

Economic analysis of motor neurone disease in Australia

Motor Neurone Disease
Australia

November 2015

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Glossary

ABS	Australian Bureau of Statistics
AIHW	Australian Institute of Health and Welfare
ALS	amyotrophic lateral sclerosis
ALSFRS-R	ALS functional rating score
AR-DRG	Australian refined diagnosis related groups
CPI	Consumer Price Index
DALY	disability-adjusted life year
DES	Disability Employment Services
DSP	Disability Support Pension
DWL	deadweight loss
EAOS	Employment Assistance and Other Services
GP	general practitioner
GRIM	General Record of Incidence of Mortality
HACC	Home and Community Care Program
IHPA	Independent Hospital Pricing Authority
LMN	lower motor neurone
MND	motor neurone disease
MNDRIA	Motor Neurone Disease Research Institute of Australia
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NHMRC	National Health and Medical Research Council
NPV	net present value
NRCP	National Respite for Carers Program
PBP	progressive bulbar palsy
PBS	Pharmaceutical Benefits Scheme
PLS	primary lateral sclerosis
PMA	progressive muscular atrophy
RACF	residential aged care facility
SDAC	Survey of Disability, Ageing and Carers
SOD1	superoxide dismutase-1

UMN	upper motor neurone
UK	United Kingdom
US	United States
VSL	value of a statistical life
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

Motor neurone disease (MND) is a rare, degenerative nervous system condition that affects approximately 1 in 11,434 Australians. Awareness of MND has advanced considerably over the past decade. It is clear that MND imposes substantial costs to the Australian community, in terms of both economic burden and quality of life impacts.

In this report, Deloitte Access Economics estimates the total cost of MND to Australia, including health, productivity and other financial costs (“economic costs”) and the burden of disease costs (the loss of healthy life). To provide context to this analysis, an overview of the epidemiology of MND is included.

MND is the name given to a group of progressive degenerative neurological diseases affecting the motor neurones or nerve cells under voluntary control, which results in an inability to voluntarily control movements. Currently, there are no treatments available that stop or reverse the progression of MND. Expert and timely symptom management and psycho-social support are the primary aspects of treatment for people diagnosed with MND. The effects of MND – initial symptoms, rate and pattern of progression, and survival time after diagnosis – vary significantly from person to person. Prognosis is poor, with average survival times of around 2.5 years from disease onset.

Prevalence and mortality

It is estimated that there are 2,094 Australians living with MND in 2015, of whom 60% are male and 40% are female. The highest prevalence rate is reported in males aged between 75 and 84 years. The prevalence rate is estimated to be 8.7 per 100,000 Australians, or 1 in 11,434 Australians.

In comparison to other countries, Australia has a relatively high level of prevalence, with recent studies conducted in Europe finding prevalence rates of 7.9 per 100,000 population. Sensitivity analysis indicates that prevalence rates in Australia may be between 7.9 and 9.6 per 100,000 Australians.

Mortality rates due to MND are relatively high in all age groups. Males aged between 75 and 84 years are most likely to die as a result of MND. The mortality rate is estimated to be 3.14 per 100,000 across the entire population, which is equivalent to 752 deaths due to MND in 2015. Approximately 55% of deaths occur in males. Deaths associated with MND are typically due to respiratory failure as a result of weakened muscles.

Costs of MND

The costs of MND comprise both economic costs, as well as burden of disease costs.

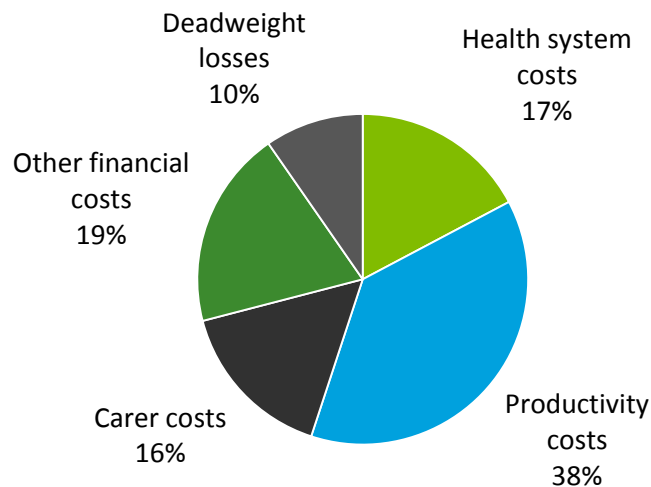
The total per person economic cost of MND is estimated to be \$205,812 in 2015. This is estimated to cost the Australian economy \$430.9 million in 2015. Productivity costs comprise 38% of these costs.

The components of economic costs are:

- health system costs of \$74.4 million, or \$35,510 per person with MND. Health system costs are mainly comprised of admitted and out-of-hospital medical costs, and other professionals such as allied health professionals;
- productivity losses of \$162.8 million, or \$77,776 per person with MND. Productivity costs are mainly comprised of losses due to premature death, due to the high mortality rates in people with MND;
- informal care costs of \$68.5 million, or \$32,728 per person with MND. Informal carers are estimated to provide 7.5 hours a day providing care to people with MND;
- other financial costs of \$83.6 million, or \$39,921 per person with MND. Other financial costs are mainly comprised of aids and equipment, and the cost of home and vehicle modifications; and
- deadweight losses of \$41.6 million, or \$19,876 per person with MND. These losses accrue as a result of government transfers and lower taxation revenue receipts due to MND.

Chart i shows the share of each cost to the total economic costs (excluding burden of disease costs).

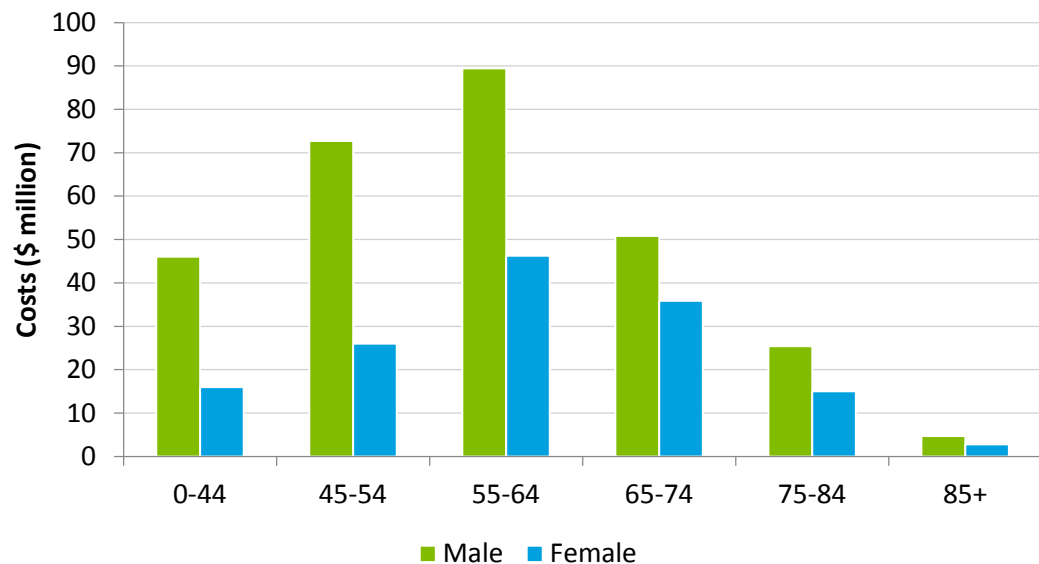
Chart i: Economic costs associated with MND in Australia, 2015



Source: Deloitte Access Economics calculations.

Males of working age bear the highest costs associated with MND, due to the high productivity losses associated with these age groups (Chart ii).

Chart ii: Total economic costs by age and gender, 2015



Source: Deloitte Access Economics calculations.

In addition to economic costs, the burden of disease, which measures the suffering and premature death of people with MND, is estimated to cost an additional 10,356 disability adjusted life years (DALYs). In 2015, the net value of the burden of disease is estimated to be \$1.94 billion, or \$0.9 million per person with MND. DALYs comprise 8,953 years of life lost due to premature death and 1,403 years of healthy life lost due to disability, reflecting the fact that mortality due to MND is high.

The total cost of MND is estimated to be \$1.13 million per person with MND in 2015. The total cost of MND in Australia is estimated to be \$2.37 billion.

The per person costs of MND are substantially higher than a number of other diseases, including stroke (\$133,108), chronic obstructive pulmonary disease (\$95,599), eating disorders (\$80,289), vision loss (\$32,646), and chronic kidney disease (\$758).¹

Sensitivity analysis was conducted on these estimates, by increasing and decreasing the prevalence by 10%, based on findings in the academic literature (see section 3.2). This had a minor impact on total costs, which increased by \$47.1 million when prevalence increased by 10%, and vice versa.

Costs of MND in different settings

Deloitte Access Economics was requested to compile the following estimates of the costs of care and management of MND under alternative scenarios:

¹ All cost estimates have been taken from other Deloitte Access Economic reports and as such, can be accurately compared as a consistent methodology and approach was applied in each study. Costs have been expressed in 2015 dollars.

- The annual cost of staying at home was found to be more expensive (\$112,088) compared with the annual cost of staying in a residential aged care facility (\$78,631) – noting that these residential aged care costs are likely conservative.
- The cost of using an MND equipment loan service (\$19,625) is less expensive than the cost of equipment purchase under the NDIS (\$24,030).
- The annual cost of MND advisor support for a person with MND (\$2,865) is not fully recovered under the NDIS funding model for these services (\$2,257).
- Annual government costs of MND in the aged care system (\$8.3 million) are higher than government costs of MND in the NDIS (\$2.6 million) – noting that the NDIS is still in its infancy and so these costs will increase as more people with MND join the NDIS.

Deloitte Access Economics

1 Introduction

Deloitte Access Economics was commissioned by Motor Neurone Disease Australia to undertake an analysis of the economic costs of motor neurone disease (MND) to individuals, Commonwealth and State and Territory Governments, and the broader Australian community.

This report has been structured in the following manner:

- **Chapter 2** provides an overview of MND, including the causes, symptoms, diagnosis, prognosis, current treatment options and recent medical advances;
- **Chapter 3** presents prevalence and mortality estimates for MND in Australia in 2015;
- **Chapter 4** discusses the approach taken to estimate the economic costs of MND;
- **Chapter 5** estimates the costs of MND to the health system by type of cost, and by payer;
- **Chapter 6** discusses the productivity costs of MND, including a literature review of relevant studies and a summary of productivity loss estimates;
- **Chapter 7** outlines other financial costs that arise from MND;
- **Chapter 8** summarises transfer costs associated with MND and calculates the resultant deadweight loss;
- **Chapter 9** estimates the burden of disease due to MND;
- **Chapter 10** summarises the total costs of MND; and
- **Chapter 11** presents a comparison of costs associated with managing and caring for people with MND in various settings including the National Disability Insurance Scheme (NDIS) and residential aged care.

2 Background

The following chapter provides a brief overview of MND, including its risk factors, causes, symptoms, prognosis and current treatment options. The information in this chapter is mostly derived from the MND Australia publication *Motor Neurone Disease Aspects of Care: for the primary health care team* (MND Australia, 2014), and other publications from MND Australia.

2.1 What is MND?

MND is the name given to a group of progressive degenerative neurological diseases affecting the motor neurones or nerve cells under voluntary control. The most common form of MND is amyotrophic lateral sclerosis (ALS) and this is the term used in the United States (US) and other parts of the world to describe MND. Throughout this report, this group of diseases are referred to as MND.

According to the National Institute of Neurological Disorders and Stroke (2015):

“The motor neurone diseases (MNDs) are a group of progressive neurological disorders that destroy cells that control essential muscle activity such as speaking, walking, breathing, and swallowing. Normally, messages from nerve cells in the brain (called upper motor neurons) are transmitted to nerve cells in the brain stem and spinal cord (called lower motor neurons) and from them to particular muscles. When there are disruptions in these signals, the result can be gradual muscle weakening, wasting away, and uncontrollable twitching (called fasciculations). Eventually, the ability to control voluntary movement can be lost. MNDs may be inherited or acquired, and they occur in all age groups.”

MND is complex and each person diagnosed will vary in presentation, rate and pattern of progression. Sensory signs and symptoms are rare and the motor nuclei controlling eye movements and the voluntary pelvic sphincter muscles usually remain intact. Typically patients present with symptoms in one muscle group, for example, weakness and wasting of one hand or a unilateral foot drop. Lower motor neurone (LMN) or upper motor neurone (UMN) signs may be present elsewhere on examination and it is typical to find evidence of LMN and UMN features in the same limb, for example, leg muscle wasting and fasciculation in combination with reduced muscle tone, exaggerated reflexes and an extensor plantar response. Some people may present with acute respiratory symptoms. As the disease progresses, other muscle groups become involved and cognition may be affected.

MND occurs sporadically in about 90 to 95% of cases, meaning it develops without any clearly identifiable cause. Familial or inherited MND accounts for about 5-10% of all MND cases. Clinically the sporadic and familial forms of MND are indistinguishable.

2.1.1 Types of MND

MND can be categorised on the basis of sites of involvement at presentation and the balance between LMN and UMN features. The different MND clinical groups are commonly confused. As the disease progresses there may be considerable overlap resulting in more generalised muscle wasting and weakness. The four main phenotypes of MND are:

- **ALS** – this is the most common type of MND and is characterised by muscle weakness and wasting and stiffness, overactive reflexes and, in some cases, rapidly changing emotions. Initially the limbs cease to work properly. As this type progress, the muscles of speech, swallowing and breathing are usually affected. ALS affects both UMNs and LMNs.
- **Progressive bulbar palsy (PBP)** - this type of MND begins in the muscles of speech and swallowing, and is characterised by speech and swallowing muscle weakness and wasting. PBP is similar to mixed bulbar palsy and pseudo-bulbar palsy, which are characterised in the same way. The nerves that control speech and swallowing functions are located in the bulb (the lower part of the brain), hence the term bulbar palsy (paralysis). The limb muscles may also be affected later. PBP affects both UMNs and LMNs.
- **Progressive muscular atrophy (PMA)** - PMA is characterised initially by LMN signs resulting in more generalised muscle wasting and weakness, absent reflexes, loss of weight and muscle twitching. PMA can be the hardest form of MND to diagnose accurately. Recent studies indicate that many people diagnosed with PMA subsequently develop UMN signs. This would lead to a reclassification to ALS. PMA may begin in the arms (flail arm type) or the legs (flail leg type). PMA typically has slower rates of progression and substantially longer survival from onset compared to ALS and PBP.
- **Primary lateral sclerosis (PLS)** – PLS is similar to the above types and features muscle weakness and wasting. PLS only affects the UMNs, and can typically be diagnosed if there are no LMN signs after approximately four years. PLS is very rare and diagnosis is often provisional.

Kennedy's disease

Kennedy's disease, also known as spino bulbar muscular atrophy, is a disorder of motor neurones which is not MND. It is an inherited disorder affecting adult males causing slowly progressive weakness and wasting of muscles. Kennedy's disease only affects LMN.

2.2 Symptoms of MND

Early symptoms of MND are mild and may include stumbling due to weakness of the leg muscles, difficulty holding objects due to weakness of the hand muscles, and slurring of speech or swallowing difficulties due to weakness of the tongue and throat muscles. Emotional responses may be more easily triggered and the person with MND may be aware of laughing and crying more readily than previously. Cognitive change or a frontotemporal dementia may be present. Cramps and muscle twitching are also common symptoms. The effects of MND – initial symptoms, rate and pattern of progression, and survival time after diagnosis – vary significantly from person to person.

2.3 Risk factors and causes of MND

There are no known causes of MND for the majority of cases. In some familial cases, a faulty inherited gene is implicated. Possible causes include genetic factors, physical trauma, protein aggregation or misfolding, glutamate toxicity, mitochondrial dysfunction, exposure to environmental toxins and chemicals, oxidative stress (free radical damage), immune mediated damage, and dysfunctional signalling pathways. Each of these potential causes are discussed further below. It is thought that the cause of MND is multifactorial.

2.3.1 Genetic factors

In 1993, it was discovered that 20% of familial MND cases were linked to mutations in the superoxide dismutase-1 (SOD1) gene. Two decades later a substantial proportion of the remainder of cases of familial MND have now been traced to mutations in the C9orf72 gene (Turner et al, 2013). Although there are still some MND families in which the faulty gene has not yet been identified, SOD1, C9orf72 and other MND-related gene mutations discovered in recent years now account for about 60% of all people with familial MND.

It has long been standard practice to reassure patients without a family history of MND that they most likely have the sporadic form of the disease and therefore their children will not be affected. However, the identification of C9orf72 repeat expansions in patients without a family history of MND challenges the traditional division between familial and sporadic disease (Turner et al, 2013).

It is widely accepted that sporadic MND likely arises from the interplay of genetic mutations and developmental, environmental and age-related factors and events. The interplay between these factors is less well understood (Turner et al, 2013).

2.3.2 Physical trauma

Several occupations have been associated with an increased incidence of MND, including professional footballers in Italy, the military and manual workers. Other studies have found that a lower than average body mass index may be associated with MND and this has been linked to an observation of hyper metabolism. To date, there is no firm evidence that exercise exerts a harmful effect (Turner et al, 2013).

2.3.3 Protein aggregation/misfolding

Accumulation and aggregation/misfolding of the intracellular and membrane protein, with consequent formation of toxic oligomers, appear to be involved in MND and certain other neurodegenerative diseases. The misfolded proteins also seem to interfere with anti-apoptotic mechanisms leading to programmed motor neurone death. The protein misfolding occurs as a consequence of protein post-translational modification triggered by interaction with free radicals. The free radical formation occurs due to excessive activation of N-methyl-d-aspartate-type glutamate receptors (see section 2.3.4) (BMJ Publishing Group, 2015).

2.3.4 Glutamate toxicity

Glutamate is one of many neurotransmitter chemicals in the nervous system that carries signals between nerve cells. There is evidence that in people with MND, glutamate accumulates in the spaces around a nerve cell after it has completed its signalling function, causing problems for the nerve cells in its vicinity. The problem could be caused by inadequate transport of glutamate away from the cells. The only approved therapy for MND, riluzole, works by reducing glutamate levels.

2.3.5 Mitochondrial dysfunction

The mitochondria are microscopic energy "factories" inside cells. They resemble miniature cells themselves and have their own DNA. Abnormalities of the mitochondria are well documented in people with sporadic and familial MND and may be involved in the cause of MND or its progression.

2.3.6 Exposure to environmental toxins and chemicals

For many years, experts have tried to find factors common to people who develop MND, such as environmental toxins, occupational hazards, places of work or residence, exposure to chemicals and other factors. So far, the evidence for these risk factors and triggers has been unclear. A recent finding of an association between developing MND and having served in the military, particularly the Gulf War, is one of the strongest of these proposed risk factors. Cyanobacteria are microorganisms that are found in bodies of water and in desert sands. Some experts believe that they could be among the reasons for the elevated risk of MND in those who served in the Gulf War.

Some heavy metals that are toxic to the nervous system such as lead, mercury and arsenic, have not been shown to be causative agents in MND.

2.3.7 Oxidative stress (free radical damage)

Superoxide radicals, oxygen, and hydrogen peroxide might induce neuronal damage and ultimately death through various mechanisms: by inducing aggregation of mutant SOD1 and other intracellular proteins with direct toxic effect leading to cell malfunction, through activation of apoptotic pathway, or by damaging neuronal mitochondria (BMJ Publishing Group, 2015).

2.3.8 Immune mediated damage

There is evidence that the immune system, particularly the immunologic cells in the nervous system known as microglia, can be both beneficial and harmful in MND. Modifying the actions of the immune system is an active area of MND research.

2.3.9 Dysfunctional signalling pathways

Deficient axonal transport appears to relate to initiation and progression of MND (BMJ Publishing Group, 2015). Axonal transport is a process responsible for the movement of mitochondria, lipids, synaptic vesicles, proteins and other cell parts to and from a neurone's

cell body. Motor neurones typically have long axons, and fine-tuning axonal transport is crucial for their survival (Ikenaka et al, 2012). The obstruction of axonal transport may be a cause of neuronal dysfunction in MND. Depletion of dynein and dynactin-1, which are motor molecules that regulate axonal transport, can cause motor neurone degeneration. It has been suggested that axonal transport be an important target of therapy development for MND (Ikenaka et al, 2012).

2.4 Diagnosis

The diagnosis of MND is often clinically difficult and sometimes it is necessary to review a person for some time before the diagnosis becomes reasonably certain. A general practitioner (GP) may suspect a neurological problem and organise referral to a neurologist. There is no specific investigation available to diagnose MND and diagnosis is therefore based on symptoms, clinical examination and the results of electro-diagnostic, neuroimaging and laboratory studies. This means that great care needs to be taken to ensure a timely and accurate diagnosis (Andersen et al, 2012). Andersen et al (2012) recommend that people who present with symptoms suggestive of MND should be assessed as soon as possible by a neurologist with experience of MND.

Evidence indicates that the mean time from the onset of symptoms to confirmation of the diagnosis of MND is 10–18 months. In Australia, delays may arise if initial symptoms are not recognised by the GP or because of delayed referral to a neurologist with an understanding of MND. Giving a diagnosis of MND requires skill and empathy and if not performed appropriately, the effect can be devastating, leaving the person with MND and their family with a sense of abandonment, and psychologically and emotionally distressed (Andersen et al, 2012). Diagnosis should be made as early as possible by a neurologist expert in MND to ensure early intervention and support, access to disease modifying therapies and optimal care and symptom management.

