (1997).

11.2 Health system costs

As outlined in chapter 5, the health system cost estimates for 2011 are based on 2000-01 AIHW data, adjusted for health cost inflation and growth in the prevalence of PD. Using these costs as a basis for estimation implicitly assumes that the use of the health system has not changed since 2000-01 (e.g. assuming that the average cost of providing inpatient hospital services has not changed assumes there have been no changes to procedures, equipment or upgrades etc that would have increased/decreased the per person cost of hospitalisations). It therefore neglects any additional funding for upgrades and innovations.

This assumption also implies that there have been no changes to the usage rates of pharmaceuticals or (for example) deep brain stimulation.

This assumption is clearly quite significant, and given the relative weight of health system costs in total financial costs of PD, it has the potential to have a material impact on the results. However, whether the average health system cost per PWP has increased or decreased since 2000-01 is not clear and where there is uncertainty, it is best to use the best available data and note the sensitivity of the estimates to this assumption. As such we performed a high/low sensitivity analysis of the health system costs provided in Table 5.1.

Notably, changes in treatments may also affect the burden of disease, since for example, deep brain stimulation has been shown to improve quality of life for PWP. Increases in health system costs may therefore be associated with reductions in the burden of disease costs.

AIHW projections indicate that health care expenditure on PD will increase by around $41 million per year between 2002-03 and 2032-33 (in 2011 dollars) (AIHW, 2008). Of this, it is estimated that increased utilisation of the health system by PWP will contribute $14.8 million per year, and increased prevalence of PD will contribute $0.76 million per year. The remainder of the increase is attributed to ageing, population, and price. Our estimates of health system costs in Chapter 5 have accounted for ageing and population impacts through updated demographic data and price impacts through health cost inflation.

Drawing on the AIHW estimates outlined above, we can estimate a high scenario for health system costs in 2011 due to PD (Table 11.2) and test the sensitivity of the results to these assumptions (Table 11.3).

Table 11.2: Health system expenditure

	2000-01 expenditure	Base case 2011 expenditure	High case 2011 expenditure
0-4	0.1	0.0	0.0
5–14	0.0	0.0	0.0
15–24	0.2	0.0	0.0
25–34	0.3	0.4	0.6
35–44	1.3	2.3	3.7
45–54	4.9	9.1	14.6
55–64	18.6	43.2	69.1
65–74	53.2	105.8	169.4
75-84	81.2	157.1	251.5
85+	32.9	84.0	134.5
Total	**192.7**	**402.0**	**643.4**

Table 11.3: High health expenditure scenario sensitivity analysis

	Base case	High case
Total financial costs	775.4	1,067.8 (+37.7%)
Burden of disease	7,564.2	7,564.2 (no change)
Total economic costs	**8,339.5**	**8,632.0** **(+3.5%)**

Under the high case scenario for health system costs (which assumes that health system expenditure due to growth in prevalence of PD and utilisation of the health system per case of PD grows according to AIHW (2008) projections) total economic costs of PD are estimated to be around $8.5 billion in 2011, 3.1% higher than in the base case scenario. The increase is entirely captured within total financial costs, which are around 38% higher due to higher health system costs, as well as higher formal care costs and consequently, higher DWLs.

11.3 Deadweight Losses

Deadweight losses are the third largest cost component of the total economic cost of PD in 2011, accounting for 16% of financial costs. Section 8.4 describes the calculation of deadweight losses due to PD using a rate of 28.75% (the base case). A DWL rate of 28.75% was selected to follow the methodology of the 2007 report. However, there are sensible arguments that support the selection of a higher and a lower rate. For example, it could be argued that based on a meta-analysis of the literature, 28.75% is too high, for instance, Campbell (1997) finds it to be 24%. On the other hand, although the rate itself is quite high, the transfers that the DWL is applied to in this report are conservative estimates of the actual transfers relating to PWP in Australia. For instance, as outlined in section 8.1, the estimate of Government expenditure on PWP through government programs is highly conservative as it disregards expenditure on community care programs and assumes public expenditure on palliative care has been unchanged since 2005. Thus, it could be argued that a higher DWL should be used to offset the 'low' estimate for transfers.

As such, this section presents the results of high and low sensitivity analyses using a DWL rate of base case +/- 5%pts.

