ACTING POSITIVELY: STRATEGIC IMPLICATIONS OF THE ECONOMIC COSTS OF MULTIPLE SCLEROSIS IN AUSTRALIA

REPORT BY
ACCESS ECONOMICS PTY LIMITED

FOR

MULTIPLE SCLEROSIS AUSTRALIA

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GLOSSARY OF COMMON ABBREVIATIONS

ABS	Australian Bureau of Statistics
AIHW	Australian Institute for Health and Welfare
AMSLS	Australian Multiple Sclerosis Longitudinal Study
BEACH	Bettering the Evaluation and Care of Health
DALY	disability adjusted life year
DCIS	Disease Costs and Impact Study
AMSLS EIS	Economic Impact Study (a sub-study of the AMSLS)
GP	general practitioner
IFN	Interferon
MRI	magnetic resonance imaging
MS	multiple sclerosis
NOHSC	National Occupational Health and Safety Commission
PBS	Pharmaceutical Benefits Scheme
PPMS	primary progressive multiple sclerosis
QALY	quality adjusted life year
RRMS	relapsing remitting multiple sclerosis
SPMS	secondary progressive multiple sclerosis
VSL	value of a statistical life
YLD	years of healthy life lost due to disability
YLL	years of healthy life lost due to premature death

EXECUTIVE SUMMARY

Australia needs to move towards more positive public awareness of MS to enable improved community participation by people with MS, encouraging the health and general community to better understand the challenges of this disabling condition – both to reduce the levels of discrimination and disadvantage and to provide appropriate solutions.

- In 2005**, over 16,000 Australians** have MS, a chronic progressive and incurable neurological disease causing disability and premature death.
- MS has an onset in early adulthood and a lifelong impact. It is most frequently diagnosed in people between the ages of 20-40, a time of career building, relationship building and the early stages of family life.
- The constellation of long term disabling symptoms caused by MS, including extreme fatigue, immobility, vision disturbance, muscle weakness, chronic pain and executive cognitive impairment have a life changing effect on individuals, families and employers.
- People with MS, like others with a lifelong chronic illness, experience lower income levels than the general community.
  - 74% are women, and **87% are of working age**, since peak incidence is in the mid-twenties. 21% experience severe disability, 46% moderate disability and 33% mild disability, with life expectancy reduced by 6-7 years.
  - **MS has higher one-year prevalence than breast cancer, bowel cancer, sports injuries or poisoning**.
  - Prevalence is expected to grow 6.7% in the next 5 years, faster than population growth due to demographic ageing.

The total financial costs of MS in 2005 are estimated as over $600m (0.07% of GDP) and $37,333 per person with MS, or $30 per Australian, each year. Lost productive capacity and the replacement valuation of informal community care are the two largest cost components.

- **Informal care** for people with MS in the community from families and others, represents 43% of total costs (replacement costs are valued at $257.7m), with an average of 12.3 hours per week of informal care required per person with MS, based on data from the Australian MS Longitudinal Study (AMSLS).
- **Production losses**, which derived from reduced work hours, temporary absences, early retirement and premature death, are around 26.4% ($158.6m).
  - 3,195 people with MS will not work in 2005 due to the illness.
  - Of those who are employed, more will work part-time and far fewer full time, on a standardised basis, than in the general population.
- **Pharmaceuticals** for people with MS, mainly new generation interferons, are estimated to cost $84.1m in 2005 (14% of total costs).
  - These therapies have a strong evidence basis showing cost effectiveness in slowing progression and enhancing wellbeing and productivity for people with MS.
- **Nursing home** accommodation is around $25.8m (4.3%) in 2005.

- There are an estimated 730 people with MS in (high care) nursing homes in 2005, of whom 268 (37%) are younger people aged under 65.

- **Other health costs** – including hospitalisations, specialist and primary care and allied health, are $26.2m (4.4%).
  - Research is 1.9% of health expenditure, below the average of 2.4%.
- **Aids and modifications** for people with MS include walking aids, special kitchen and hygiene items, wheelchairs, ramps, car and home adaptations.
  - These were estimated to cost $27.8 (4.6% of total financial costs).
- **Formal community care services** cost $432 per person with MS according to early data from the AMSLS Economic Impact Study (EIS) – $7.0m (1.2%) overall.
- **Deadweight losses** arising from **taxation revenue foregone** and **welfare payment transfers** are estimated as $13.5m or 2.3% of total costs in 2005.