2.5 Prognosis

There are a number of confounding factors that affect the progression and prognosis of MND. Consequently, predicting progression and prognosis in individuals at diagnosis is problematic due to the heterogeneous nature of MND. For example, a frontotemporal syndrome occurs in 20-50% of people with MND and is associated with a poorer prognosis. Andersen et al (2012) state:

“Cognitive dysfunction occurs in 20–50% of cases, and 5–15% develop dementia usually of frontotemporal type. Death because of respiratory failure follows on average 2–4 years after symptom onset, but 5–10% of patients may survive for a decade or more. The mean age of onset is 43–52 years in familial and 58–63 years in sporadic cases of ALS. The life-time risk of developing ALS is 1 in 350–500, with male sex, increasing age and hereditary disposition being the main risk factors.”

Identifying the phenotype, where possible, will provide a prognostic pattern and help to guide prognosis. According to Turner et al (2013):

“These patterns include rapid decline in patients with respiratory-onset disease, reduced survival in those with executive impairment and slower progression in those with upper motor neuron-predominant disease (consistent with the extreme example of primary lateral sclerosis). Consistent regional (generally contiguous) patterns of symptom spread are also recognisable, and simple clinical parameters at diagnosis can allow robust stratification of prognosis for clinic-based patients. In view of these developments, a formal staging system for ALS has been proposed that attempts to incorporate clinical phenotypes better.”

Some diagnostic tools are used to help with prognosis and progression of MND. One such scale is the ALS functional rating score (ALSFRS-R). This scale is pending validation of the numerous and varied candidate biomarkers. However, it is frequently used in clinics to measure progression and severity and as an outcome measure in therapeutic trials. Further adjustments to this scale are being considered that would include assessment of executive function. Further data are needed to validate available cognitive tools for ALS. Motor unit number estimation, axonal excitability, electrical impedance myography, the neurophysiological index, and cortical excitability all have potential as alternative outcome measures (Turner et al, 2013).

2.6 Current treatment and symptom management

Currently, there are no treatments available that stop or reverse the progression of MND. Consequently, expert and timely symptom management and psycho-social support are the primary aspects of treatment for people diagnosed with MND.

The rapid progression of MND results in increasing and changing support needs and reliance on a range of aids and equipment to maintain quality of life and social inclusion. Support needs include assistance with: feeding, communicating, breathing, movement, transferring, toileting and other daily activities.

MND imposes a large social and emotional impact due to its complex nature and the speed of its progression. This can lead to adjustment issues for people who have MND and their families, and it may impose substantial burden on carers and families. Further, MND can be challenging for health professionals, disability services, community care, and aged care providers. This is particularly important in regional, rural and remote areas of Australia.

MND care is addressed through an evidence based approach that involves a coordinated multi and interdisciplinary team approach with timely referrals to services that will address identified needs (Ng et al, 2009). For example, Miller et al (2013) state:

“The diagnosis of ALS has profound implications for the patient and his or her family. In recent analysis, too few patients received evidence-based treatment that can ease the disease burden. Although incurable at this time, advances in contemporary care options to the patient with ALS have been shown to prolong life and also to improve quality of that life.”

2.6.1 Evidence based interventions

The American Academy of Neurology's ALS quality measures encourage multidisciplinary care plans, regular review, treatments for respiratory and nutritional dysfunction, use of the single disease-modifying agent available (riluzole), and plans for a smooth transition to palliative care. The aim of these practical and meaningful quality measures for the care of patients with MND is to raise the standard of care with the aim of increasing life expectancy and enhancing quality of life (Miller et al, 2013).

2.6.1.1 Riluzole

Until the mid-1990s, all controlled trials related to disease specific therapies for MND were negative. At that time evidence emerged that glutamate excitotoxicity may contribute to neuronal death in MND and this provided a rational basis for undertaking a clinical trial with riluzole, a glutamate inhibitor. In 1994 the first randomized controlled trial of riluzole demonstrated a modest increase in survival. Other trials followed and confirmed that riluzole slowed the disease process by an average of three months. In 2004, riluzole was approved in Australia and made available through the Pharmaceutical Benefits Scheme (PBS). Riluzole remains the only therapeutic currently available for MND worldwide. In 2012 an updated Cochrane Review of riluzole confirmed that (Miller et al, 2012):

" ... riluzole 100 mg probably prolongs median survival in people with ALS by two to three months and the safety of the drug is not a major concern. The evidence from randomized controlled trials indicates that participants taking riluzole probably survive longer than participants taking placebo. The beneficial effects are very modest and the drug is expensive. There was a small beneficial effect on both bulbar and limb function, but not on muscle strength. Adverse effects from riluzole are relatively minor and for the most part reversible after stopping the drug."

A large number of other drugs have been tested in MND but none have been proven to be effective.

2.6.1.2 Multidisciplinary care

Attending specialist multidisciplinary clinics can contribute to longer survival, better quality of life, and greater access to therapies for people living with MND. Patients attending multidisciplinary clinics can also have fewer hospital admissions and shorter inpatient stays than those who attend general clinics. The increased use of riluzole and non-invasive ventilation, attention to nutrition and earlier referral to palliative care services are likely to contribute to the increased survival of those attending multidisciplinary clinics (Andersen et al, 2012).

Respiratory support and non-invasive ventilation

Respiratory weakness can develop at any stage of disease progression and may cause shortness of breath, fatigue, impaired quality of life and somnolence. Dyspnoea is caused by weakened respiratory muscles – intercostal, diaphragm and abdominal muscles. The diagnosis and management of respiratory insufficiency is critical because the majority of

deaths from MND are due to respiratory failure (Miller et al, 2009; National Institute for Health and Clinical Excellence, 2010).

Respiratory muscle function significantly predicts survival and quality of life in people living with MND. More than half of patients with MND have respiratory symptoms and need some form of respiratory management. A multidisciplinary team should coordinate and provide ongoing management and treatment for a patient with MND, including regular respiratory assessment (National Institute for Health and Clinical Excellence, 2010). Evidence confirms that non-invasive positive-pressure ventilation increases survival and improves quality of life and is therefore the preferred therapy for the management of symptoms of respiratory insufficiency (Andersen et al, 2012).

The National Institute for Health and Clinical Excellence (2010) guidelines conclude that:

“ ... there is evidence to suggest that non-invasive ventilation improves the quality of life of patients with MND. However, there is a lack of evidence relating to the costs associated with non-invasive ventilation. Despite this lack of robust evidence with regard to cost analyses, the use of non-invasive ventilation by patients with MND is perceived to be cost effective compared with standard care.”

In Australia access to and cost of non-invasive ventilation varies between jurisdictions.

Alternative feeding mechanisms

Dysphagia refers to difficulty in swallowing caused by weakness and paralysis of the lips, facial muscles, tongue, larynx and pharynx resulting from affected trigeminal, facial, glossopharyngeal, vagus, accessory and hypoglossal nerves. Eventually about two thirds of people with MND experience dysphagia. The goal of managing swallowing difficulties is to maintain optimal levels of nutrition and hydration, manage sialorrhea (drooling) and reduce choking episodes.

Best evidence to date supports the use of alternative feeding via a percutaneous endoscopic gastrostomy or radiologically inserted gastrostomy to improve nutrition and potentially prolong life. Respiratory muscle weakness and malnutrition can affect recovery from the procedure, so timely access to this intervention is important for the person living with MND to obtain maximum benefit (Andersen et al, 2012).

2.6.2 Symptom management

As noted in section 2.2, there are a range of symptoms that present in people with MND, aside from the respiratory and swallowing symptoms outlined in section 2.6.1.2. These symptoms are managed in different ways.

2.6.2.1 Communication

Dysarthria is impairment of speech production caused by weakness and paralysis of the lips, facial muscles, tongue, larynx, and pharynx resulting from affected trigeminal, facial, glossopharyngeal, vagus, accessory and hypoglossal cranial nerves. Weakness of the muscles of respiration will also impact on speech volume. Impairment of speech

production may begin with slurring, hoarseness or weak voice and may progress to total loss of speech (anarthria).

Difficulties with communication can lead to decreased social interaction and feelings of isolation, loss of control, lowered self-esteem and increased vulnerability. Speech and language impairment can have a profound impact on the quality of life of people with MND and their carers and can make clinical management difficult. Augmentative and alternative communication systems can substantially improve the quality of life for both people with MND and their carers (Andersen et al, 2012).

2.6.2.2 Cognitive change

Symptoms of cognitive dysfunction may appear before or after the onset of motor symptoms. Frontotemporal dementia is prominent in 5-15% of MND cases (Andersen et al, 2012). Recent neuropsychological studies suggest that approximately two thirds of people with MND may suffer from mild changes in cognitive skills, processes and/or behavioural change. Cognitive change has an impact on decision making, carer management and carer burden. Screening and neuropsychological assessment to diagnose cognitive change should be available to support and inform carers and the healthcare professionals involved in a person's care (Andersen et al, 2012).

2.6.2.3 Depression

Depression can be present in some cases of MND. Miller et al (2009) suggest the prevalence of depression in MND ranges from 0% to 44%, with some studies suggesting a prevalence of 10% in the later stages of MND. Anti-depressants may be prescribed to help manage depressive symptoms.

2.6.2.4 Emotional lability

UMN involvement is associated with pseudobulbar affect or emotional lability. Emotional lability occurs in at least 50% of people with MND irrespective of the presence or absence of bulbar motor signs. Prominent pseudobulbar features such as pathological weeping, laughing or yawning can be socially disabling and negatively impact quality of life. A range of medications have been trialled to address this symptom. The most commonly used agents are tricyclic antidepressants and selective serotonin reuptake inhibitors (Andersen et al, 2012).

2.6.2.5 Fatigue

Fatigue is a frequent and potentially debilitating symptom. It may be of central and/or peripheral origin (Andersen et al, 2012). As MND attacks motor neurones, they become unable to send commands from the brain to the muscle cells that they control and movements must then be performed by a depleted number of nerve and muscle cells. This means that muscles tire quickly. In addition other metabolic changes take place and the person with MND can feel very tired. Weight loss and reduced food intake due to swallowing difficulties are likely to affect the person's energy levels. When MND affects breathing muscles, less air is drawn into the lungs when activity increases and it becomes more difficult for the lungs to supply enough oxygen to the body causing general fatigue.

Some medications such as modafinil have been shown to reduce fatigue, and managing other symptoms may also assist with reducing fatigue (Andersen et al, 2012).

2.6.2.6 Movement and joints

The degeneration of UMNs and LMNs leads to progressive weakness of bulbar, limb, thoracic and abdominal muscles causing muscle weakness, stiffness and immobility. As muscle weakness progresses, most people with MND will experience some pain, spasticity and/or cramps. Regular review, medications, assistive technology and the introduction of therapies such as physiotherapy, massage, gentle physical exercise and hydrotherapy in heated pools will help to address these symptoms (Andersen et al, 2012).

People living with MND have complex and progressing needs related to assistive technology. The timely provision of a full range of quality assistive technologies to meet identified needs related to activities of daily living and communication is important to support independence and quality of life for the person with MND and their carer.

2.6.2.7 Sialorrhea

Sialorrhea (or drooling) is estimated to occur in up to 50% of people with MND. Sialorrhea is also associated with the development of aspiration pneumonia. A range of oral and subcutaneous medications may be prescribed to help manage sialorrhea. For some cases of MND, injections of botulinum toxin type A into the parotid gland have been shown to be effective in managing this symptom (Miller et al, 2009).

2.6.3 Other interventions

At present, treatments for MND only offer the potential to slow the disease process. This requires both a palliative care approach and support from carers, families and a number of organisations for the person with MND to have the best possible quality of life.

2.6.3.1 Palliative care

A palliative care approach is required from diagnosis to ensure that early discussions around future care management and advance care planning are held, and optimal symptom management for the person with MND and their family is achieved (Oliver et al, 2006). Discussions around end-of-life care need to be instigated as soon as the person with MND is ready, preferably before speech is affected, to ensure optimal interaction and communication to address their more profound concerns.

It is important that people living with MND are able to access quality end of life care based on the needs and wishes of that individual and their family. There is considerable evidence that palliative care intervention improves quality of life for people living with MND and their carers (Bede et al, 2011).

The United Kingdom (UK) publication *Improving end of life care in neurological disease a framework for implementation (National End of Life Care Programme, 2010)* highlights that, from diagnosis, any changes in neurological disease progression should be recognised by all health and community professionals as triggers for the introduction and subsequent involvement of palliative care. The framework states that care should be based on holistic

assessment that includes multidisciplinary and service provider collaboration, good communication, regular review and the needs of carers. It recommends multidisciplinary team involvement from diagnosis and that co-ordination of care is therefore essential. Like the MND Pathways Project undertaken by MND Victoria and the Victorian Government Department of Human Services (2008), a single point of initial contact is also recommended using a key worker model.

Access varies significantly between and within jurisdictions, which precludes equal access to optimal end of life care for many people diagnosed with MND in Australia. Furthermore in some regional, rural and remote areas of Australia specialist palliative care services may be limited or non-existent.

A recent exploratory qualitative study in Western Australia to investigate MND carers' experiences of caring, palliative care and bereavement identified that on the whole, the participants' experiences with palliative care services were reported in positive and appreciative terms (Aoun et al, 2011). However, the timeliness of and access to, palliative care was a common issue. Only one participant indicated that palliative care services were offered and accessed right from the point of diagnosis, with the other participants reporting that services were accessed from 2.5 to 15 months before the person with MND died. On average, the participants' spouses received palliative care services less than two months before their deaths. Some participants in this study were unclear about what help was actually available, and experienced worse outcomes accessing palliative care later in the disease progression.

2.6.3.2 Support for carers of people with MND

Increasing loss of function and associated increase in a persons need for help with all activities of daily living have a profound impact on the primary carer. Carer burden relates to personal and social restrictions and to psychological and emotional distress. Certain symptoms cause particular strain in carers. If the patient loses effective communication, carers can become intellectually and emotionally isolated. The use of augmentative alternative communication devices can help to restore communication (Andersen et al, 2012). Access to a range of services and ongoing support to meet identified needs is vital to support and sustain the carer in their caring role and to reduce carer burden and distress.

2.6.3.3 MND Support Service

The MND Association Support Service is focused on a simple strategy to address the key needs of people living with MND. Through addressing these needs, MND Associations support the health, disability, aged, allied, palliative and other service sectors in their role. The focus is to ensure that no person with MND has a high level of unmet needs.

MND Associations have developed their MND Support Service to be the interface between the person with MND (and their families and carers) and the service sector. People with MND have expressed their wish to continue living within their community, and seek facility-based care rarely and when absolutely necessary. MND Associations have a commitment to support people living with MND wherever they choose to live. The focus is to ensure that the generic service systems of health, disability, palliative and aged care are able to

provide a timely response to meet the complex and changing needs of people living with MND.

To meet these goals and appropriately support people with MND, MND Associations provide a range of services. This includes the provision of information and peer support, and providing education about MND and advocacy to both care providers and those living with MND and their families and carers. MND Associations also heavily subsidise necessary equipment such as mobility aids and communication devices, and they enable volunteer programs across the country to assist people living with MND.

As highlighted throughout this chapter, the needs of people with MND are complex and vary from person to person, and care provision that is able to cross traditional barriers between care provided by the health sector is important.

2.7 Recent medical advances

Over the last five years the pace of MND research has accelerated and transformed understanding of the disease. MND associations in Australia have invested \$13.5 million in Australian researchers over the last 10 years. Many of these researchers are at the forefront of MND research globally.

Global investment in a collaborative approach to sequencing whole genomes from large cohorts of people living with MND, and controls will likely lead to a better understanding of the genetic mutations associated with sporadic MND. This may result in the identification of key pathways amenable to therapeutic intervention.

Although animal modelling for MND remains challenging, and rodent models have limitations, new models may hold promise for rapid assessment of therapeutic potential. The development of induced pluripotent stem cell technology offers an additional and potentially cost effective 'disease in a dish' approach for early modelling of pathology and testing therapeutic candidates. This approach marks a significant divergence from the traditional view of stem cells as a potential therapy for MND (Ravits et al, 2013).

Ravits et al (2013) indicate that rationally designed therapy that stops the advance of MND neurodegeneration would be the optimal outcome for MND research. Further, talking about MND, Ravits et al (2013) state:

" ... different gene mutations cause identical clinical phenotypes means that multiple mechanisms exist and ALS is a syndrome. However, that one single gene mutation causes many different ALS phenotypes means that there must be common mechanisms. With the transformative understanding of clinical, neuropathological, and molecular-genetic aspects of ALS over the last five years, this quest for rational fundamental therapy has become a realistic hope."

3 Epidemiology

This chapter outlines the prevalence and mortality estimates for MND in Australia. As MND is a rare condition, a variety of sources are used to estimate and triangulate the prevalence and mortality due to MND.

Key findings:

- The estimated prevalence of MND in Australia is 2,094 people in 2015, or 8.7 in 100,000 people. Prevalence is higher among males than females.
- The highest prevalence rate is reported in males aged between 75 and 84 years, although the disease is not considered to be related to ageing, with approximately 58% of people with MND under the age of 65.
- MND is estimated to be the cause of 752 deaths in Australia in 2015.

3.1 Prevalence of MND

There is no definitive source of prevalence for MND in Australia. The latest publication which provided age and gender breakdowns was published by the Australian Institute of Health and Welfare (AIHW) in their flagship *Burden of disease and injury in Australia* study in 2003 (Begg et al, 2007). The AIHW is currently working to update their study, and may provide updated estimates of the prevalence of MND when the new publication is released.

Historically, international estimates of the prevalence of MND have varied greatly, and have been reported to be anywhere between 1 per 100,000 to 11 per 100,000 (Chiò et al, 2013). Typically, prevalence estimates are based on a number of MND Association registrations data in varying countries, as the severity of the disease means that a high proportion of people are diagnosed and subsequently register with MND Associations. MND Australia provided Deloitte Access Economics registration data from MND Associations in Australia, which allows for a similar approach to estimate prevalence as used internationally.

To estimate the total prevalence of MND in Australia, Deloitte Access Economics takes a similar approach to international methods that incorporates MND Association registration data, and makes adjustment for the estimated proportion of registrations to the true prevalence. This is done using the ratio of deaths in people with MND registered with MND Associations to the total deaths in Australia using death certificate data.

Prevalence is estimated by solving for an unknown variable, with three known variables – prevalence and deaths registered with MND Associations, and the total deaths across all Australians. It is assumed that the ratio of registered deaths to total deaths will be the same as the ratio of registered cases of MND to total cases of MND. The average male and female age and gender prevalence distributions found in the literature are then applied to the total estimated cases of MND to produce age gender breakdowns of prevalence.

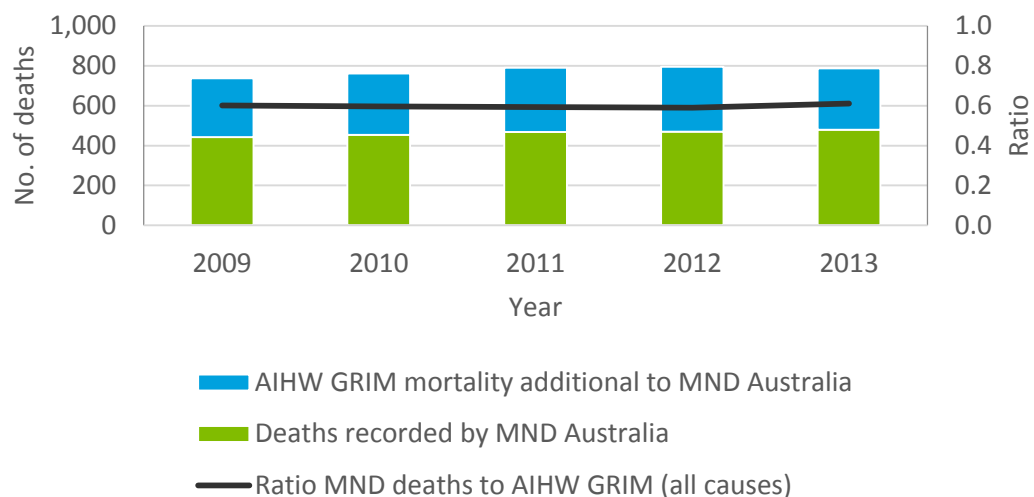
3.1.1 Prevalence data

In Australia, MND Australia maintains a record of registrations which includes both people with a confirmed diagnosis of MND and their carers. MND Australia supplied Deloitte Access Economics with data on the number of people with MND who registered with MND Associations between 2009 and 2015. The data provided indicates the point number of registrations at 30 June for each of the respective years. It is important to note that this data varies by state depending on the reach of each State Association. However, it is assumed that this data is relatively representative of each State's population.

Total deaths due to MND are derived from the AIHW's General Record of Incidence of Mortality (GRIM) book data through a special request. The latest year of data available is for the year 2013, and provides data where MND is listed as the underlying cause of death. Data is also provided for deaths in people with MND where MND has been listed as an additional cause of death, but not the primary cause. These deaths are associated with MND. Adding both associated causes and underlying causes of death together gives the total known deaths associated with MND in Australia. This data is provided in section 3.2.