Table 11.4: High and low DWL scenarios sensitivity analysis

	Base case DWL = 28.75%	High case DWL = 33.75%	Low case DWL = 23.75%
Total financial costs	775.4	796.5 (+2.7%)	754.3 (-2.7%)
Burden of disease	7,564.2 (no change)	7,564.2 (no change)	7,564.2 (no change)
Total economic costs	**8,339.5**	**8,360.6 (+0.3%)**	**8,318.4 (-0.3%)**

Source: Deloitte Access Economics' calculations

Increasing (decreasing) the rate of DWL by five percentage points increases (decreases) the estimate of total economic costs of PD in 2011 by 0.3%.

12 Conclusions

This report provides an update to the report 'Living with Parkinson's Disease', which was based on 2005 data (released in June 2007).

The analysis highlights the growing burden of PD and its extent throughout many sectors of society and the economy. Although there have been some advances since the 2007 study, adoption of many of the positive steps advocated in the 2007 report has been limited and many of the issues impeding advancement outlined in the 2007 report (such as the lack of a definitive test for PD diagnosis) still apply.

A major challenge facing advancement in reducing the burden of PD is the lack of government funding for services focussed specifically on PD – in particular – funding for the education of specialist Parkinson's nurses. Acute specialist knowledge regarding medication and symptoms is required to provide effective care for PWP. The Movement Disorders Faculty of the Royal College of Nursing has advised that there are 33 nurses who can be considered as specialists, compared with 264 in the UK. None of the Australian nurses are funded by the Australian Government and there is no policy to provide them on a basis similar to the UK. Recognised benefits and select examples from the UK's investment in specialist Parkinson's nurses are provided below (Parkinson's UK, 2011):

- **A singe Parkinson's nurse can save, on average, £43,812 (A$57,831[24]) in consultant appointments each year:**

  "For an average 12-month period between January 2009 and February 2010, 504 patients were seen in a nurse-led clinic, or at home, rather than by the consultant. At a local tariff of £194, the Parkinson's nurse saved on average £97,776 in avoided consultant appointments for this trust each year." – Western Cheshire Primary Care Trust

- **Community-based Parkinson's nurses can save more than £80,000 (A$105,600) per year in avoided hospital admissions:**

  "Admission figures for patients with Parkinson's from Bury Primary Care Trust to Fairfield Hospital from 2008-2009 compared to 2009-2010, have reduced from 172 to 154. This is an admissions reduction of 10% since the Parkinson's nurse started in post. The trust calculated the fixed annual cost saving of this reduction is £81,522 each year."

- **Parkinson's nurses can save on average £147,021 (A$194,068) per year in bed days:**

  "The Parkinson's nurse appointed in 2009 saved Pennine Acute Trust £190,218 each year by reducing the number of bed days for people with Parkinson's. Between 2008/09 and 2009/10 there were 294 fewer bed days used for Parkinson's patients at a cost of £647 per day."

[24] All exchanges are done using OECD Purchasing Power Parity (PPP) exchange rates: http://stats.oecd.org/Index.aspx?DataSetCode=CPL

Another key issue is the lack of formal recognition of PD as a chronic disease. The Australian Government's National Chronic Disease Strategy covers cancer, diabetes, heart disease, stroke and vascular disease, but not PD, or any other neurological condition (NHPAC, 2006). However, the 2007 Access Economics report notes that over a lifetime, PWP experience more DALYs than people with any of the aforementioned conditions. In fact, the number of DALYs per PWP is second only to congenital malformations and associated illnesses (Access Economics, 2007: page 110). This lack of recognition limits funding and services that are available only to 'chronic' diseases.

As well as a lack of funding for PD, there is also a lack of awareness in the general community, and in many parts of the health services community, of the challenges and needs of those suffering from PD, their families and carers. This often results in sub-optimal care, increasing the burden of the disease. These challenges and needs are exacerbated for people with early onset PD, which is generally considered as those younger than 65 years with PD, of which there were an estimated 11,865 persons in 2011. Young PWP often have additional needs relating to forming relationships and rearing children, as well as asset acquisition and financial planning. Awareness and services dedicated to these people are currently very limited, further magnifying the burden of the disease.

Although there are a number of effective treatments available for PWP in Australia, a lack of synthesis in the approach to tackling PD has resulted in many of these treatments being too expensive since even if the drug itself is listed on the PBS, oftentimes the consumables required to administer the drugs are not. This example highlights the need for a collaborative approach to addressing the issues and challenges faced by PWP, especially since the number of PWP is expected to almost double over the next two decades alongside the finding of this report that the burden of PD per PWP is increasing.

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