In addition, the burden of disease – the suffering and premature death experienced by people with MS – is estimated to cost an additional 8,968 DALYs (years of healthy life lost), with two thirds due to disability and one third due to premature death.

- **MS causes more disability and loss of life than all chronic back pain, slipped disks, machinery accidents, rheumatic heart disease or mental retardation**.
  - The disability weight for progressive MS is higher than for moderate dementia, AIDS, rheumatoid arthritis or severe hearing loss.
  - For relapsing-remitting MS, the disability weight is similar to that of a major depressive episode and over four times higher than that of chronic back pain.
- The **net disease burden in 2005 is equivalent to $1.34 billion** ($1.08-$1.59 billion), **over twice the financial costs**.[1]
  - **Altogether the financial and disease burden of MS is estimated to cost nearly $2 billion per annum**.

Challenges exist to reduce the costs of MS and enhance the quality and options for care. The age of onset of MS is generally in early adulthood and means that a significant number of people with MS are working, studying, starting families, or financially committed (eg, buying their first home).

- The first best solution from an economic and equity perspective involves policies that enable people with MS to **retain employment** where possible, while recognising the need to have a solid welfare response for those that cannot maintain employment due to health and mobility restrictions.
- Given the profile of financial costs, **support for informal carers** will be a key issue. In this study, the costs of residential care for people with MS have been found to be some 60% higher than for the replacement value of informal care, aids and modifications and support services from the formal sector, for people with MS residing in the community.

[1] This estimate is based on the value of a statistical life of $3.7m and a discount rate of 3.3%.

- **Young people in nursing homes** has become an endemic problem. Aged care is inappropriate for younger people for a variety of reasons and addressing the unmet need for appropriate accommodation must be a priority.
- **Timely and cost-effective health interventions** have the potential to retard growth in future direct and indirect costs of MS and enhance the quality of life of people with MS in Australia over the longer term. These include pharmacotherapies, psychosocial interventions (especially those provided without Federal funding through MS Australia), achieving better linkages between health and disability programs, developing care pathways across jurisdictional boundaries, health promotion programs, enhancing collaboration, meeting the special needs of disadvantaged groups (MS is over-represented in rural areas), and adopting innovative financing solutions.
- **Investment in research** is an important way of bringing about improvements in the overall understanding of the disease, treatments and ultimately a cure. A major challenge is the development of a critical mass in ethical MS research to increase new lines of investigation, opportunities for collaboration and commercialisation of new treatments and products in Australia – particularly in the areas of genetics, remyelination and nerve regeneration.
- **Improving community understanding and reducing discrimination** through formal sector education and training, targeted training and support for employers of people with MS or their carers as well as general community awareness. MS still carries stigma and mythology in the community, and the invisibility of symptoms contribute to poor acceptance in many settings.

To this end, this report makes the following recommendations.

1. Employment support: It is recommended that:

- a discrete policy focus is created within DEWR (covering Disability Open Employment sector and the Job Network) to develop programs aimed at retention and adaptation of existing jobs for people with MS and other chronic illnesses;
  - such programs should involve innovative strategies such as workplace environment adaptation, job restructuring or tailoring, part-time and flexible work-from-home options, and transport assistance, as appropriate;
  - rehabilitation and workers compensation models should be considered for integration into job retention policy and programs;
  - existing employer incentive schemes could be extended to include employers supporting workers with MS and other disabilities in job retention programs; and
- education and awareness strategies are developed to counter workplace misperceptions and discrimination against people with disabilities (including MS) and encourage employers and employees to identify and implement positive long term solutions.

2. Early intervention and health promotion: It is recommended that the range of specific health, wellness and self management programs for people with MS and their carers is extended to improve health and lifestyle outcomes for both groups, including:

- early access to cost-effective pharmacological and other therapies that will improve health outcomes and workforce participation; and

- a change in community perceptions and attitudes to MS so that the potential for positive strategies and outcomes is realised by employers, policy makers and the community.