The number of deaths in people with MND that are registered with MND Australia are compared with the number of deaths recorded on death certificates in Australia. Over the period 2009 to 2013 – the last available year for AIHW GRIM book data – the deaths recorded by MND Australia captured approximately 60% of the total deaths in people with MND. This is shown in Chart 3.1.

Chart 3.1: Deaths in people with MND, registrations and death certificates, 2009-2013



Note: data in this chart represent all deaths in people with MND without identifying the cause of that death.
Source: MND Australia, AIHW GRIM special data request.

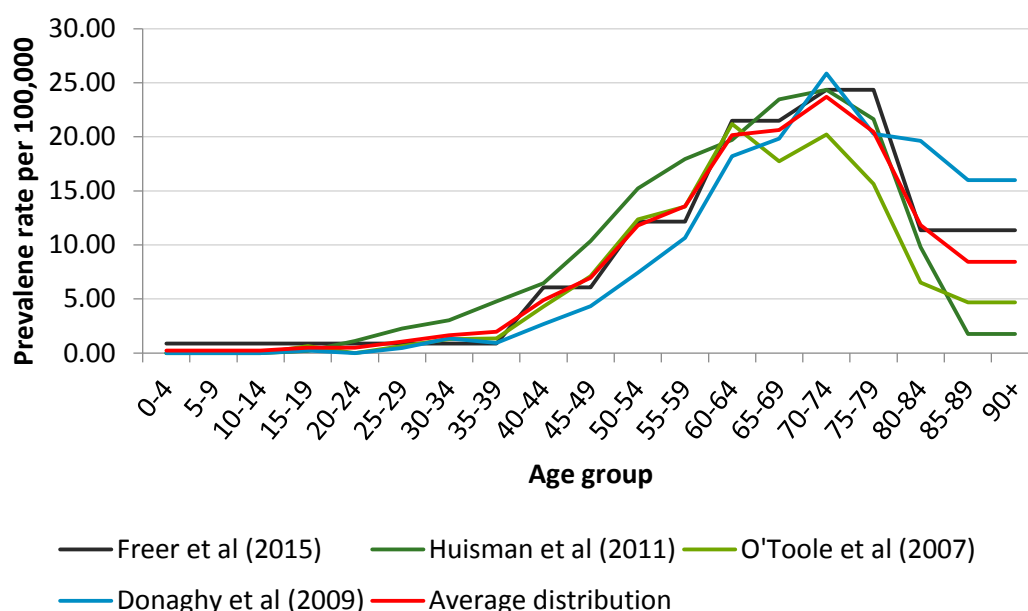
It is assumed that the ratio of deaths in people registered with MND Australia, to deaths recorded in GRIM, also holds for the ratio of people registered with MND Australia, to total MND prevalence. In 2013, MND Australia had a total of 1,209 people with MND registered with their State Associations. This implies that total prevalence in Australia was 2,022 in 2013 ($1,209 / 0.60$). The prevalence rate was 8.7 per 100,000 Australians in 2013.

Applying the prevalence rate to the total Australian population in 2015, it is estimated that there are 2,094 Australians with MND in 2015.

3.1.2 Prevalence by age and gender

There is no official estimate of the age and gender distribution of people with MND in Australia. Recently there have been a number of epidemiological studies conducted in the US, UK, and Europe. Studies by Freer et al (2015), Huisman et al (2011), Donaghy et al (2009) and O'Toole et al (2007) have provided similar age and gender distributions of MND. The age distributions are shown in Chart 3.2. The average distribution across these studies also shows the ratio of males to females with MND is approximately 1.5.

Chart 3.2: Prevalence of MND by age (rate per 100,000)



Source: As noted in chart.

The average age and gender distribution across these studies is applied to the total estimated prevalence in Australia in 2015. It is important to note that this data would vary slightly by location. However, this age distribution is in line with high level data from MND Associations for NSW, Victoria and Tasmania – showing that approximately 52% are over the age of 65. The age distribution derived from these studies indicates a median age of approximately 62, showing that 50% are over this age. Table 3.1 shows the prevalence and estimated prevalence rates of MND in Australia.

Table 3.1: Estimated prevalence rates of MND, 2015

Age	Prevalence rates (per 100,000 people)			Prevalent cases		
	Males	Females	Total	Males	Females	Total
0-44	1.9	1.3	1.6	136	92	228
45-54	14.9	9.7	12.3	232	154	387
55-64	27.5	16.6	22.0	372	231	604
65-74	30.7	26.2	28.4	304	268	572
75-84	34.9	13.0	23.1	174	76	250
85+	25.6	3.0	11.3	44	9	53
Total	10.6	6.9	8.7	1,263	830	2,094

Note: Rows and columns may not sum due to rounding.

Source: AIHW GRIM special request, MND Australia, Freer et al (2015), Huisman et al (2011), Donaghy et al (2009), O'Toole et al (2007), ABS 2015, and Deloitte Access Economics' calculations.

3.1.3 Summary of prevalence literature

A literature search was conducted to evaluate the extent to which the estimated prevalence is consistent with findings from other studies in Australia and overseas. A number of studies were found, with the majority representing international research. These studies and their prevalence estimates are summarised in Table 3.2.²

Table 3.2: Summary of prevalence literature

Study	Brief description
Worms (2001)	The author undertook a meta-study of the epidemiology of MND in Europe and North America during the 1990s. Five prevalence studies were analysed (including from Italy, Ireland and Canada) which diagnosed MND using varying diagnostic criteria. These studies defined a prevalence range of 2.7 to 7.4 per 100,000 people. The average prevalence was found to be 5.2 per 100,000.
Chiò et al (2013)	One of the most comprehensive reviews of MND prevalence to date, including more than 20 studies that reported on prevalence of MND across Europe, North America, Asia and the Pacific, and South America. The majority of studies have been conducted in Europe. The review stratified studies by retrospective and prospective study type. The range of prevalence rates across these studies were reported to be between 1.0 per 100,000 people and 11.3 per 100,000 people. The median prevalence rate was 5.4 per 100,000 across all European studies.

² MND encompasses several different conditions, including ALS which is the most common. While in the UK and Australia it is common to use MND as an umbrella term for these conditions, in the United States ALS is often used as the umbrella term. Accordingly, studies from the United States referring to ALS may be interpreted as referring to the group of motor neuron diseases.

Study	Brief description
Huisman et al (2011)	The study investigated MND epidemiology in a large population-based register in The Netherlands between 1 January 2006 and 31 December 2009. A capture-recapture ³ methodology was applied across separate age and gender groups to adjust for the number of unobserved patients. Prevalence was found to be 10.3 per 100,000 individuals (with a 95% confidence interval of 9.8 to 10.9)
Freer et al (2015)	This study reports on a state-wide surveillance project conducted in Florida in the US. Neurologists were asked to submit all cases of MND between 1 January 2009 and 31 December 2011. Medical records were reviewed by an independent neurologist to confirm diagnosis. Mortality data was also used to assist with data collection. Period prevalence for 2009 was 1,450 people or 4.0 per 100,000. It was noted that some physicians refused to report cases to the study, although the authors believe the underreporting was minimal as a result. Hospital data may have also indicated up to 951 additional cases of ALS, although these were not included in the study.
Donaghy et al (2009)	The authors conducted a population-based prospective study of MND in Northern Ireland and the Republic of Ireland. The Northern Ireland and Republic of Ireland MND registers were used to identify people with MND. The prevalence of MND was 5.0 per 100,000 people.
O'Toole et al (2007)	The authors conducted a prospective, population based study to examine trends in incidence and prevalence of MND in Ireland between 1995 and 2004. The Irish ALS register was used to identify people with ALS. The crude prevalence rate on 31 December 2003 was 6.4 per 100,000 population aged over 15.
Garcia et al (2013)	The study collected data from the Spanish Network of Rare Diseases Registries which is based on primary care databases, mortality registries and hospital discharge records. The data was collected from 13 autonomous regions in Spain that represent approximately 67% of the total Spanish population. The average MND prevalence for the population was 11 per 100,000.
Department of Health Western Australia (2008)	The Epidemiology Branch of the Western Australia Department of Health collected data on the number of people with MND by Area Health Service. These included the North Metropolitan Area Health Service, South Metropolitan Health Service and WA Country Health Service. In 2006, there were 133 people with MND across the Area Health Services. By comparing this value with the Western Australia population for that year (ABS ⁴ , 2006), a prevalence rate of 6.6 per 100,000 people is derived.
Mehta et al (2014)	The study analysed data from the US National ALS Registry. The registry contains data collected from national administrative databases as well as a secure web portal launched to the public, allowing people who have MND to register and provide information through online surveys. During October 2010 to December 2011, a total of 12,187 persons meeting the definition of definite MND were identified by the Registry, giving a prevalence of 3.9 cases of MND per 100,000 persons in the US general population. MND was most common among white males, non-Hispanics, and persons aged 60-69 years.

Source: As indicated in the table above.

³ A capture-recapture methodology involves measuring the number of people with a condition or disease at a particular point in time, and then measuring the number of people with the same condition or disease at a later time. This method allows epidemiologists to estimate the true prevalence, or number of cases missed by a register, by examining how many people are the same in both samples.

⁴ Australian Bureau of Statistics.

Overall, the studies describe a range of prevalence estimates (from 1 to 11 per 100,000). One of the most comprehensive reviews of MND prevalence to date was conducted by Chiò et al (2013). The review found 20 studies that reported on prevalence across Europe, North America, Asia and the Pacific, and South America. The review stratified studies by retrospective and prospective study type. The range of prevalence rates across these studies were reported to be between 1.0 per 100,000 people and 11.3 per 100,000 people. The **median prevalence rate of 5.4 per 100,000 across all European studies** suggests that the prevalence estimate for Australia is towards the higher end of the prevalence range. That said, the prevalence rate estimate for Australia still falls within the estimated prevalence range (1 per 100,000 people to 11 per 100,000 people). Moreover, **the median prevalence rate across 6 recent prospective studies⁵ conducted in Europe was approximately 7.9 per 100,000 people** (Chiò et al, 2013) – only slightly lower than the total prevalence rate estimated for Australia of 8.7 per 100,000 people, and fall within the 10% lower bound prevalence (7.9 per 100,000 people) which have been developed as part of the sensitivity analysis in section 10.2.2.

These studies show the range and uncertainty associated with estimated prevalence of MND in various countries. While there are undoubtedly some differences due to various risk factors (section 2.3), it is likely that the wide range of prevalence estimates are due to the various techniques employed to estimate prevalence, the reach of MND Associations in other countries (and within Australia), and the small number of people (in absolute terms) who have MND.

3.2 Deaths due to MND

There are a substantial number of deaths in people with MND every year. The average time from disease onset to death is approximately 2.5 years (Paulukonis et al, 2015).

Deaths associated with MND are derived from the AIHW's GRIM book data through a special request. The latest year of data available is for the year 2013, and provides data where MND is listed as the underlying cause of death. Data is also provided for deaths in people with MND where MND has been listed as an additional cause of death, but not the primary cause. These deaths are associated with MND. Adding both associated causes and underlying causes of death together gives the total known deaths associated with MND in Australia. This data indicates that there were 787 known deaths of people with MND in 2013 due to any cause, of which 711 deaths were specifically due to MND (MND was listed as an underlying cause).

⁵ Prospective studies can be more comprehensive than retrospective studies in that they analyse prevalence in a cohort at the commencement of the study and then track this cohort over time. Retrospective studies may be limited by the data source that is analysed retrospectively. It is possible that both studies may return prevalence that is otherwise equivalent.

Table 3.3: Estimated deaths due to MND, 2013

Age	Mortality rates (per 100,000 people)			Number of deaths		
	Males	Females	Total	Males	Females	Total
0-44	0.18	0.07	0.12	13	5	18
45-54	2.05	0.69	1.37	32	11	43
55-64	5.69	4.96	5.32	77	69	146
65-74	11.21	9.89	10.54	111	101	212
75-84	24.43	16.92	20.38	122	99	221
85+	19.73	12.36	15.05	34	37	71
Total	3.26	2.68	2.97	389	322	711

Note: Rows and columns may not sum due to rounding.

Source: AIHW GRIM special request, ABS 2015a.

There is one potential issue with AIHW GRIM book data for deaths due to MND. It is possible that deaths due to MND will be either overstated or understated depending on the cause of death recorded on the death certificate of people with MND. For example, Paulukonis et al (2015) notes that MND may not be recorded as a cause of death even in cohorts diagnosed with MND where the cause of death is consistent with being caused by MND, meaning that total deaths due to MND are understated.

To address these issues of overstated and understated deaths, a recent systematic review by Marin et al (2011) suggests mortality data should be considered as both the underlying cause and the associated cause. Across the studies reported in Marin et al (2011), MND is considered to be the cause of death in approximately 80% of cases, and MND is not listed in 20% of deaths in people with MND. This would suggest that as many as 20% of deaths in people with MND are coded as another cause. That said, this was highly dependent on the country where deaths data was obtained from. For example, Italian studies found lower rates of accurate causes of death data and England and Finland studies found that MND was correctly reported as a cause of death in almost all cases. Considering only the UK and US, which have many epidemiological factors in common with Australia, as many as 13% of deaths do not have MND listed as a cause of death – indicating that deaths are understated by approximately 13%.

Recent data from the US found that MND was not considered to be a direct cause of death in 9% of deaths in people with MND (Paulukonis et al, 2015). This was despite MND being listed as either the underlying cause or an associated cause, meaning deaths were overstated by 9%. However, Paulukonis et al (2015) also found that 5% of cases had no indication of MND in the record despite these deaths being associated with MND – deaths were understated by 5%. Gil et al (2008) found that 10% of deaths were not due to MND in their cohort, meaning deaths were overstated by 10%.

Taking the average of the US and UK studies reported in Marin et al (2011) and Paulukonis et al (2015), **deaths are understated by approximately 10%**. Taking the average of Paulukonis et al (2015) and Gil et al (2008), **deaths are overstated by approximately 10%**. This data indicates that official cause of death data may have up to 10% error either way when reporting deaths due to MND. Consequently, it is assumed that the underlying deaths data

published by the AIHW is accurate, as we do not have evidence that developed countries consistently overstate or understate deaths due to MND.

Based on deaths with MND as an underlying cause reported in AIHW GRIM book data, Table 3.4 presents the number of deaths by age and gender due to MND in Australia in 2015. **There were estimated to be 752 deaths as a result of MND in 2015, with males accounting for 55% of total deaths.** Mortality rates are highest in the 75-84 year old cohort.

Table 3.4: Estimated deaths due to MND, 2015

Age	Mortality rates (per 100,000 people)			Number of deaths		
	Males	Females	Total	Males	Females	Total
0-44	0.18	0.07	0.13	13	5	18
45-54	2.10	0.70	1.39	33	11	44
55-64	5.91	5.18	5.54	80	72	152
65-74	12.11	10.74	11.41	120	110	229
75-84	25.84	17.50	21.34	129	102	232
85+	21.91	13.12	16.33	38	39	77
Total	3.46	2.82	3.14	413	340	752

Note: Rows and columns may not sum due to rounding.

Source: AIHW GRIM special request, ABS 2015a.

To recognise that deaths data may be up to 10% overstated or understated (as reported in the literature), section 10.2 presents sensitivity analysis for prevalence estimates given that deaths are used as the basis for estimating total prevalence.

4 Estimating the economic costs of MND

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

4.1 Incidence and prevalence approaches

This report utilises a **prevalence (annual costs) approach** to estimate the costs of MND in Australia for the year 2015. The alternative approach is the incidence (lifetime costs) approach. The difference between incidence and prevalence approaches is illustrated in Figure 4.1.

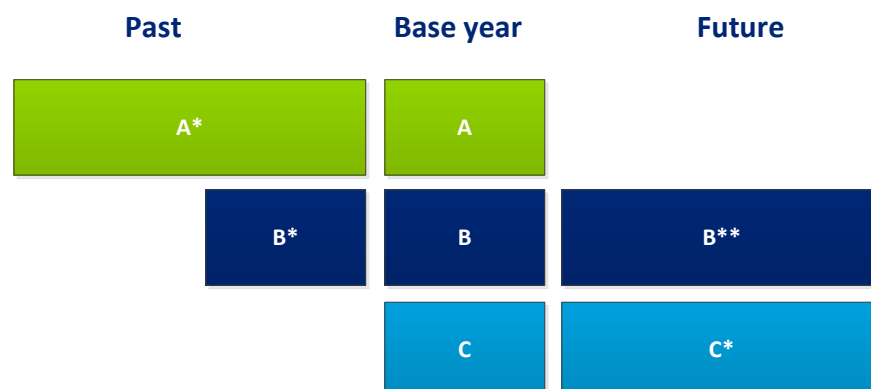
Consider three different cases of people with MND:

- a, who was diagnosed with MND 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 MND in the past and has incurred the associated costs in 2015 as well as in the past and future, with associated lifetime costs of $B + B^* + B^{**}$, shaded in dark blue; and
- c, who was diagnosed with MND in 2015, with lifetime costs of $C + C^*$, shaded in light blue.

All costs should be expressed as present values relative to 2015:

- Annual prevalence-based costs in the base year = $\Sigma(A + B + C)$;
- Annual incidence-based costs in the base year = $\Sigma(C + \text{present value of } C^*)$

Figure 4.1: Incidence and prevalence approaches to measurement of costs



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

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

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

Using a prevalence approach, costs in 2015 relating to a, b and c would all be included, with total costs equal to $\Sigma(A + B + C)$. Costs in all other years are excluded.

4.2 Classification of costs

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

- **Direct and indirect costs:** Although literature often distinguishes between direct and indirect costs, the usefulness of this distinction is dubious, as the specific costs included in each category vary between different studies, making comparisons of results somewhat difficult.
- **Real and transfer costs:** Real costs use resources such as capital or labour, which thus reduces the economy's capacity to produce and consume goods and services. Transfer payments, however, are payments from one party to another which do not use up real resources. For example, the real cost associated with someone losing this job is their lost production, while the associated fall in income taxation paid to the government (due to not having an income) is a transfer.
- **Economic and non-economic costs:** Economic costs encompass loss of goods and services that have a price in the market or that could be assigned an approximate price by an informed observer. 'Non-economic' costs include the loss of wellbeing of the individual as well as of their family members and carers. This classification is ill-defined, since 'non-economic' costs are often ascribed values and the available methodologies are becoming more sophisticated and widely accepted. We acknowledge that controversy still surrounds the valuation of 'non-economic' costs and that the results should be presented and interpreted cautiously.
- **Prevention and case costs:** We distinguish between: the costs following from, and associated with a disease; and costs directed towards preventing the disease. Prevention activities include public awareness and education about MND. In a similar vein, costs of insuring against impacts of the disease are excluded, but the study includes the gross costs of the impacts themselves.

There are six types of costs associated with MND.

- **Direct financial costs to the Australian health system** include the costs of running hospitals and residential aged care facilities (buildings, care, consumables), GP and specialist services reimbursed through Medicare and private funds, the cost of pharmaceuticals (PBS and private) and of over-the-counter medications, allied health services, research and "other" direct costs (such as health administration).

- **Productivity costs** include productivity losses of the people with MND, premature mortality and the value of informal care (including lost income of carers).
- **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 (DWLs) 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 MND. Although more difficult to measure, these can be analysed in terms of the years of healthy life lost, both quantitatively and qualitatively, known as the “burden of disease”.

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

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

While it may be convenient to think of these costs as being purely borne by the employer, in reality they may eventually be passed on to end consumers in the form of higher prices for goods and services. Similarly, for the costs associated with the health system and community services, although government meets this cost, taxpayers (society) are the ultimate source of funds. However, for the purpose of this analysis, a ‘who writes the cheque’ approach is adopted, falling short of delving into second round or longer term dynamic impacts.

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

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

- people with MND;
 - friends and family (including informal carers);
 - employers;
 - Federal government;
 - State and local government; and
 - the rest of society (non-government, not-for-profit organisations, private health insurers, workers’ compensation groups, and so on).
- } The household

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

4.3 Net present value and discounting

Where future costs are ascribed to the year 2015 throughout the report the formula for calculating the net present value (NPV) of those cost streams is:

$$NPV = \sum C_i / (1+r)^i \text{ for } i=0,1,2,\dots,n$$

Where:

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

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

Generally, the minimum option that one can adopt in discounting expected healthy life streams is to set values on the basis of a risk free assessment about the future that assumes future flows would be similar to the almost certain flows attaching to a long-term Government bond. Another factor to consider is inflation (price increases⁶), so that a real rather than nominal discount rate is used. If there is no positive time preference, the real long term government bond yield indicates that individuals will be indifferent between having something now and in the future. In general, however, people prefer immediacy, and there are different levels of risk and different rates of price increases across different cost streams.

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

⁶ The Reserve Bank has a clear mandate to pursue a monetary policy that delivers 2% to 3% inflation over the course of the economic cycle. This is a realistic longer run goal and a consumer price inflation rate of around 2.5% per annum on average has been achieved over recent years.

5 Health system costs

This chapter estimates individual components of health system costs, to provide an estimate of the overall health system expenditure in Australia.

Health system costs comprise the costs of running hospitals, GP and specialist services funded through Medicare and patient contributions, the cost of prescribed and over-the-counter pharmaceuticals, optometry and allied health services, research and 'other' direct costs such as health administration. Government costs associated with residential aged care are also typically included in the health system.

Health system costs are estimated using a combination of a bottom-up approach and top-down approach.⁷

Key findings:

- The total health system costs due to MND are estimated to be \$74.4 million in 2015, or \$35,510 per person with MND.
- The largest component of health system expenditure was estimated to be inpatient admissions (\$16.2 million), followed by out-of-hospital medical services (\$14.4 million) and other health system professionals (\$11.4 million).
- Governments bore around two thirds of the health system costs (68.3%), while individuals bore 17.8%, and other parties (such as private health insurers and charities) bore the remaining 13.9%.

5.1 Hospital expenditure

Hospital expenditure data in Australia includes general public and private hospital admissions, including expenditure for admissions to specialist clinics. The Western Australian Department of Health is the only publicly available, comprehensive expenditure data that is specific to MND in Australia. For the year 2011-12, the average cost of an inpatient admission where MND was listed as the primary cause was \$9,627 (Department of Health Western Australia, 2015). To determine the admitted patient expenditure across all of Australia, this figure is inflated to 2015 using 10-year historical average health price inflation from the AIHW (2014), which is applied to the number of hospital separations specifically relating to MND in 2013, brought forward to 2015 using age-gender demographic changes. Separation statistics were retrieved from the National Hospital Morbidity Database for 2012-13 (AIHW, 2015).

The average cost per separation where MND is listed as a primary cause is estimated to be \$10,387 in 2014-15. There were estimated to be 1,564 separations in 2015, (1,510 separations in 2012-13 adjusted for demographic changes). **The total admitted patient hospital expenditure for MND is estimated to be \$16.2 million in 2015.**

⁷ The AIHW is the gold standard for health expenditure publications in Australia. Typically, the AIHW is able to provide data which breaks expenditure down by disease. At the time of writing this report, the AIHW was unable to respond to Deloitte Access Economics' special request for this data.

In addition to admitted hospital expenditure, non-admitted hospital expenditure is also substantial on a per-capita basis. No publicly available data analyses the service utilisation for non-admitted patient services associated with MND. Consequently, AIHW data for the broader category 'other nervous system' conditions (of which MND is a subset) is used to derive the total hospital expenditure in Australia. This data shows that non-admitted patient expenditure is 47% of total admitted patient expenditure (AIHW, 2004).

By applying this percentage, it is estimated that there was **\$7.7 million of non-admitted expenditure for MND in 2015**. This may be an underestimate as it is likely that people with MND will use a multidisciplinary team for their care (section 2.6).

Total hospital expenditure for MND is defined here as the sum of both admitted and non-admitted patient services. Total hospital expenditure for MND was estimated to be \$23.9 million in 2015.

5.2 Medication expenditure

The medication riluzole is the only drug used to treat MND specifically, and has been shown to slow the progression of MND and prolong life by up to 3 months on average (section 2.6). Therefore, medication expenditure is expected to primarily be associated with PBS-listed riluzole, although there are other medications not on the PBS that are used to help manage symptoms. PBS data is used to estimate expenditure associated with riluzole, while expenditure for other non-PBS MND medications is based on the ratio of non-PBS to PBS expenditure for the broader category 'other nervous system' conditions.

For a person with MND to receive riluzole, it has to be prescribed by a neurologist initially, and can be prescribed by a GP for follow up. This prevents riluzole being prescribed for conditions other than MND.

In 2014-15, the government paid \$4.56 million in benefits for riluzole (Department of Human Services, 2015). Adding average co-payment rates, individuals would have paid a further \$74,000. Therefore, **the total estimated expenditure on riluzole in Australia is \$4.63 million in 2015**.

To estimate expenditure associated with the range of medications used to help manage symptoms of MND, the ratio of non-PBS medications to PBS medications for the condition 'other nervous system' as reported by AIHW (2004) is applied to expenditure on riluzole. This suggests that there was **\$1.04 million of expenditure for non-PBS medications to help manage MND symptoms in 2015**.

Expenditure for medications used to help treat and manage MND was estimated to be \$5.7 million in Australia in 2015.

5.3 Research expenditure

A number of research projects have been funded by various organisations. To estimate health research expenditure on MND in Australia in 2015, two primary sources of

information were utilised: from the National Health and Medical Research Council (NHMRC), and from the Motor Neurone Disease Research Institute of Australia (MNDRIA).

In 2015, NHMRC (2015) estimated that they would provide \$8.07 million for MND research projects. Additional to this, MNDRIA indicated that they would provide \$2.57 million for MND research projects in 2015 (MND Australia, 2015).

Expenditure on research is expected to continue to be strong in coming years. The Cure for MND Research Foundation, established in 2014, conducted a successful fundraising campaign for MND research, which will provide an additional \$2.5 million in research funding commencing in 2016. The funding will be delivered by the Foundation and MNDRIA, and will be additional to current funding delivered by MNDRIA.

The research expenditure for MND in Australia is estimated to be \$10.6 million in 2015.

This may be a conservative figure as it does not capture research expenditure from private research companies, as this data is not publicly available. While these companies are able to recoup research expenditure through the price of goods sold, until new treatments are developed they are unable to do so and any MND specific research would not be captured in pharmaceutical expenditure estimates.

5.4 Out-of-hospital medical and other health professionals expenditure

There are limited data surrounding service usage for out-of-hospital medical services and services provided by other health professionals for people with MND. As such, the estimates for these aspects of the health system are based on the proportions for the broader category of 'other nervous system' conditions reported by the AIHW (2004).

It is assumed previous shares of total expenditure for 'other nervous system' conditions were maintained in 2015. The AIHW (2004) estimated that out-of-hospital medical services for 'other nervous system' conditions comprised 19.3% of total health system expenditure, while other professional services comprised 15.4% of total health system expenditure. These percentages were applied to Deloitte Access Economics' estimate of total known health system expenditure on MND.

Based on these proportions, MND-related expenditure for out-of-hospital medical costs and other health professionals is estimated to be \$14.4 million and \$11.4 million in 2015, respectively.

5.5 Residential aged care expenditure

As with out-of-hospital medical services and services provided by other health professionals, there are no publicly available data that estimate utilisation of aged care services for people with MND. The best available data of people receiving residential aged

care support was provided by MND Australia to Deloitte Access Economics. This data indicates that of those people with MND registered with their State Associations, 11.0% were currently residing in residential aged care (30 June 2015). This implies that of the estimated 2,094 people with MND in Australia in 2015, 229 are in residential aged care.

The government cost of aged care for the average person with MND was assumed to be the same as the average cost of aged care across all permanent aged care placements in 2013-14. Data from the Productivity Commission (Steering Committee for the Review of Government Service Provision, 2015) shows that government expenditure on residential aged care in 2013-14 was \$9.98 billion, and there were approximately 231,500 permanent residential aged care placements and 49,300 respite residential aged care placements. The average cost of residential aged care placements to government was approximately \$35,654 in 2013-14. This is estimated to increase to \$36,193 in 2014-15 (inflated using CPI⁸).

Expenditure by government for residential aged care services for MND is thus estimated to be \$8.3 million in 2015.

This is likely to be a conservative estimate as it does not consider the high cost associated with the complex health care needs of people with MND.

5.6 Summary of health system costs

Total health system costs associated with MND in Australia were estimated to be \$74.4 million in 2015 (Table 5.1 and Chart 5.1). The largest component was associated with inpatient hospital expenditure (\$16.2 million), followed by out-of-hospital medical services (\$14.4 million). Other large components include research (\$10.6 million), which has seen a considerable rise over the last decade due to NHMRC funding, and other health professionals (\$11.4 million).

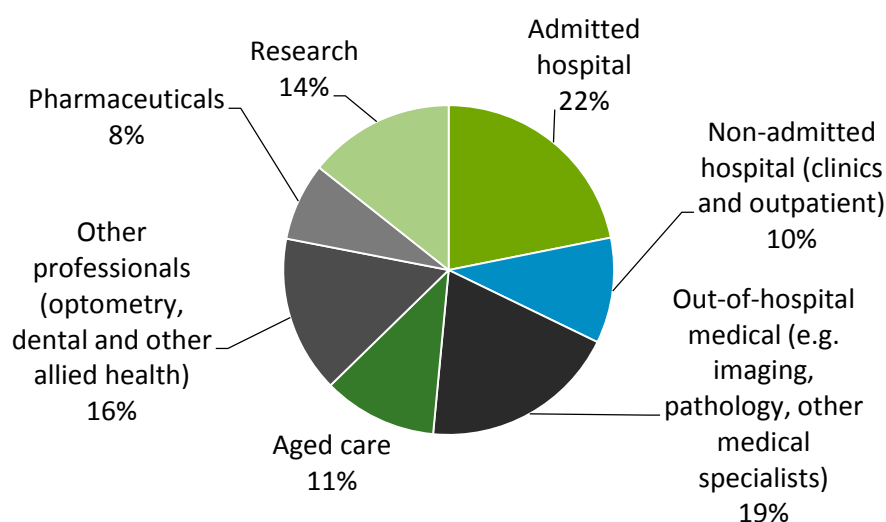
While these costs may seem substantial, they are likely to be conservative as they are based on broader level data for a variety of nervous system conditions, or average costs across all conditions, without accounting for the severity of MND.

⁸ Consumer Price Index.

Table 5.1: Health system costs by sector, total and per person, 2015

Health expenditure sector	\$ (million)	Per person (\$)
Admitted hospital	16.2	7,758
Non-admitted hospital (clinics and outpatient)	7.7	3,678
Pharmaceuticals	5.7	2,710
Research	10.6	5,083
Out-of-hospital medical (e.g. imaging, pathology, other medical specialists including GPs)	14.4	6,854
Other professionals (other allied health, optometry and dental)	11.4	5,464
Aged care (government)	8.3	3,964
Total health system expenditure	74.4	35,510

Source: Deloitte Access Economics calculations.

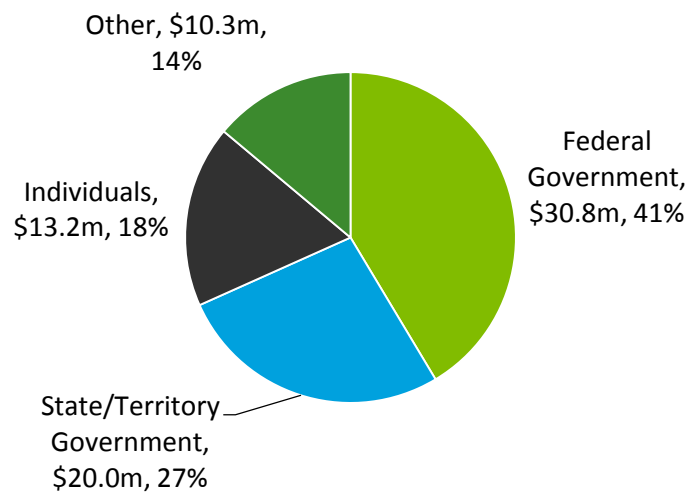
Chart 5.1: Health system expenditure by sector, 2015

Source: Deloitte Access Economics' calculations.

Chart 5.2 presents estimates of the burden for different sectors of society based on data from the AIHW (2014). In 2015, MND cost:

- the Federal Government \$30.8 million;
- State and Territory Governments \$20.0 million;
- individuals and families \$13.2 million; and
- other parties (such as private health insurers and charities) \$10.3 million.

Chart 5.2: Health system expenditure by who pays, 2015



Source: Deloitte Access Economics calculations using AIHW (2014).

6 Productivity and carer costs

This chapter describes the approach that was used to estimate productivity costs associated with MND in Australia. Broadly, the costs included here cover lost productivity for people with MND due to their condition, and lost productivity for people who care for people with MND.

Key findings:

- The productivity loss in individuals with MND is \$162.8 million in 2015, or \$77,776 per person with MND. Individuals (\$101.8 million) and government (\$57.7 million) bear most of these costs. The productivity cost is largely due to losses as a result of premature death (\$128.1 million).
- The productivity loss due to informal care was \$68.5 million in 2015, or \$32,728 per person. Individuals bear most of these costs (\$44.0 million), with government bearing the rest (\$24.5 million). Each informal carer is estimated to provide 7.5 hours of care per day to people with MND.

6.1 Productivity

Productivity costs associated with MND can be extensive. Individuals may work less than they otherwise would, retire early, be absent from work more often, have lower productivity while at work, or die prematurely. These costs are real costs to the economy. For example, if employment rates are lower for people with MND, a firm's output may be reduced, resulting in a cost to the firm.

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

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

6.1.1 Absenteeism

People with MND may be temporarily absent from paid employment due to being unwell more than the average worker. This may include days off to visit health professionals, or days at home where they are not well enough to work.

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

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

Average employment rates and average weekly earnings for people with MND are based on ABS data for the general population by age and gender (ABS, 2015a; ABS 2015b). This is used for all productivity loss calculations.

Two studies have been used to estimate the additional sick days. One study found that people with MND were likely to take 23 days off work (Schepelmann et al, 2010), although it was not clear if this represented *additional* days off work. Due to this uncertainty, and to ensure that the productivity loss estimates are conservative, the amount of sick days the general population takes off has been removed from this (average 5.2 days a year, ABS 2013a)⁹. This study also had a large range of days off work due to illness – reporting a range between 2 and 60 days off work.

As the reported range was large and the sample size in Schepelmann et al (2010) was small (n = 46), this is supplemented with another study of people with Parkinson's disease – which is also a neurodegenerative disease and can have similar productivity impacts as MND, although the duration of the disease is generally much longer with slower progression. Deloitte Access Economics (2015) estimated that people with Parkinson's would have an additional 11.2 days off from work each year due to their condition.

The average of these studies indicates **people with MND are likely to take an additional 14.5 days off work each year** due to their condition. **The total economic cost associated with absenteeism is estimated to be \$7.1 million in 2015 – or \$3,389 per person with MND.**

While this impact may seem small, many people with MND stop working altogether as a result of their diagnosis. Indeed, some studies have shown that by two years after diagnosis, no one is able to work anymore with 39% immediately leaving the workforce upon diagnosis (Gladman et al, 2014). Premature workforce separation is discussed further in 6.1.3.

⁹ The 5.2 days are subtracted as these would occur even in the absence of MND.

6.1.2 Presenteeism

Presenteeism refers to attending work despite illness, often resulting in a lower productivity at work. This methodology assumes that the average weekly earnings of people in the economy are equal to their productivity output. As such, reduced productivity of people with MND at work will translate into a reduction in average weekly earnings over the long run.

No studies could be identified that examined long-term productivity decreases associated with MND. Due to the fast progressing nature of MND, it is likely that longer-term presenteeism impacts will be small as many people with MND may leave employment relatively shortly after diagnosis. The literature search for this report did not find any estimates of the presenteeism impacts due to MND, and as such no estimates of the lost productivity while at work have been included.

6.1.3 Reduced employment

Reduced employment refers to people with MND leaving the workforce prematurely due to their condition. Ultimately it would be best to use large Australian studies of the general community to identify the impact of MND on workforce participation. The application of results of the international studies to the Australian context is often limited due to differences in the social security system and access to health care, which impact on the ability for people with MND to continue working.

No studies could be identified that examined the long-term reduction in employment associated with MND in Australia. However, in the US, Mehta et al (2014) found that just 19% of people with MND were employed compared to 58% of the general population. Applying this proportionality to Australia, it is estimated that people with MND are 41.3% less likely to be employed than the general workforce in absolute terms.

Applying this to Australian general employment rates and average weekly earnings (ABS 2015a; ABS 2015b), **the total economic cost associated with reduced employment is estimated to be \$27.4 million in 2015 - \$13,101 per person with MND.**

6.1.4 Premature mortality

As MND results in a substantial amount of premature mortality, it is expected that this will reduce lifetime earnings as a result of the disease. Losses from premature mortality are calculated by multiplying deaths due to MND and expected remaining lifetime earnings of people with MND, which is weighted by the probability of being employed by age and gender.

To derive lifetime earnings, the annual income (based on average weekly earnings, ABS 2015b) is multiplied by the average employment rate at each age group while alive (ABS 2015a). Income earned at each age is then summed to calculate the expected total income over a person's lifetime, and this is discounted back to present values.

Premature deaths due to MND impose a substantial cost in Australia. **Lost lifetime earnings were estimated to be \$128.1 million in 2015 - or \$61,168 per person with MND.**

6.1.5 Administrative costs

Employers incur administrative costs associated with short run and long run productivity costs.

Each time a person with MND is temporarily absent from work, it is estimated that **2.5 hours of management time is lost processing those absent employees** (Health and Safety Executive, 2011). This includes the time of line managers in rearranging work and the time of back office personnel. The value of a manager's time is \$44.70 per hour (ABS, 2015a).

Premature retirement and premature mortality results in increased employee turnover costs, such as search, hiring and training costs. **These costs are estimated to be equal to 26 weeks salary of the incumbent worker** (Access Economics, 2004). However, this cost is merely 'brought forward' a number of years because there would be some normal turnover of people with MND in the absence of their condition – approximately 15% per annum (which implies that people change jobs, on average, approximately once every 6.7 years (Access Economics, 2004).

The administrative costs associated with MND are estimated to be \$0.3 million in 2015 – or \$127 per person with MND.

6.1.6 Summary of productivity costs

Productivity costs are summarised in Table 6.1. **The total productivity costs in people with MND are estimated to be \$162.8 million annually. This is equivalent to \$77,776 per person living with MND.**

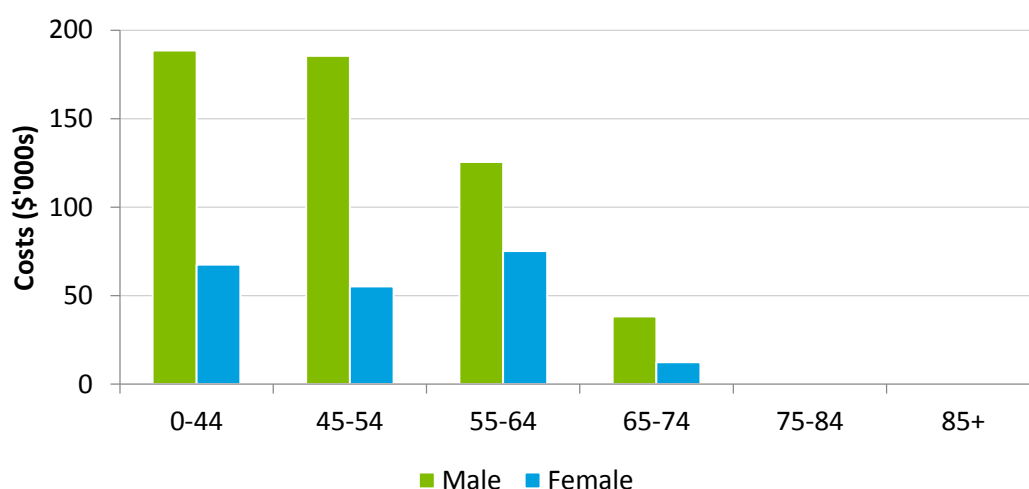
The vast majority of productivity costs are associated with premature mortality (\$128.1 million) and premature workforce separation (\$27.4 million). This does not include the significant burden placed on carers through carer time and the carers quality of life (discussed further in section 6.2 – although this is also a productivity loss).

Table 6.1: Summary of productivity costs

Source of productivity loss	2015 \$m	Per person (\$)
Temporary absenteeism from work (including management time)	7.1	3,389
Premature workforce separation	27.4	13,101
Premature mortality	128.1	61,158
Administrative costs	0.3	127
Total	162.8	77,776

Source: Deloitte Access Economics' calculations.

As shown in Chart 6.1, the average productivity cost per person with MND differs vastly by age and gender.

Chart 6.1: Productivity cost per person by age and gender, 2015

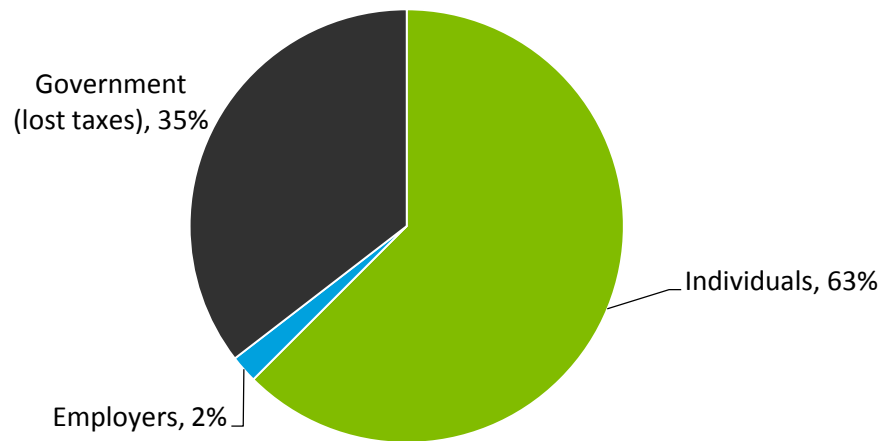
Source: Deloitte Access Economics' calculations.

The average productivity cost per person is primarily related to premature mortality. This means that costs per person are higher in younger age groups as the lost lifetime earnings for these groups are larger. This is particularly relevant for males aged 0-44 years old and 45-54 years old. Average costs are higher for males for two reasons – higher mortality rates and higher average weekly earnings for males.

The productivity costs are shared between workers, employers and governments (through tax losses). Post-tax, the shares of productivity losses are:

- **Workers:** the productivity cost of MND borne by workers is \$101.8 million – this largely consists of lost earnings as a result of lower productivity in the workplace and lost lifetime earnings due to premature mortality.
- **Employers:** the productivity cost of MND borne by employers is \$3.3 million – this is primarily productivity losses associated with temporary absenteeism.
- **Government:** the productivity cost of MND borne by government is \$57.7 million, which again is largely the result of lower lifetime earnings for people with MND, which results in lower taxation revenue.

The share of total productivity costs borne by each payer are shown in Chart 6.2. Employees bore the largest share of costs (63%), followed by government (35%) and employers (2%).

Chart 6.2: Productivity costs by who bears the cost, 2015

Source: Deloitte Access Economics' calculations.

6.2 Informal care costs

This section describes the approach that was used to estimate the costs of informal care for people with MND in Australia. Carers are people who provide care to others in need of assistance or support. An informal carer provides this service free of charge and does so outside of the formal care sector. An informal carer will typically be a family member or friend of the person receiving care, and usually lives in the same household as the recipient of care. As such, many people receive informal care from more than one person. The person who provides the majority of informal care is known as the primary carer.

While informal carers are not paid for providing this care, informal care is not free in an economic sense. Time spent caring involves forfeiting time that could have been spent on paid work or undertaking leisure activities. As such, informal care can be valued as the opportunity cost associated with the loss of economic resources (labour) and the loss in leisure time valued by the carer. To estimate the dollar value of informal care, the opportunity cost method measures the formal sector productivity losses associated with caring, as time devoted to caring responsibilities is time which cannot be spent in the paid workforce.¹⁰

Evidence is clear that carers of people with MND can experience increased rates of depression, anxiety and burden, which negatively impact their quality of life and would impose further costs on society (Aoun et al, 2012). Various factors such as assisted ventilation and cognitive behaviour changes can increase carer burden. Further, it has been reported by some studies that different opinions surrounding end-of-life care between the person with MND and their carer can also cause burden for carers. Moreover, some studies

¹⁰ It is also possible to use the replacement cost method (which measures the cost of 'buying' an equivalent amount of care from the formal sector if the informal care was not supplied), and the self-valuation method (which measures how much carers themselves feel they should be paid for undertaking their responsibilities). However, these options were not explored further in this report.

have reported that as many as 37% of carers cope poorly or very poorly, which can last for a number of years post-death (Aoun et al, 2012).

The needs and strains for caregivers of people with MND increase over time, suggesting more time is likely to be required towards the end of the disease (Bruletti et al, 2014). Bruletti et al (2014) observed this increasing strain in a longitudinal study, finding that 77% of carers cared for a person with MND for up to 6 hours a day, while 23% provided care for more than 6 hours a day. Less than 12 months later, 36% reported providing care for more than 6 hours a day.

To determine the amount of, and costs associated with, informal care given by carers of people with MND, a literature search was undertaken to determine how many people with MND receive care, the number of hours each carer provides on average, and who generally provides this care (i.e. a spouse or other family member). Who provides this care is important to ascertain, in order to correctly value the carer's opportunity cost of time, which is calculated based on the weighted average weekly earnings (ABS, 2015b) and chance of being employed (ABS, 2015a).

6.2.1 Care recipients

Typically, data from the ABS' Survey of Disability, Ageing and Carers (SDAC) would be used to determine the demographic profile of the informal carers for people with MND (ABS, 2013b). However, this data does not provide sufficient granularity to estimate the informal carers for MND specifically – rather, estimates are provided for broader categories such as *paraplegic* and *other nervous system*. Because these broader categories are a bit too broad to be solely used for MND estimates, this section relies primarily on literature.

Rabkin et al (2009) found that 50% of patients were totally dependent for self-care. The sample included in Rabkin has similar characteristics to an Australian cohort (Ng and Khan, 2011). While this provides an estimate of those that are entirely reliant on informal (and formal care), this does not indicate how many people receive care overall. A study by Lima and Nucci (2011) found that only 10.3% of patients had no care provided to them. This means that 89.7% of people with MND receive some level of care for day to day activities.

Similarly, The Lewin Group (2012) found that 11.6% of respondents did not need care (n=13/109), while 88.4% required varying levels of care between 0 and 24 hours a day. This study reported that 15 people did not provide information on their care requirements, although for the purposes of this review they are excluded here.

Giles and Lewin (2008) surveyed people registered with the MND Association of Western Australia about a number of factors including care needs and level of difficulty performing various tasks. In terms of difficulties, more than 80% had mild or worse difficulties with balance, clumsiness, fatigue/tiredness, muscle spasms and involuntary movements, and weak arms and or legs. Just over 70% also experienced sleep disturbance. These restrictions meant that 46 out of 54 (85%) people with MND were care recipients, while 8 (15%) did not receive care.

Taking an average across all of these studies, **it is estimated that in any year 88% of people with MND (estimated to be 1,836 people) require at least some level of care (greater than 0 hours a day).**

6.2.2 Care providers

There are a range of carers that provide informal care to people with MND. Typically, this is a close family member although it can include friends or other more distant family members as well. The care providers observed in the literature are reported below.

In up to 80% of cases, the care is provided by a spouse or partner, while the other 20% is provided by another immediate family member that is not a spouse or partner (Pagnini et al, 2012). Similarly, Lima and Nucci (2011) observed that partners and friends accounted for approximately 75% of caregivers, while immediate family (parents, children or cousins) accounted for 25%. For those not receiving formal care services, Krivickas et al (1997) found that 85% of primary caregivers were a spouse or partner of the person with MND.

In a cohort of patients presenting to one clinic, Bruletti et al (2012) observed that almost 67% of carers were the spouse or partner, with 31% being a child.

Giles and Lewin (2008) found that the age range of carers was 35-82 years, while for people with MND it was 40-85 years. This suggests a similar age distribution, although it is possible that children are caring for their parents and vice versa within this sample.

These studies show that **care is primarily provided by the spouse or partner, and as such the distribution of carers is assumed to be similar to the distribution of people with MND.** This is important for estimating the opportunity cost of carer time.

6.2.3 Hours of informal care provided

As people with MND experience significant, rapid decline in their functional ability, they can require substantial amounts of care from family, friends and formal caregivers. This increases as the disease progresses (Aoun et al, 2012).

To estimate the hours spent caring for people with MND in Australia, a range of estimates were taken from the literature, and applied to Australian data surrounding the severity of MND where available.

Chiò et al (2006) examined caregiver time in MND patients, breaking carer time down by severity. There were a total of 70 patients included in the study who were attending a clinic in Italy at the time. Carers were asked to record their time spent undertaking activities in nine activities using a specific caregiver time survey – the Caregiver Activity Time Survey. Chiò et al (2006) found that mean caregiving time for people with mild disability due to MND was 313.6 minutes each day, 626.7 minutes for moderate disability, and 848.7 minutes and 899.6 minutes for more severe stages of the disease – as defined by the ALS-FRS scale. **The average time spent caring for people with MND, irrespective of whether patients were receiving care from paid caregivers, was 570 minutes each day (or 10.2 hours).** This cohort was less severe than an Australian cohort (Ng and Khan, 2011).

Krivickas et al (1997) found that primary carers spend, on average, **12.6 hours a day caring for people with MND when they were receiving formal care services** (and this was additional to the formal care services provided). **In those not receiving formal care, primary caregivers spent, on average, 6.2 hours each day providing care.** Data from Giles and Lewin (2008c) in Western Australia showed that of people with MND, approximately

65% were receiving formal care services, while 35% were not. **The weighted average of care hours in this study was 10.4 each day.**

The Lewin Group (2012) conducted a survey to establish economic costs associated with a number of nervous system conditions in the US including MND. Results were stratified by condition, and the hours of daily care required were reported in groups of no care required, 1 to less than 8 hours required, 8 to less than 16 hours required, and 16 to 24 hours required. Taking the midpoint of each group, and weighting this by the number of people with MND receiving each level of care, **recipients received an average of 13.9 hours of care each day.** This included estimates of just being present at home in the event that the person with MND required care.

Hecht et al (2003) found that 11 carers provided less than 2 hours caring, 13 carers provided between 2 and 6 hours of care, and 12 carers provided more than 6 hours of care. As no information was provided on the range of hours in the highest category, no weighted average could be calculated and so this study is removed from the average across all people with MND.

Lima and Nucci (2011) surveyed 29 people with MND through an outpatient clinic in Brazil. They found that the **primary caregiver provided an average of 6.2 hours each day of care.**

The average care time provided across all of these studies (excluding Hecht et al, 2003) to people with MND is 10.2 hours each day. However, data included in these surveys typically includes housekeeping tasks or being present in case the carer is needed. These tasks are not assumed to be additional costs due to having MND (for example, a carer could undertake leisure time activities or potentially work from home despite being present 24 hours a day). To account for this effect, it is assumed that housekeeping tasks – estimated to take 2.6 hours a day (Chiò et al, 2006) – would have occurred otherwise.

The average informal care hours provided to people with MND are estimated to be 7.5 hours per day.

6.2.4 Cost of informal care

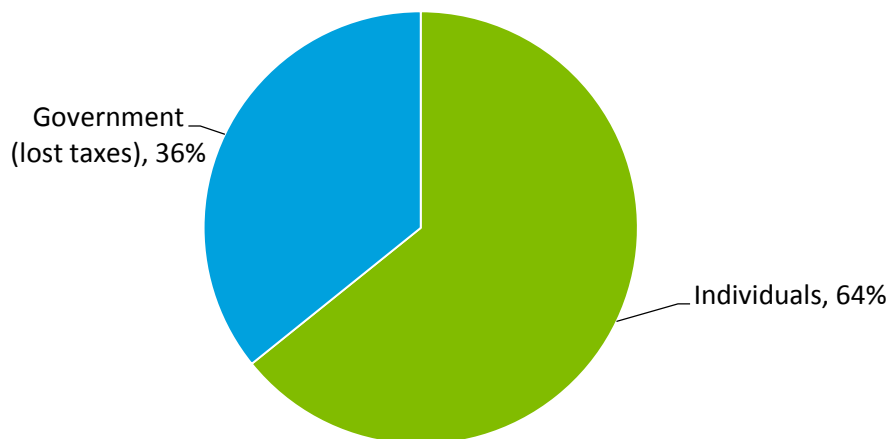
To estimate the carer costs, estimates of the number of people requiring care are multiplied by the annual hours of care provided (7.5 hours per day for 365 days per year), and the opportunity cost of carers time.

Overall, **informal care provided to people with MND cost the economy around \$68.5 million in 2015.** This represents \$13.60 per hour of informal care based on an opportunity cost approach. Of the total cost:

- carers (post-tax) bore around \$44.0 million in the form of lost income; and
- government bore around \$24.5 million in the form of lost taxes.

The distribution of informal care costs by the respective payer is shown in Chart 6.3.

Chart 6.3: Informal care costs by who bears the cost, 2015



Source: Deloitte Access Economics calculations.

7 Other financial costs

In addition to productivity and carer costs, there can be other burdensome costs, such as the costs of special aids and modifications, costs of formal care, costs of respite for informal carers, travel and accommodation costs to access health services, the cost of other government programs, and funeral costs. There are also costs to society which result from distortionary measures in the market such as taxation – these costs are known as dead weight losses (DWLs).

Key findings:

- Total other financial costs incurred due to MND are estimated to be \$83.6 million in 2015, or \$39,921 per person with MND.
- The largest component of other financial costs is expenditure on aids, equipment and modifications to the home or vehicle for people with MND. These were estimated to be \$66.2 million, or \$31,598 per person.
- People with MND receive only a small amount of formal care, with data showing that approximately 1 in 3 people with MND receive 10.7 hours of formal care each week. The costs associated with this are estimated to be \$12.6 million in 2015, or \$6,025 per person with MND.

7.1 Aids and modifications

In the early stages of the disease, many people with MND are able to remain independent, and continue to perform everyday activities. However, the rapid progression of MND in many cases means people with MND are unable to remain independent for long without additional assistance such as increased care and aids and modifications. As symptoms worsen over time, their ability to perform activities such as getting in and out of a bathtub or shower, standing up from a chair, or walking becomes more restricted. Aids and modifications help people with MND (and their carers) in performing these activities, allowing them to remain independent for as long as possible. Establishing the use of, and costs associated with, aids and modification is essential to estimate the total cost of aids and modifications for people with MND in Australia.

The two most comprehensive studies found were conducted in the US (The Lewin Group, 2012) and Canada (Gladman et al, 2014). The Lewin Group (2012) used a survey to establish any costs associated with aids and modifications, while the Gladman et al (2014) study used a cost diary and tracked the expenditure of these costs over time.

All of the costs reported in these studies have been converted to Australian dollars using purchasing power parity¹¹, and inflated to 2015.

¹¹ Purchasing power parity is a relative measure of the value of one currency compared to another currency when used to purchase a particular bundle of goods in the market. This allows for effective comparison between the value of the currencies rather than exchange rates, which may infer a higher real cost in one of the currencies due to exchange rate fluctuations.

The Lewin Group (2012) study found that 88% of people with MND incurred costs related to moving or modifying their home. The mean costs of these modifications were \$12,010 in 2015. This study also found that 86% of people with MND were required to make modifications to their vehicle, or had to purchase a new vehicle. The mean costs of these modifications were \$3,488 in 2015.

Gladman et al (2014) found that 90% of people with MND required modifications to their home, or were required to move. The average costs of these modifications were \$15,703 in 2015. The study also found that 92% required mobility aids and modifications (including to their car), with the mean costs being \$14,014 in 2015. The costs of these aids and modifications related to the use of manual and power wheelchairs, walking aids, transfer discs, delivery costs, and vehicle modifications.

Gladman et al (2014) also reported on medical equipment required at home. Of all people with MND, 92% required some equipment, and the mean costs associated with this were \$6,987 per person. Medical equipment costs included, but were not limited to, out-of-pocket medications expenditure, suction devices, ventilators, enteral feeding pumps, and communication aids.

Table 7.1: Cost of aids, equipment and modifications

	Mean cost	% requiring	No. requiring	Costs (\$ million)
Average cost of home modifications	13,856	89%	1,860	25.8
Average cost of mobility aids	14,014	92%	1,923	26.9
Average cost of medical equipment	6,987	92%	1,923	13.4
Total cost				66.2

Source: Gladman et al (2014), The Lewin Group (2012), and Deloitte Access Economics calculations.

The total cost of aids, equipment and modifications are estimated to be \$66.2 million in Australia in 2015. This is equivalent to \$31,598 per person with MND.

The costs of aids and equipment are substantial. It is important to note that these costs are likely to vary substantially by person depending on the progression of their MND. It is also likely that these costs would vary by location. For example, non-invasive ventilation – which can cost between \$150 and \$375 per month – is fully subsidised by the state government in Victoria, while people accessing these services can be expected to pay up to 20% of the cost in NSW. The NSW MND Association assists with these costs by reimbursing \$100 per month, plus 50% of the cost of a mask – which is typically \$250 to \$300 (CPAP Australia, 2015). Therefore, the burden of these costs falls on different payers depending on local policy and guidelines, and their ability to pay.

7.1.1 Use of specific aids and modifications

In preparing this report, a number of studies were located which reported on the use of specific aids and modifications in people living with MND. The scope of these studies is too broad to be included in the calculations of costs, although they provide insight into the use of specific aids and modifications.

In the US, 27% of people with MND use non-invasive ventilation and 11% use invasive ventilation (The Lewin Group, 2012). This is similar to another study in the US which found that 38% of those surveyed were using ventilators (Ward et al, 2010). The users in this survey were possibly more severe than samples found in Australia (Ng and Khan, 2011), although this is indicative of the amount of people that will require ventilation.

Krivickas et al (1997) found that a substantial proportion of people with MND received ventilatory support (20%), percutaneous endoscopic gastrostomy tube (25%), had assistive devices for mobility (63%) or had home equipment (64%). This cohort had moderate disability and is similar in characteristics to a cohort in an Australian study (Ng and Khan, 2011). The use of these devices increased substantially with factors of severity.

van Teijlingen et al (2001) reported on the service use and needs of people with MND in a Scottish cohort. The study conducted face-to-face interviews with 153 people on the caseload of MND advisors. These interviews found that 56% of people with MND used manual wheelchairs, 26% used powered wheelchairs, and 26% use other mobility aids such as walkers, canes and crutches.

A survey of members of the MND Association of Western Australia (Giles and Lewin, 2008), reported that 14.8% had no trouble walking, 16.7% had trouble walking but did not use aids, and the remaining 68.5% used varying aids in and out of home.

This study also reported that 77% (43/56) of people with MND have some level of equipment needs. The type of equipment required was not specified further. This survey also included questions surrounding home modifications – finding that 71% of people with MND had made changes to their existing home, while 25% had moved to a new home as a result of their condition. Data indicated that smaller size, increased accessibility, and less maintenance were some key reasons for their move.

A survey of people with MND in the US found that 88% (109/124) were required to move from their home or make modifications to their home (The Lewin Group, 2012). Similarly, this study also reported that 86% (107/124) of people with MND had made modifications to their vehicle, or purchased a new vehicle.

Gladman et al (2014) interviewed people with MND in Canada about the costs associated with MND since the time of diagnosis. This study collected all costs information associated with usage, and collected receipts where possible. Of all people surveyed, 92% incurred costs associated with medical equipment, 92% incurred costs associated with mobility aids (including modifications to their car), and 90% report incurring costs associated with home renovations.

Table 7.2 presents a summary of the use of various types of aids and modifications found in the literature.

Table 7.2: Use of specific aids and modifications

Type of aid, equipment or modification	Detailed type of aid	Usage	Source
Mobility	Manual wheelchair	56%	van Teijlingen et al 2001
	Powered wheelchair	26%	van Teijlingen et al 2001
	Other aids (walkers, canes, crutches etc.)	26%	van Teijlingen et al 2001
	Any mobility aid	63%	Krivickas et al 1997
	Any mobility aid	69%	Giles and Lewin 2008
	Any mobility aid (including car)	92%	Gladman et al 2014
Medical	Ventilator	20%	Krivickas et al 1997
	Ventilator	38%	The Lewin Group 2012
	Ventilator	38%	Ward et al 2010
	Percutaneous endoscopic gastrostomy tube	25%	Krivickas et al 1997
	Any medical	92%	Gladman et al 2014
Home modification	Any modification or moved	71%	Giles and Lewin 2008
	Any modification or moved	88%	The Lewin Group 2012
	Any modification or moved	90%	Gladman et al 2014
Car modification	Any modification	86%	The Lewin Group 2012

The literature outlined in Table 7.2 shows considerable usage of aids and modifications by people with MND. The majority of people use mobility aids and have had to either modify their home or move homes. Further, there are substantial costs associated with medical equipment with 20%-38% of people with MND using ventilators and as many as 25% using assistive medical equipment for feeding.

7.2 Formal care, accommodation and travel costs

It is common for people with MND to receive (or incur costs associated with) formal care, accommodation and travel cost support in addition to the informal care support discussed in section 6.2.

7.2.1 Formal care

Formal care can include help with childcare, housekeeping, gardening, shopping and private nursing that is not covered by private health insurance or the government. This additional assistance can help people with MND to remain living at home. These costs are out-of-pocket expenses borne by the individual and their family, although it is possible that some government assistance is provided through programs such as home assistance programs as discussed in section 7.3.4. It is possible to estimate the cost of formal care for people with

MND by establishing how many people with MND receive formal care support and the number of hours each person receives. A literature search was undertaken to establish these parameters.

Chiò et al (2006) in a review of caregiver time found that people with MND, on average (weighted by participants), required 102 minutes of care each day from paid caregivers, or 10.2 hours of care each week. This was additional to care already provided by informal carers.

In a Canadian study, personal support workers were required for anywhere between 0 and 68 hours per week, while the mean time required was 14.3 hours a week (Gladman et al, 2014).

In Australia, a survey of people with MND conducted in Western Australia found that 32% of people with MND received formal support, and these people received 4.5 hours of home care support each week (Giles and Lewin, 2008c).

In a German setting, 37% of people with MND receive formal care services (Schepelmann et al, 2010). This study also indicated that people with MND received an average of 12 hours of formal care each week.

Across these studies, the average formal care required per week was 10.7 hours each week, which is multiplied by the hourly cost of services provided in the formal care sector to estimate the costs of formal care. Deloitte Access Economics (2015) estimated that the cost of formal care is \$31.36 per hour of care in 2015 (Deloitte Access Economics, 2015).

It is estimated that 35% of people with MND receive formal care services – the average of Giles and Lewin (2008c) and Schepelmann et al (2010). Assuming that these proportions are still representative in 2015, this indicates that 673 people with MND received formal care services in 2015.

There are estimated to be 402,278 hours of formal care provided to people with MND in Australia in 2015. **The total costs of formal care are estimated to be \$12.6 million in 2015, or \$6,025 per person.**

This is similar to the formal care provided in the US, where The Lewin Group (2012) found that professional caregiving cost \$4,570 per person with MND, in 2010 US dollars. Converted to Australian dollars using purchasing power parity and inflated to 2015, professional caregiving cost \$7,724 per person with MND – slightly higher than the estimated \$6,026 per person in Australia.

7.2.2 Travel and accommodation costs

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

No data was found that considered these costs for people with MND and their families. Studies by van der Steen (2009), The Lewin Group (2012) and Larkindale et al (2013) included travel costs, although they were not identified separately. One study separately identified travel costs, but found that it only cost 10 euros annually on average (Schepelmann et al, 2010). Consequently, as it was not possible to separately identify the use of travel and accommodation costs in Australia, these costs are not included in this report.

7.3 Government programs

There are a range of government programs that support people with MND and their families with everyday living. This can include respite services for carers, palliative care services for end-of-life care, and home assistance programs which include packages for a range of support items such as formal care. The NDIS is another government program that also aims to provide support to people with MND to access services they require.

7.3.1 Palliative care

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

Palliative care costs can be substantial. A large proportion of palliative care services are delivered in hospital and are not considered additional to the health system costs estimated in section 5.1. Consequently, the estimated palliative care expenditure is not attributed to the total expenditure due to MND in Australia.

Data from the AIHW (2013) shows that 471 palliative care separations were listed with MND as the principal cause. Applying age and gender demographic changes, there were estimated to be 518 palliative care separations for people with MND in 2015. To triangulate this data, Aoun et al (2010) found that 52% of neurodegenerative conditions in South Australia received palliative care. Applied to deaths in people with MND (total causes of 833 in 2015), this would indicate that approximately 430 people with MND received palliative care this year. Approximately 42% of all deaths occurred at home.

IHPA (2014) estimates that the average cost of palliative care per day was \$1,052 in 2011-12, which is estimated to be \$1,126 in 2014-15 after inflating using CPI. The average length of stay for all conditions was 12.0 days in 2010-11 (the latest data available). Applying the average length of stay (12 days), and the cost of palliative care per day (\$1,126) to the total admissions due to MND (estimated 518 in 2015), **it is estimated that the total cost of palliative care in hospital settings was \$7.0 million in 2015.**

7.3.2 National Respite for Carers Program

Respite for carers of people with MND is often required when:

- the carer is undergoing hospital in-patient treatment;
- the burden of caring psychologically overwhelms the carer or person with MND;

- home modifications is being undertaken; and/or
- the carer needs time to shop, socialise, or undertake recreational activities as a break from the burden of caring.

The National Respite for Carers Program (NRCP) enhances the quality of life for older people, people with disabilities, and their carers. The NRCP provides services for at-home carers of people who are unable to look after themselves due to frailty, disability, or chronic illness (most people with MND would fall into this category). There are four components of the NRCP (DSS¹², 2014):

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

Funding for the NRCP was \$212.3 million in 2013-14, which assisted 108,197 people in 2013-14 (Steering Committee for the Review of Government Service Provision, 2015). The average cost of accessing respite care was \$1,962 per carer in 2013-14, which inflated to 2015, is estimated to be \$1,992 in 2015.

The 2012 SDAC survey collects information on whether carers have accessed respite care in the past three months (ABS, 2013b). While the survey did not contain data on carers of people with MND, it found that 12.7% of carers for people with Parkinson's disease accessed respite care. It is plausible that carers of people with MND would access respite care in similar (or higher) amounts than carers of Parkinson's disease do, due to the rapid progression of MND. This may be a conservative estimate; however, no data specific to MND is available.

Applying the rate of carers accessing respite care (12.7%) against the estimated number of carers as in section 6.2, there were estimated to be 233 carers of people with MND that accessed respite care in 2014-15. **The total NRCP expenditure for people with MND is estimated to be \$0.46 million in 2014-15.**

7.3.3 National Disability Insurance Scheme

The NDIS supports people with disability where that disability prevents participation in everyday activities. NDIS plans are designed to help people with disability achieve goals such as independence, community involvement, education, employment and health and wellbeing. The NDIS is designed to give more certainty, choice and control surrounding supports for people with disability (NDIA¹³, 2014). The NDIS commenced in July 2013, with a number of trial sites around Australia. The roll out of the full scheme is expected to

¹² Department of Social Services.

¹³ National Disability Insurance Agency.

commence from July 2016 (NDIA, 2014a). All people who are able to access support under the current National Disability Agreement are covered by the NDIS, and the NDIS is intended to replace the current system (Buckmaster, 2013).

At the end of 2014-15, there were a limited number of trial sites for the NDIS that would cover people with MND, and expenditure from the NDIS was small as a result. The rate of people currently accessing the NDIS would differ by location – for example, some trial sites currently only allow for children to access the NDIS. As such, the cost comparisons made in chapter 11 are limited by the relative infancy of the NDIS (in terms of both reporting and access to the scheme).

A special request was submitted to the NDIA to determine how many people with MND currently receive NDIS plans. As of 30 June 2015, there were a total of 40 people with MND receiving NDIS plans. The average annual cost of these packages was \$64,000, which indicates that **the current total cost of MND to the NDIS is \$2.56 million**.

This is substantially higher when compared with ‘other neurological’ diseases, which is the category that contains MND. The average annual cost of a plan was approximately \$46,060 for this category (NDIA, 2015). This indicates that MND requires substantially more support than the broad level category of ‘other neurological’.

7.3.4 Other government programs

There are a number of other government programs that people with MND and their families may receive assistance from. For example, some people with MND may receive assistance through the Disability Employment Services (DES) and Employment Assistance and Other Services (EAOS) programs, enabling them to remain at work. There are also home assistance programs that enable people with MND to remain living at home.

7.3.4.1 DES and EAOS

DES began in 2010 and targets support at individuals with a substantially reduced capacity for work who are assessed as needing specialist support to build capacity or maintain employment. The objective of the program is to help individuals with disabilities, injuries or health conditions to secure and maintain employment. While DES helps individuals to find work, the EAOS program targets support at employers to employ individuals with disabilities. There are no publicly available data for either program that detail how many people with MND, if any, are assisted by these programs. Consequently, no estimate of the expenditure on people with MND can be provided.

7.3.4.2 Home assistance programs

There are other government programs that provide assistance to frail older people and to people with a disability, aimed at allowing them to stay in their homes longer and preventing premature admissions to residential aged care. These are known as home assistance programs and include Home and Community Care (HACC) packages and Home Care packages. Unfortunately, there was no information available on the use of these programs by people with MND, and costs associated with these programs were unable to be included.

7.3.5 Summary of government programs

There are a considerable range of services provided by government to assist people with MND and their families. It was only possible to determine the expenditure for people with MND in two of these programs (where expenditure is not considered elsewhere) – the NRCP and NDIS. **The total expenditure for government programs was estimated to be \$3.0 million in 2015.**

7.4 Funeral expenses

The additional cost of funerals borne by family and friends of people with MND is based on the number of deaths due to MND. However, everyone must die eventually, and thus incur funeral expenses, so the additional cost imposed by MND is the brought forward funeral cost adjusted for the likelihood of dying anyway. The Australian Securities and Investment Commission (2015) reports that average funeral costs likely range between \$4,000 and \$15,000 in Australia. Taking the midpoint value (\$9,500), **the discounted value of funeral costs associated with premature deaths was \$1.8 million, or \$2,376 per death due to MND.**

7.5 Summary of other indirect costs

Overall, **other financial costs for people with MND were estimated to be \$83.6 million in 2015, or \$39,921 per person living with MND.** It is not surprising that the main cost component was aids, equipment and modifications, followed by formal care. That said, there may be considerably more expenditure providing assistance to people with MND by government programs, although some programs were unable to be allocated (home assistance and employment support programs).

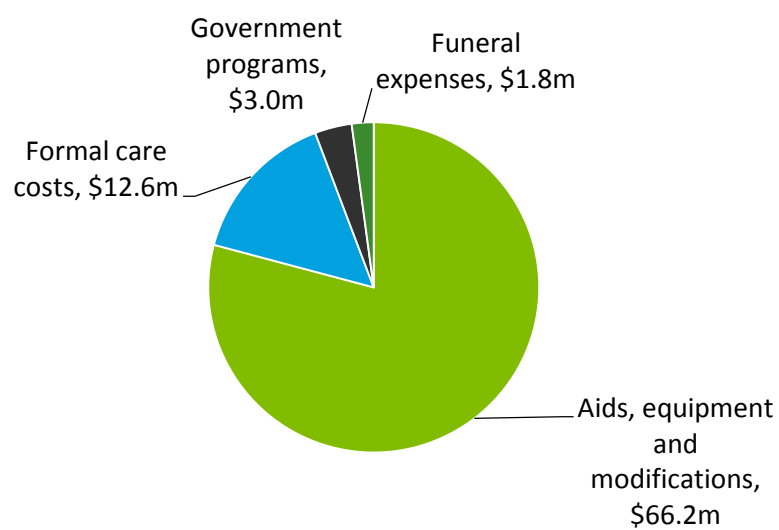
The estimated expenditure associated with other financial costs is outlined in Table 7.3. Chart 7.1 presents the other financial costs associated with MND graphically.

Table 7.3: Other financial costs of MND, 2015

Financial cost	Annual cost (\$m)	Per person (\$)
Aids, equipment and modifications	66.2	31,598
Formal care	12.6	6,025
Government programs	3.0	1,444
Funeral expenses	1.8	854
Total	83.6	39,921

Source: Deloitte Access Economics' calculations.

Chart 7.1: Other financial costs of MND, 2015



Source: Deloitte Access Economics calculations.

8 Transfers

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

Key findings:

- Around \$8.7 million, or \$4,143 per person with MND, will be paid via welfare payments to people with MND and their carers in 2015.
- Government lost \$82.3 million in tax revenue as a result of MND's negative impact on employee productivity, and the amount of hours of informal care that will be provided to people with MND. This is equal to \$39,295 per person with MND
- The DWL associated with health system costs borne by government, lost taxes, welfare payments and other costs borne by government is estimated to be \$41.6 million in 2015, or \$19,876 per person with MND.

8.1 Income support for people with MND

The main source of income support for people aged less than 65 years is the Disability Support Pension (DSP). People aged 65 years and older are eligible for the Age Pension, however, following, Deloitte Access Economics' standard methodology, this section only considers people aged less than 65 who are receiving the DSP.

DSP is an income support payment for people who are unable to work for 15 hours or more per week at or above the relevant minimum wage, independent of a Program of Support, due to permanent physical, intellectual or psychiatric impairment. A DSP claimant must be aged 16 years or over and under the age pension age at date of claim. However, once a person is receiving the DSP they will continue to do so beyond the age pension age (Department of Human Services, 2015a).

A special data request was submitted to the DSS to obtain information on the number of people who received the DSP as a result of their MND. **Across all people with MND aged 15-64 years, there were 263 receiving the DSP** as at 27 March 2015, which represents approximately 55% of all people with MND in this age cohort.

According to the DSS annual report, as of June 2014, there were 830,454 people in Australia who were listed to have received the DSP, at a total cost of \$16.11 billion over 2013-14, or \$19,387 per person (DSS, 2014). This amount was adjusted to 2015 using CPI, which results in a per person cost of \$19,680. Using this estimate, approximately \$5.1 million will be paid in DSP payments to people with MND in 2015.

However, it is likely that some of these people would have received DSP payments even in the absence of MND, which must be netted out to estimate the additional welfare payments due to MND. A University of Melbourne study (Tseng and Wilkins, 2002) estimates that the 'reliance' of the general population (aged 15-64 years) on income support is 10.2% for males and 14.9% for females. Weighting these results by the number of males and females with MND who accessed the DSP in 2015, the weighted average is 13.2% (Table 8.1).

Table 8.1: Reciprocity rates by payment type for DSP

	Males (%)	Females (%)	Weighted average (%)
Other pensions (includes DSP)	10.2	14.9	13.2

Source: Tseng and Wilkins (2002); Deloitte Access Economics calculations.

Therefore, **an estimated \$4.4 million in additional DSP payments was paid to people of working age with MND in 2015**. This is an estimated \$3,204 per person living with MND, or \$16,828 per recipient of DSP living with MND.

8.2 Income support for carers of people with MND

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.¹⁴
- **Carer Allowance** is a non-means tested income supplement for people who provide daily care to a person with a long-term disability or health condition.

Information on income support for carers of people with MND was specially requested from DSS. Data is based on recipients caring for a person with MND as the primary medical condition. The average weekly payment and the number of recipients were recorded as at 27 March 2015, and are reproduced in Table 8.2. There were estimated to be 208 carers receiving Carer Payment, and 390 carers receiving Carer Allowance.

Table 8.2: Cost of income support to carers, 2015

	Average weekly payment (\$)	Number of recipients	Total cost per annum (\$m)
Carer Payment	281.93	208	3.0
Carer Allowance	59.10	390	1.2
Total			4.2

Source: DSS special request.

¹⁴ The person with MND must also be in receipt of an income support payment.

As shown in Table 8.2, **income support for carers of people with MND was estimated to be \$4.2 million in 2015**. This is an estimated \$2,029 per person living with MND.

8.3 Newstart Allowance

People with MND may also receive payments to assist them with returning to work. The Newstart Allowance is paid to people who are aged 22 years or over and who have not reached the age pension age. Recipients are also unemployed and looking for work.

A special request was submitted to DSS to determine how many people with MND receive Newstart Allowance. For confidentiality reasons, the data was suppressed, meaning that there were **less than 20 people with MND receiving Newstart Allowance**. Consequently, no estimates of the total payments to people with MND are made here.

8.4 Taxation revenue

People with MND 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.

- people with MND lost \$157.6 million in wage income due to reduced productivity in their employment, and premature death;
- carers lost \$68.5 million in wage income due to caring for a person with MND; and
- employers lost \$5.2 million in productivity on account of absenteeism of the person with MND, lost management time to manage the absenteeism, and direct worker hiring and retraining costs.

Consistent with Deloitte Access Economics' standard methodology, in terms of allocating these losses to either personal income or company income, only the employer losses were included as lost company revenue, with the remainder allocated as lost personal income in one form or another. In 2015, the **average personal income tax rate is 22.8% and the average indirect tax rate is 13.0%**, based on the Deloitte Access Economics Macroeconomic model. Furthermore the vast majority of company income is distributed to domestic shareholders (as franked dividends) and thus the income is charged at the relevant personal tax rate.

Together, these calculations generate a **total loss of tax revenue of \$82.3 million in 2015**. This represents taxation lost that must be collected from other parts of the economy (e.g. those that remain in the workforce) given no change in expenditure. That is, small tax changes are unlikely to change the level of demand for expenditure.

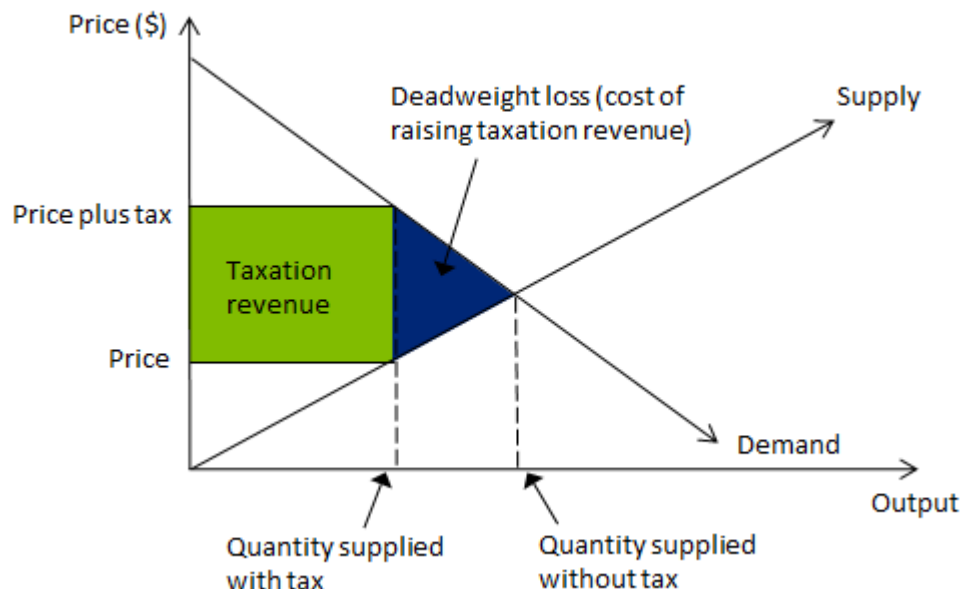
8.5 Deadweight loss of taxation payments and administration

Transfer payments (government payments and taxes) are not a net cost to society, as they represent a shift of consumption power from one group of individuals to another in society. If the act of taxation did not create distortions and inefficiencies in the economy, then

transfers could be made without a net cost to society. However, these distortions do impose a DWL on the economy.

DWL is the loss of consumer and producer surplus, as a result of the imposition of a distortion to the equilibrium (society preferred) level of output and prices (Figure 8.1). Taxes alter the price and quantity of goods sold compared to what they would be if the market were not distorted, and thus lead to some diminution in the value of trade between buyers and sellers that would otherwise be enjoyed. The principal mechanism by which a DWL occurs is the price induced reduction in output, removing potential trades that would benefit both buyers and sellers. In a practical sense, this distortion reveals itself as a loss of efficiency in the economy, which means that raising \$100 dollars of revenue requires consumers and producers to give up more than \$100 of value.

Figure 8.1: Deadweight loss of taxation



Source: Deloitte Access Economics.

In line with Deloitte Access Economics' standard methodology, **the rate of DWL used in this report is 27.5 cents per \$1 of tax revenue raised, plus 1.25 cents per \$1 of tax revenue raised for Australian Taxation Office administration** (Productivity Commission, 2003). The DWL rate is applied to:

- lost tax revenue from foregone earnings of people with MND, their carers and employers (which must be raised from another source);
- welfare payments made to people with MND and their carers; and
- government services provided (for example, 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.

8.6 Transfer costs summary

Using the rate of DWL (28.75%), the expected total DWL associated with MND is estimated to be \$41.6 million in 2015, or \$19,876 per person with MND. This is summarised in Table 8.3.

Table 8.3: Components of deadweight loss, 2015

Component of deadweight loss	2015 (\$million)
Health system costs borne by government	50.8
Lost taxes	82.3
Welfare payments	8.7
Other costs borne by government*	3.0
Total transfers	144.8
Rate of deadweight loss	28.75%
Resulting deadweight loss	41.6

Source: Deloitte Access Economics calculations.

Note: * these include the cost of government programs including the NRCP and the NDIS.

9 Burden of disease

This chapter adopts the ‘burden of disease’ methodology in order to quantify the impact of MND on wellbeing. The approach is non-financial, where pain, suffering and premature mortality are measured in terms of disability-adjusted life years (DALYs).

Key findings:

- In 2015, the total DALYs arising from MND are 10,356, comprising of 8,953 years of life lost due to premature death, and 1,403 years of healthy life lost due to disability.
- The associated economic burden totals \$1.94 billion.

9.1 Valuing life and health

Life and health can be measured in terms of DALYs, where 0 represents a year of perfect health and 1 represents death. The DALY approach has been adopted and applied in Australia by the AIHW. Mathers et al (1999) separately identify the premature mortality (years of life lost due to premature death - YLL) and morbidity (years of healthy life lost due to disability - YLD) associated with disability due to a condition:

$$\text{DALYs} = \text{YLLs} + \text{YLDs}$$

In any year, the disability weight of a health condition reflects a relative health state. For example, the disability weight for a broken wrist is 0.18, which represents losing 18% of a year of healthy life because of the inflicted injury.

The burden of disease as measured in DALYs can be converted into a dollar figure using an estimate of the **value of a statistical life** (VSL). The VSL is an estimate of the value society places on an anonymous life. To overcome issues in relation to placing a dollar value on a human life, a non-financial approach to valuing human life is used.

As DALYs are enumerated in years of life rather than in whole lives it is necessary to calculate the **value of a statistical life year (VSLY)** based on the VSL. This is done using the formula:¹⁵

$$\text{VSLY} = \text{VSL} / \sum_{i=0, \dots, n-1} (1+r)^i$$

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

¹⁵ The formula is derived from the definition:

$$\text{VSL} = \sum \text{VSLY}_i / (1+r)^i \text{ where } i=0,1,2,\dots,n$$

where VSLY is assumed to be constant (i.e. no variation with age).

The Department of Prime Minister and Cabinet (2014) provided an estimate of the ‘net’ VSLY (that is, subtracting financial costs borne by individuals). The VLSY was estimated to be \$151,000 in 2007, which inflates to around **\$187,500 in 2015 dollars**.

9.1 Estimating the burden of disease due to MND

The disability weight for MND is essential to estimate the burden of disease due to MND in Australia. The most recent estimate of the disability weight is provided by the AIHW (Begg et al, 2007), which estimated a **disability weight of 0.67**. The disability weight was based on the progressive phase of multiple sclerosis – a condition with similarities to MND – found in a Dutch burden of disease study (Stouthard et al, 1997).¹⁶ YLDs are estimated using the disability weight of 0.67 multiplied by the number of people with MND as estimated in section 3.1.

The YLLs are based on the number of deaths from MND (section 3.2), and the years of expected remaining life at the age of death from standard life tables published by the ABS (ABS, 2014a). A discount rate of 3% has been applied to the calculations (a standard rate in discounting life), and no age weighting has been applied.

Overall, people with MND experienced (Table 9.1):

- 1,403 YLDs, or 0.67 YLDs per person with MND;
- 8,953 YLLs, or around 4.3 YLLs per person with MND; and
- 10,356 DALYs overall, or around 4.9 DALYs per person with MND.

¹⁶ At the time of writing this report, the AIHW is in the process of updating the burden of disease estimates for Australia and for the Aboriginal and Torres Strait Islander population, with results to be published in early 2016. The study is building on methodological developments in recent global burden of disease studies, which will be tailored to the Australian context. This will potentially include a revision to the disability weight(s) used for MND. At this stage, the AIHW is planning to use disability weights from the 2013 Global Burden of Disease study, which was published in Vos et al (2015). However, the 2013 Global Burden of Disease study does not provide an estimate of the disability weight for MND specifically. Rather, and if a similar approach is taken, the AIHW may use the disability weights for multiple sclerosis which are presented by mild, moderate and severe with disability weights of 0.183, 0.463 and 0.719 respectively. As it is not clear what approach the AIHW will take at this stage, the disability weight of 0.67 previously provided by the AIHW (Begg et al, 2007) is maintained for this report.

Table 9.1: Burden of disease from MND by age and gender, 2015

Age	YLDs	YLLs	DALYs	DALYs (\$m)
Male				
0-44	91	329	421	78.9
45-54	156	680	836	156.7
55-64	250	1,352	1,602	300.4
65-74	204	1,485	1,689	316.6
75-84	117	1,038	1,155	216.5
85+	30	165	195	36.5
Total	846	5,050	5,896	1,105.6
Female				
0-44	62	124	186	34.9
45-54	103	224	327	61.4
55-64	155	1,207	1,362	255.4
65-74	179	1,367	1,546	289.9
75-84	51	813	864	161.9
85+	6	168	174	32.5
Total	556	3,903	4,459	836.1
Person				
0-44	153	454	607	113.8
45-54	259	904	1,163	218.0
55-64	405	2,560	2,964	555.8
65-74	383	2,852	3,235	606.6
75-84	168	1,851	2,018	378.5
85+	36	333	368	69.1
Total	1,403	8,953	10,356	1,941.7

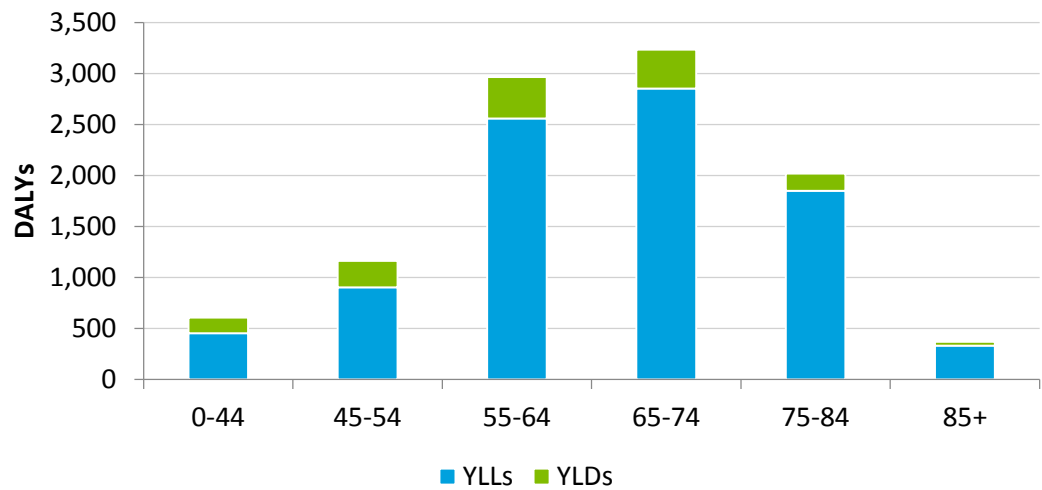
Source: Deloitte Access Economics' calculations.

The economic value of the burden of disease from MND is estimated to be \$1.94 billion in 2015 – which is predominately due to the YLLs associated with MND.

While those aged between 65-74 years bore the most burden out of all the age groups (Chart 9.1), DALYs per person with MND increase with age, with the exception of the 85+ age category (Chart 9.2). This finding of DALYs per person increasing with age seems counterintuitive given that YLLs comprise a large proportion of DALYs due to MND, and that a death at a younger age incurs more YLLs than a death at an older age.¹⁷ However, lower mortality rates in younger age groups mean that there are fewer deaths per prevalent case, which reduces the YLLs per person (and thus DALYs per person) in younger age groups. This effect outweighs the effect of YLLs per death being higher in younger age groups.

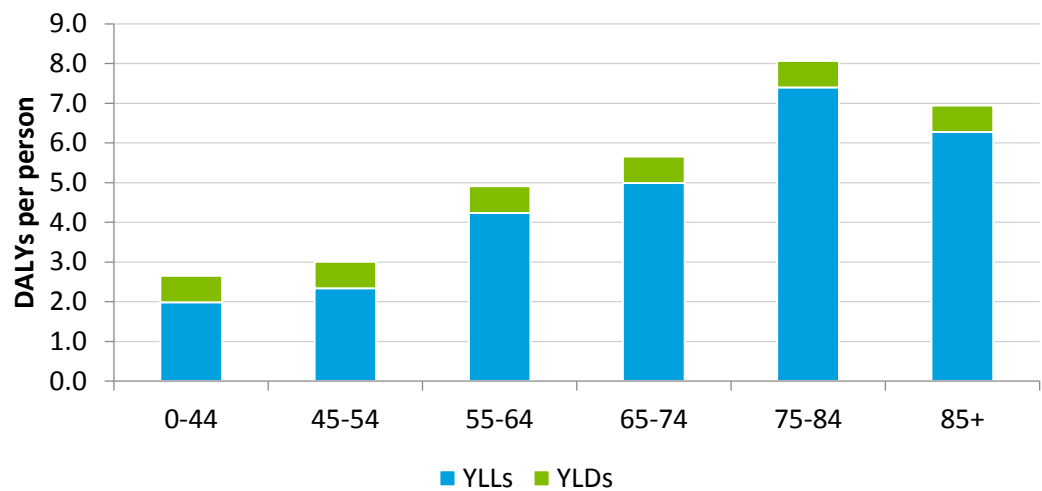
¹⁷ A person who dies at a younger age foregoes more years of potential life than a person who dies at an older age.

Chart 9.1: Total disability-adjusted life years by age, 2015



Source: Deloitte Access Economics' calculations.

Chart 9.2: Disability-adjusted life years per person with MND by age, 2015



Source: Deloitte Access Economics' calculations.

10 Summary of costs

This chapter summarises the total costs of MND from chapters 5 to 9, and performs sensitivity analysis on these estimates.

Key findings:

- The total cost of MND in Australia is \$2.37 billion in 2015, comprised of \$430.9 million in economic costs and \$1.94 billion in burden of disease costs. This equates to over \$1.1 million per person in both economic costs and burden of disease costs.
- Sensitivity analysis on the prevalence estimate gives a higher and lower range for the cost estimate of \$2.42 billion and \$2.33 billion, respectively.

10.1 Total costs of MND

The total cost of MND is estimated to be \$2.37 billion in 2015. The breakdown of these costs is provided in Table 10.1. Costs associated with the burden of disease imposed by MND are considerable, and are largely driven by the value of the loss of life due to premature mortality. The economic costs associated with MND are estimated to be \$430.9 million in 2015, of which productivity costs are estimated to be 38% of the total. Chart 10.1 shows the share of each cost to the total economic costs (excluding burden of disease costs).

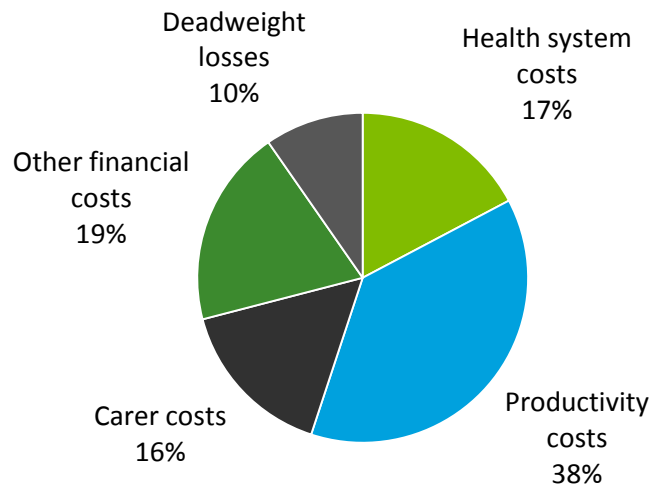
Table 10.1: Total costs of MND, 2015

Component	Value (\$m)	Per person (\$)
Health system costs	74.4	35,510
Productivity costs	162.8	77,776
Carer costs	68.5	32,728
Other financial costs	83.6	39,921
Deadweight losses	41.6	19,876
<i>Total economic costs</i>	<i>430.9</i>	<i>205,812</i>
<i>Total burden of disease costs</i>	<i>1,941.7</i>	<i>927,355</i>
Total costs	2,372.6	1,133,167

Source: Deloitte Access Economics calculations.

Note: numbers may not add due to rounding.

Chart 10.1: Economic costs associated with MND in Australia, 2015



Source: Deloitte Access Economics calculations.

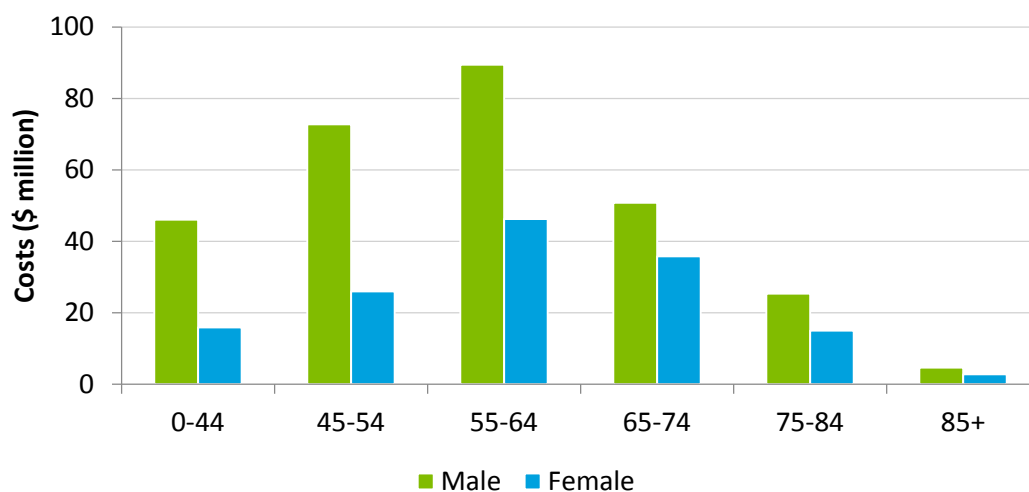
The total costs by age and gender are shown in Table 10.2, Chart 10.2 (economic costs) and Chart 10.3 (burden of disease). Males of working age bear the highest costs associated with MND, due to the high productivity losses associated with these age groups.

Table 10.2: Total costs by age and gender, 2015

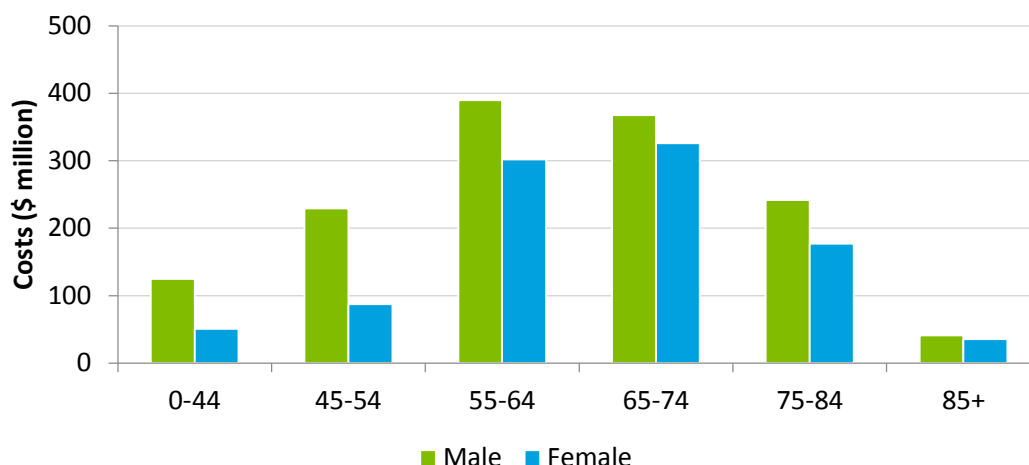
Total costs	Economic cost (\$m)	Burden of disease (\$m)	Total cost (\$m)
Male			
0-44	46.0	78.9	124.9
45-54	72.7	156.7	229.4
55-64	89.4	300.4	389.8
65-74	50.8	316.6	367.5
75-84	25.4	216.5	241.9
85+	4.7	36.5	41.3
Total male	289.1	1,105.6	1,394.7
Female			
0-44	16.0	34.9	50.9
45-54	26.0	61.4	87.3
55-64	46.2	255.4	301.7
65-74	35.8	289.9	325.8
75-84	15.0	161.9	177.0
85+	2.8	32.5	35.3
Total female	141.8	836.1	977.9
Person			
0-44	62.0	113.8	175.8
45-54	98.7	218.0	316.7
55-64	135.7	555.8	691.4
65-74	86.7	606.6	693.2
75-84	40.4	378.5	418.9
85+	7.5	69.1	76.6
Total person	430.9	1,941.7	2,372.6

Source: Deloitte Access Economics calculations.

Note: numbers may not add due to rounding.

Chart 10.2: Total economic costs by age and gender, 2015

Source: Deloitte Access Economics calculations.

Chart 10.3: Total burden of disease by age and gender, 2015

Source: Deloitte Access Economics calculations.

10.2 Sensitivity analysis

As noted in section 3.1.3, there are a wide range of estimates for the prevalence of MND internationally. The international literature presented a range between 1 and 11 people with MND per 100,000 population. As there are a small number of people with MND, it is difficult to accurately estimate prevalence due to sampling errors. The sensitivity analysis conducted here recognises the fact that there may be small errors in the data used to derive the prevalence estimates.

In the base case approach (section 3.1), there are estimated to be 2,094 Australians living with MND in 2015 – or 8.7 per 100,000 people. The approach used to derive this estimate was based on AIHW GRIM book data specifically for deaths in people with MND, and MND Association registration data that records both deaths in people with MND and the number of people registered that have MND. The baseline assumption was that the ratio of deaths recorded by MND Australia in their registration data accounted for 60% of total deaths in people with MND. Based on the literature discussed in section 3.2, it is estimated that deaths data can be incorrectly coded in up to 10% of deaths, and this can be in either direction. For example, it has been found that up to 10% of deaths in people with MND do not have MND listed as either a primary cause of death or an associated cause of death, while it has also been estimated that up to 10% of deaths have been incorrectly attributed to MND.

Thus, the first sensitivity analysis scenario assumes that there may be 10% more deaths in people with MND overall than the AIHW GRIM book data shows (section 10.2.1), and the second sensitivity analysis scenario assumes that there may be 10% fewer deaths in people with MND overall (section 10.2.2)

10.2.1 Deaths higher by 10%

As noted in section 3.2, the average of MND cause of death data in US and UK studies reported in Marin et al (2011) and Paulukonis et al (2015) suggests that approximately 10%

of known deaths due to MND do not have MND listed as an underlying or associated cause. This indicates that deaths in people with MND may as much as 10% higher than is actually reported.

The baseline assumption was that the ratio of deaths recorded by MND Australia in its registration data accounted for 60% of total deaths in people with MND. Revising this estimate up by 10%, this scenario assumes that MND Australia captures 54% of the total deaths, and therefore captures 54% of the total prevalence in Australia.

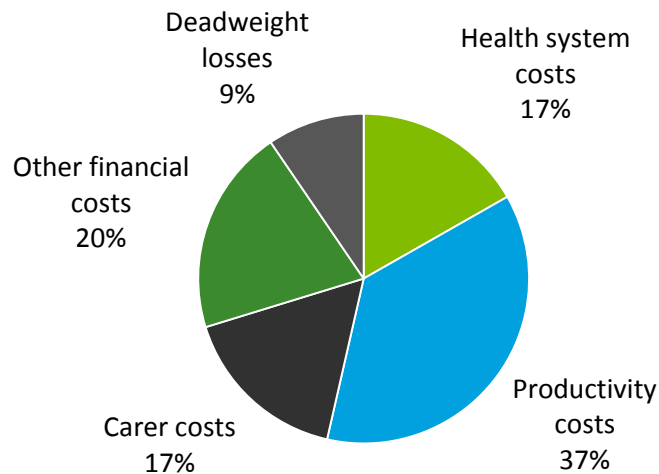
Applying this ratio to the prevalent cases captured by MND Australia, **the total prevalence under this scenario is estimated to be 2,303 in Australia in 2015 – a prevalence rate of 9.6 per 100,000 Australians**. That is, prevalence is higher by 10%.

This prevalence is then used as the basis for the calculations in chapter 5 through to chapter 9. **The total costs under this scenario are estimated to be \$2.42 billion, or \$1.05 million per person**. Table 10.3 and Chart 10.4 present the breakdown of these costs. The overall costs are estimated to be 2% higher under this scenario.

Table 10.3: Total costs of MND (deaths 10% higher), 2015

Component	Value (\$m)	Per person (\$)
Health system costs	75.6	32,834
Productivity costs	166.3	72,205
Carer costs	75.4	32,728
Other financial costs	91.5	39,732
Deadweight losses	42.9	18,637
<i>Total economic costs</i>	<i>451.7</i>	<i>196,136</i>
<i>Total burden of disease costs</i>	<i>1,968.0</i>	<i>854,471</i>
Total costs	2,419.7	1,050,607

Source: Deloitte Access Economics calculations.

Chart 10.4: Economic costs associated with MND in Australia, 2015

Source: Deloitte Access Economics calculations.

10.2.2 Deaths lower by 10%

As noted in section 3.2, the average of MND cause of death data in Paulukonis et al (2015) and Gil et al (2008) suggests that approximately 10% of deaths with MND as an underlying or associated cause are not directly due to MND. This indicates that deaths in people with MND may be as much as 10% lower than is actually reported.

The baseline assumption was that the ratio of deaths recorded by MND Australia in their registration data accounted for 60% of total deaths in people with MND. Revising this estimate up by 10%, this scenario assumes that MND Australia captures 66% of the total deaths, and therefore captures 66% of the total prevalence in Australia.

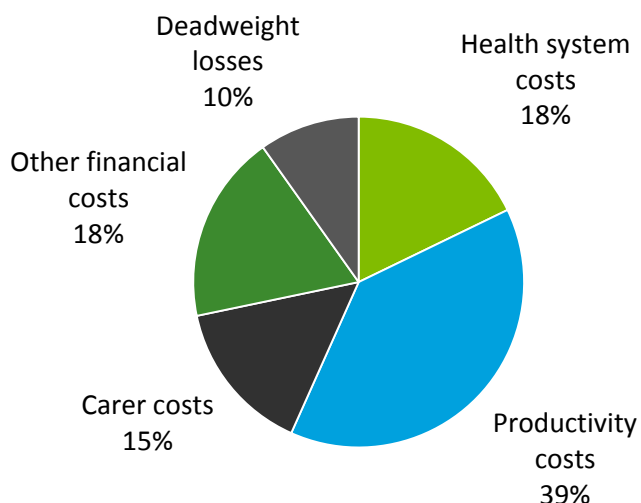
Applying this ratio to the prevalent cases captured by MND Australia, **the total prevalence under this scenario is estimated to be 1,884 in Australia in 2015 – a prevalence rate of 7.9 per 100,000 Australians.** That is, prevalence is lower by 10%.

This prevalence is then used as the basis for the calculations in chapter 5 through to chapter 9. **The total costs under this scenario are estimated to be \$2.33 billion, or \$1.23 million per person.** Table 10.4 and Chart 10.5 present the breakdown of these costs. The overall costs are estimated to be 2% lower under this scenario.

Table 10.4: Total costs of MND (deaths 10% lower), 2015

Component	Value (\$m)	Per person (\$)
Health system costs	73.1	38,782
Productivity costs	159.4	84,586
Carer costs	61.7	32,728
Other financial costs	75.7	40,152
Deadweight losses	40.3	21,391
<i>Total economic costs</i>	<i>410.1</i>	<i>217,638</i>
<i>Total burden of disease costs</i>	<i>1,915.4</i>	<i>1,016,436</i>
Total costs	2,325.5	1,234,075

Source: Deloitte Access Economics calculations.

Chart 10.5: Economic costs associated with MND in Australia, 2015

Source: Deloitte Access Economics calculations.

10.2.3 Summary of sensitivity analysis

Table 10.5 presents the upper and lower bound of the sensitivity analysis compared with the base case costs. The adjustment to prevalence has a minor impact on costs as a substantial proportion of costs are associated with deaths due to MND, which are independent of the estimated prevalence.

Table 10.5: Summary of sensitivity analysis

Lower sensitivity	Base case (\$m)	Upper impact on costs (\$m)	Lower impact on costs (\$m)
Total prevalence	2,094	2,303	1,884
Prevalence per 100,000	8.7	9.6	7.9
Health system costs	74.4	+1.3	-1.3
Productivity costs	162.8	+3.5	-3.5
Carer costs	68.5	+6.9	-6.9
Other financial costs	83.6	+7.9	-7.9
Deadweight losses	41.6	+1.3	-1.3
<i>Total economic costs</i>	<i>430.9</i>	<i>+20.8</i>	<i>-20.8</i>
<i>Total burden of disease costs</i>	<i>1,941.7</i>	<i>+26.3</i>	<i>-26.3</i>
Total costs	2,372.6	+47.1	-47.1

Source: Deloitte Access Economics calculations.

10.3 Comparison with cost estimates of other diseases

Estimates of the costs of other diseases to Australia have been collected and summarised in Table 10.6. Cost estimates have been taken from other Deloitte Access Economic reports and as such, can be accurately compared as a consistent methodology and approach was applied in each study.

Table 10.6: Cost estimates of other diseases

Year	Disease	Total cost (\$b)*	Cost per person (\$)
2011	Chronic kidney disease	1.3	758
2007	Allergies	35.4	8,670
2011	Sleep disorders	38.8	26,445
2009	Vision loss	18.7	32,646
2012	Eating disorders	73.4	80,289
2008	Chronic obstructive pulmonary disease	113.2	95,599
2013	Stroke	55.9	133,108
2015	MND	2.4	1,133,167

Source: Deloitte Access Economics.

Note: * costs have been expressed in 2015 dollars.

As shown in Table 10.6, per person costs of MND in Australia are estimated to be higher than for all other diseases. However, the total costs of MND in Australia are small compared to most other diseases given the relatively low prevalence.

11 Home care, aged care and the NDIS

This report has shown that there are considerable costs associated with caring for people with MND. Organisations such as MND Australia and the State MND Associations provide information, education, ongoing support, aids and equipment, and national and local advocacy to people with MND, which enables these people to remain living at home and to enjoy a better quality of life. So far, this report has outlined the costs of all care, regardless of the setting. This chapter outlines the various costs of MND care delivered in different settings with different providers.

Deloitte Access Economics was requested to compile the following estimates of the costs of care and management of MND, for comparison under alternative service delivery arrangements:

- the cost of staying at home (with MND association and community support) compared with the cost of staying in a residential aged care facility (RACF) (section 11.1);
- the cost of using an MND equipment loan service compared with the cost of equipment purchase under the NDIS (section 11.2);
- the cost of MND advisor support and advocacy compared with the cost of repeat NDIS planning (section 11.3); and
- estimates of the cost of disease to the NDIS and to the aged care system (section 11.4).

Key findings:

- The annual cost of staying at home was found to be more expensive (\$112,088) compared with the annual cost of staying in a residential aged care facility (\$78,631) – noting that these residential aged care costs are likely conservative.
- The cost of using an MND equipment loan service (\$19,625) is less expensive than the cost of equipment purchase under the NDIS (\$24,030).
- The annual cost of MND advisor support for a person with MND (\$2,865) is not fully recovered under the NDIS funding model for these services (\$2,257).
- Annual government costs of MND in the aged care system (\$8.3 million) are higher than government costs of MND in the NDIS (\$2.6 million) – noting that the NDIS is still in its infancy and so these costs will increase as more people with MND join the NDIS.

11.1 Home care compared with residential aged care

This report has shown that there can be substantial costs associated with staying at home (with MND Association and community support). Compared to the cost of staying in a

RACF, home care can be expensive as a person living with MND will require a number of changes to the home, cars and mobility aids for performing daily activities such as getting out of bed. Section 11.1.1 presents the costs associated with a RACF for a person with MND, while section 11.1.2 presents the costs associated with staying at home for a person with MND.

11.1.1 Costs of MND in residential aged care

There are no publicly available data that estimate the utilisation and costs of RACF services for people with MND. The best available data about people receiving residential aged care support was provided by MND Australia to Deloitte Access Economics. This data indicates that, of those people with MND registered with their State Associations, 11.0% were currently residing in a RACF (as at 30 June 2015). This implies that, of the estimated 2,094 people with MND in Australia in 2015, 229 are in a RACF.

There are two parties who pay for RACFs: government, and the people with MND (or their families). For government costs, the cost of aged care for people with MND was assumed to be the same as the average cost of aged care across all permanent aged care placements in 2013-14. Data from the Productivity Commission (Steering Committee for the Review of Government Service Provision, 2015) shows that expenditure on RACFs in 2013-14 was \$9.98 billion, and there were approximately 231,500 permanent residential aged care placements and 49,300 respite residential aged care placements. The average cost of RACF placements was approximately \$35,654 in 2013-14. The cost to government is estimated to be \$36,193 in 2014-15 (updated for CPI).

To compare the costs of staying in a RACF compared to staying at home, it is also necessary to estimate any contributions from the person with MND (or their family) to their residential aged care provider. The DSS website provides a calculator that estimates these contributions depending on the available assets that a person has (DSS, 2015a). The calculator requires income, homeowner status, financial and other assets, and debts as inputs into the calculator.

These inputs were collected from the ABS publication *Household Income and Wealth, Australia, 2013-14* (ABS, 2015f). It is assumed that the average person with MND will have similar financial wealth and assets as the general population. Further, as the average age of the person with MND in Australia is 60 years (section 3.1.2), the average household wealth statistics for the age group 55-64 were used from the ABS publication. The inputs used in the calculation were:

- average disposable income is estimated to be \$57,871;
- average non-financial assets are estimated to be \$620,100;
- average financial assets are estimated to be \$222,800; and
- the average debt is estimated to be \$70,000.

It is noted that this may overstate the actual wealth of families with a person with MND as the substantial productivity losses and use of aids and modifications may deplete their assets. However, due to the short duration of the disease, it is assumed that these assets will be similar to the general population.

Based on this information, it is estimated that the average person with MND will contribute \$47.86 in daily fees for items such as utilities, food and cleaning. The means-tested care fee is \$15.92 a day (although this may be higher depending on the care cost requirements of the person with MND).

Finally, it is assumed that the person with MND will pay the full accommodation payment of \$52.49 a day (DSS, 2014a). It is also possible that people with MND will request additional services such as subscription television services or a larger room. However, this analysis assumes that these additional costs are not incurred.

The costs associated with RACFs are presented in Table 11.1. The total costs for a person with MND to stay in a RACF are estimated to be \$78,631 per annum.

Table 11.1: Costs of staying in residential aged care

Costs of aged care	Per person (\$)
Government cost	36,193
Daily fees	17,469
Care fees	5,811
Accommodation costs	19,159
Total costs	78,631

Source: Deloitte Access Economics calculations; DSS 2015a.

11.1.2 Costs of staying at home

The costs of a person with MND staying at home are substantial and include informal care and formal care, access to respite for carers, aids, equipment and any modifications to the home. Costs of staying at home could include any support from MND advisors employed by MND Associations and any other community support. To compare costs with RACFs, it is also important to include the cost of living (such as utilities and food) as the daily fees and accommodation costs reported in section 11.1.1 include this. As with the RACF costs, these costs are borne by government and people with MND (or their families).

Most parameters for this estimation are drawn from the estimates presented throughout the report, with the exception of cost of living costs, and the costs of MND advisors from MND Associations.

The costs of living in this analysis include accommodation, groceries, utilities and transport costs. The costs of living are derived from the Australian Government (2015), which are outlined below:

- Shared Rental: \$70 to \$250 per week. This is an average of \$160 per week, which is multiplied by the 11% of people with MND that are living in rental accommodation (Giles and Lewin, 2008), which gives an average of \$17 per week.
- Groceries and eating out: \$80 to \$200 per week. This is an average of \$140 per week.
- Gas, electricity: \$60 to \$100 per week. This is an average of \$80 per week, to which is added approximately \$10 per week for water and sewerage.

- Phone and Internet: \$20 to \$50 per week. This is an average of \$35 per week.
- Car (running costs: \$150 to \$250 per week. This is an average of \$200 per week.

Adding these costs together, the average living costs are estimated to be \$482 per week, or \$25,070 per person each year.

Table 11.2 presents the costs of staying at home for a person with MND. The total costs of staying at home are estimated to be \$112,088 per annum.

Table 11.2: Costs of staying at home

Home care costs	Cost per person (\$)
Informal care (lost income)	32,728
Formal care (e.g. through HACC including hours for community nursing, allied health)	17,440
Aids and equipment	21,002
Home and vehicle modifications	13,856
NRCP	1,992
Food, rental, utilities (i.e. cost of living)	25,070
Total cost	112,088

Source: Deloitte Access Economics calculations.

11.1.3 Comparison of costs

The total costs of staying at home are estimated to be higher than in a RACF. The total costs for a person with MND to stay in residential aged care are estimated to be \$78,631 per annum, while the cost per person with MND of staying at home is estimated to be \$112,088 for the average person with MND.

It is noted that the assumed cost to government of residential aged care may be lower than in reality (as care costs for a person MND are likely to be higher than for other residents in a RACF), and that assumed accommodation costs in RACFs may be too high (the analysis has used the maximum rate, however, people are able to negotiate this fee with the aged care provider). Furthermore, the means-tested care fee will provide some coverage of aids and equipment for a person with MND; however, these costs are likely to reflect the minimum amount of care required. As noted elsewhere in this report, the costs of care for MND are substantially higher than this care fee.

This cost comparison also does not consider the preference of people living with MND to remain living at home. Quality of life for people living with MND who are required to transition to a RACF earlier than usual may be reduced due to the shock and emotional distress of this change. It was not possible to identify the extent to which quality of life is reduced when transitioning between these types of care.

Finally, there may be other implicit costs that are not appropriately captured in fees charged to government or people residing in a RACF. For example, MND Associations may provide additional training and education of staff working in these facilities, and they provide advice and support to people residing in either setting (estimated to be \$2,865 per

person – see section 11.3). It was not possible to estimate a cost of specialised training in RACFs, while the costs of advice and support are assumed to be same in both settings.

Due to the above limitations, the costs of residential aged care can only be considered as a lower bound of the true cost of residential aged care for a person with MND. It is likely that the family of a person with MND, MND Associations, or government will still be required to provide additional funding to support a person with MND living in a RACF.

11.2 Equipment provided by MND Associations compared with purchasing equipment through NDIS plans

To compare the costs of using MND equipment loan services, and purchasing the same equipment through NDIS plans, it is necessary to calculate the cost to each person of the same bundle of goods in each setting.

MND Australia provided Deloitte Access Economics with commercial-in-confidence data that outlines the yearly cost of renting various aids and equipment through MND Associations. This includes equipment such as wheelchairs (powered and manual), beds, cushions, modifications to the home such as ramps, communication aids and a number of other assistive devices for mobility and comfort for the person living with MND and their carers. MND Australia also provided Deloitte Access Economics with four case studies, outlining the aids and equipment that each of these people were currently using. Details of the aids and equipment required by each person in the case study are presented in Table 11.3.

Table 11.3: Case study equipment details

		Equipment
Case study 1	Electric bed	Folding ramp
	Bridge chair	Mobile shower commode
	Electric lift recliner armchair	Standard power wheelchair
	Roho cushion	Manual wheelchair
	Alternating air pressure mattress	Tilt in space power wheelchair
	Nebuliser	Around chair table
	Pillow wedge	
Case study 2	Electric bed	Remote call bell system
	Companion electric bed	Tilt mobile commode
	Electric lift recliner armchair	Over toilet frame
	Pressure cushion	Manual wheelchair
	Electric hoist	Manual wheelchair - tilt
	Sling	Tilt in space power wheelchair
	Shower chair	Wedge ramp x 4
Case study 3	Electric bed	Nebuliser
	Companion electric bed	Ramp
	Pressure cushion	Mobile shower/toilet commode
	Sling	Manual wheelchair - reclining
	Electric hoist	Manual wheelchair - standard
	Shower stool	Tilt in space power wheelchair
Case study 4	Bed cradle	Mobile shower commode
	Bed stick	Hoist
	Bridge chair	Toilet surround
	Electric life recliner chair	Manual reclining wheelchair
	Tilt in space power chair	

Source: MND Australia.

As the equipment provided by MND Associations is rented, these costs need to be revised to the lifetime rental costs for a person with MND. This requires two assumptions. First, it is assumed that the person with MND will only require equipment from the end of the first year with the disease (noting that this is likely conservative). Second, as reported in section 3.2, the average time from disease onset to death is approximately 2.5 years – meaning the average person with MND will require aids and equipment for 1.5 years. The annual costs reported for each case study are multiplied by 1.5 to derive the lifetime rental cost.

A comparative bundle of goods was derived from the NDIA's *Assistive technology price guide* for items delivered under the NDIS (NDIA, 2015). This price guide provides information on services available to NDIS participants with plans approved from 1 August 2015. Similar to the data provided by MND Australia, this list provides prices for aids and equipment that support the people with MND and their carers.

It is important to note that the aids and equipment provided between these two lists are not directly comparable for each case study. However, care has been taken to ensure that

this bundle of goods is representative of the items that can be rented through MND Associations.

Table 11.4: Cost of equipment through MND Associations and the NDIS

	Cost through MND Associations (\$)	Cost through NDIS (\$)
Case study 1	20,598	30,516
Case study 2	23,195	25,486
Case study 3	19,979	23,371
Case study 4	14,727	16,750
Average	19,625	24,030

Source: Deloitte Access Economics calculations.

As presented in the table, the price of renting these goods for 1.5 years from MND Associations are slightly lower than the cost of purchasing them through the NDIS. There are two things to note regarding these costs. First, there are costs associated with delivering, cleaning and repairing equipment; however, no data was available to estimate these costs for the NDIS so they have been excluded. Second, equipment purchased through NDIS plans could potentially be sold second hand to a third party to recoup costs. While NDIS equipment could potentially be resold, equipment that is provided on a rental basis by MND Associations is cleaned and reused almost immediately. No adjustments have been made here for these two factors.

Finally, it is important to note that the term “rental costs” used here is not necessarily a cost to the person with MND, but rather these costs are borne by MND Associations and government (through the NDIS). MND Associations provide this equipment free of charge to people living with MND registered with an MND Association, except in instances where the person receives support packages such as through the NDIS. MND Australia has indicated that its Associations will provide an aids and equipment package at a price of \$5,700 to people receiving NDIS funding.¹⁸

11.3 MND Association cost of support compared with NDIS funding for support

MND Association advisors provide information and support coordination to people with MND. This support enables people with MND, together with the MND advisor, plan and manage their care, and engage a range of service providers as required and as needs change. This support coordination may be funded through NDIS plans. The purpose of this section is to establish the costs associated with support coordination for MND advisors, and compare this with the funding provided through NDIS plans.

¹⁸ MND is a rapidly progressing disease, and so the equipment needs of a person with MND will change significantly over their lifetime. The annual cost of \$5,700 covers a basic range of equipment, including armchairs, bathroom aids, communication aids, manual wheelchairs, walking aids, etc. However, in advanced stages of MND this equipment may not be sufficient to meet the needs of a person with MND.

There are two components to MND advisor support. The first component is the support provided before the person living with MND has a plan in place. This support includes information, local advocacy, assistance in making funding choices relevant to specific circumstances, referral to other service providers, support and information for those other service providers, assistance with NDIS planning, and other similar services. The second component is the actual support coordination once a person living with MND has a plan in place and is approved for a package. MND advisors contribute a significant number of hours to assist the NDIS participant to implement the plan by coordinating supports from a range of sources, resolving points of crisis and developing capacity and resilience in a participants' network to ensure the plan meets the needs of the person living with MND.

Data provided by MND Victoria found that **MND Victoria delivered 10,497 hours of support services** to 374 people with MND **during 2014-15. The average person received 28.07 hours of support services each year, which, at \$102.08 per hour, cost \$2,865 per person** or \$1.07 million overall per annum (in Victoria only).

The coordination and support provided by MND advisors comes under the NDIS funding category of improved life choices. This can either be funded under the support coordination, or support connection hourly rates – which are \$90.46 per hour and \$55.50 per hour respectively (note that this is lower than the cost to the MND Association's for these services, which was \$102.08 per hour as reported above). MND advisors in Victoria will be required to negotiate how many hours of support are provided, and the rate these hours are funded at, with the NDIS participant. Currently in Victoria, the NDIA planners allocate 20 support coordination hours in a person's initial plan funded at \$90.46 for each hour of support, with any additional hours being funded at a lower support connection rate of \$55.50 (NDIA, 2015c).¹⁹

Currently in the NSW NDIS trial sites the number of hours and the level of support coordination allocated in a person's plan for support coordination varies significantly. Depending on the needs of the person with MND and their rate of progression up to 52 hours of support coordination may be included in a plan. The allocation of hours and funding for support services across both NSW and Victoria NDIS sites are subject to change as the NDIS continues to evolve.

The data from MND Victoria indicates that the role of support coordination requires at least 28 hours funded at the level of support coordination. **Based on this assumption the total funding for support coordination, as provided by MND advisors under the NDIS, would be \$2,253 per person per annum**²⁰.

MND is a complex disease and requires complex service delivery arrangements. The amount funded by the NDIA is lower than the actual cost to the MND Associations (\$2,865 per annum), and indicates that MND Associations will have to either subsidise their services or not provide a full range of services to people with MND that receive NDIS plans.

¹⁹ These are the hourly rates for NSW, Victoria and Tasmania as reported in NDIA (2015c). It is possible that these rates will differ slightly in other jurisdictions.

²⁰ This is calculated as $(20 * \$90.46) + ((8 * \$55.50))$.

In addition NDIS does not pay for the first component of the MND advisor role, information, referral, advocacy and service provider support. This will need to be funded by the MND Associations unless additional support is provided through the NDIS²¹.

Unfortunately, there is no publicly available data on the number of hours specifically for coordination and support in a standard NDIS plan for people with MND. Consequently, it was not possible to compare the total costs of support and coordination provided through NDIS plans with that provided by MND Associations. It is expected that the cost of planning and support would be more efficiently and effectively provided by MND advisors, as these advisors have an expert understanding of MND, care requirements, and service providers.

11.4 Government costs of MND to the NDIS and residential aged care

The NDIS represents a substantial step forward in Australia for needs based care. However, there is still an access gap for people with MND depending on when they are diagnosed and assessed to be eligible or not for care under the NDIS. Currently, a person with MND that is diagnosed before the age of 65 years can access needs based care through the NDIS providing that eligibility criteria are met, and continue to access this care after turning 65 (NDIA, 2015a). However, someone that is aged 65 years and over will have to rely on the existing aged care systems, which do not provide needs based care. This can lead to a substantial gap in the out-of-pocket expenditure faced by people with MND and their families.

This distinction of services based on age is particularly important for MND. Just under 60% of people with MND in Australia are estimated to be under the age of 65 (section 3.1.2).²² This means that approximately 60% of people will have access to needs based care, with more appropriate funding and care arrangements that enable the person living with MND to purchase required care and equipment that enables them to continue to live at home. In the absence of this funding, many of these people may be required to enter residential aged care facilities earlier than required. However, not only has residential aged care been recognised to not appropriately meet the needs of people with MND in many cases (Giles and Lewin, 2008b), this represents a current inequity in services between those able to access the NDIS, and those who are not.

Further, even those who are eligible to enter aged care tend to remain at home. As outlined in section 5.5, there are estimated to be 229 people with MND in residential aged care. This means only a quarter of those potentially eligible for residential aged care receive care in this setting. Given the higher costs associated with staying at home (see section 11.1), this may reflect both the desire to stay at home, and the appropriateness of care for MND.

²¹ The NDIA currently employs NDIA planners who work with people eligible to be a participant in the scheme to develop a plan to meet their 'reasonable and necessary support' needs.

²² It is noted that a large proportion of those aged under 65 are approaching an age where they would no longer be eligible for the NDIS. Approximately 16% of all people with MND are between 60 and 64 years old. So while 60% are estimated to be eligible for the NDIS, it is important to ensure that those people who are about to turn 65 receive timely access to the NDIS.

The following two sections outline the costs of MND to residential aged care for government, and the costs of NDIS to the government.

11.4.1 Government costs of MND to residential aged care

As noted in section 5.5, the best available data of people receiving residential aged care support was provided by MND Australia to Deloitte Access Economics. This data showed that of the estimated 2,094 people with MND in Australia in 2015, 229 are in residential aged care. The average cost to government of each of these placements was estimated to be \$36,193 in 2015.

The expenditure for residential aged care services for MND was estimated to be \$8.3 million in 2015. These are costs to the government, and do not include the costs associated with living or accommodation that were estimated in section 11.1.

11.4.2 Government costs of MND to the NDIS

As presented in section 7.3.3, data from the NDIA (obtained through special request) indicated that 40 people with MND are currently receiving NDIS plans. The average annual cost of these packages was \$64,000, which indicates that **the current total cost of MND to the NDIS is \$2.56 million**. However, it is important to note that the NDIS is still in its trial stages, and it would be expected that this number will increase significantly in the future as more people with MND are able to join the NDIS. If all people with MND under the age of 65 were to receive support through the NDIS, the total cost could be as high as \$78.0 million each year.

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