3. Pharmaceuticals: It is recommended that the Federal Government fast track the process for expanding the PBS-listed indications for anti-fatigue and anti-convulsant therapies for people with MS that have strong clinical evidence. Access to these medications can improve the management of some of the most debilitating symptoms of the disease that prevent participation in employment and other forms of community life.

4. Community and residential care: It is recommended that:

- to improve efficiency and efficacy of community care programs, alternative and better coordinated models of care are established across the Commonwealth and State jurisdictions to result in more seamless, flexible and multidisciplinary care that is able to follow the course of the disease;
- to this end, formal protocols and transfer agreements need to be struck between Commonwealth/State disability and aged care programs to formalise service access and continuity for people with MS and similar progressive conditions with the aim of supporting people in the community and delaying residential placement for as long as appropriate;
- where residential accommodation is required, it is age-appropriate and incorporates specific care for disease related symptoms as well as disability support;
- the Council of Australian Governments (COAG) Health Working Group delivers a detailed plan for the move of younger people with disabilities out of aged care, incorporating the recommendations of the National Alliance of Young People in Nursing Homes for a national taskforce to undertake the initiative, in particular to:
  - develop services in every State and Territory to provide alternative housing and support options for a targeted number of younger people wishing to move out of nursing homes;
  - reduce further admission of younger people into nursing homes through the timely provision of flexible community service packages to ensure they are able to access choices about where they live;
  - build measures and resource allocation into the Commonwealth State Disability Agreement to specify funding responsibilities and ensure sustainable service delivery for the existing target group and those others at risk of inappropriate placement in aged care; and
  - make CSTDA services available to younger people with MS and other disabilities living in nursing homes.

5. Support and respite for informal carers: It is recommended that:

- additional recurrent funding is provided for design and delivery of support, education and respite services for informal carers of people with MS;
- the recent budget initiative for respite care to assist employed carers is expanded to target the carers of people with MS to ensure that respite services are introduced in a dignified and relevant manner, and will offer greater employment continuity to carers;

- the Commonwealth National Respite for Carers program and State disability programs fund shared care and respite services for carers and people with MS (and other young people with disabilities) that:
  - are lifestyle friendly, flexible and age-appropriate;
  - are available over the long term course of the disease; and that
  - offer improved case management input to ensure good planning and packaging of services.

6. Research: It is recommended that:

- the scope to address the relative under-funding of MS is reviewed with a view to bring research spending on MS up to the national average with investments directed through MS Research Australia; and
- a National MS Register is established from 2005 to bring together accurate ongoing data about MS incidence, prevalence, impacts and services into a national framework for data collection, with appropriate linkages to other existing MS databases and as a framework for research.

7. Collaborative Partnerships: It is recommended that the National Neuroscience Consultative Taskforce establish a Brain and Mind Research Alliance in line with the recommendations of the Prime Minister's Science, Engineering and Innovation Council Report from 2003 to, as a priority, implement strategies through a national action agenda to prevent, reduce or contain the chronic and debilitating consequences of neurological disorders. This could be facilitated by a national network of neurological associations.

8. Service capacity of MS Australia: It is recommended that the scope for Federal and State funding of the MS Societies be reviewed with a view to improving national infrastructure and service delivery capacity for Australians with MS, through the introduction of new services and improvement of existing responses in the following areas:

- carer education and support programs
- rural and remote outreach programs for people with MS and their families;
- employment support, job in jeopardy programs and employer education about particular methodologies around MS in the workplace;
- community education; and
- health promotion and self management programs.

9. Disadvantaged groups: It is recommended that MS services reflect the different needs of different groups of people, with equal and improved access for people with MS and their families and carers, in particular people who live in rural and remote regions of Australia and/or who are from culturally and linguistically diverse backgrounds, through:

- better and more appropriate use of smarter new technologies in diagnosis, treatment and referral; and
- specific attention to workforce development in outer metropolitan and rural locations for allied health workers capable of working with people with MS and similar progressive neurological conditions.

10. Financing issues: It is recommended that:

- Government consider less onerous and more consistent access to preserved superannuation lump sums for younger people with MS and other chronic illnesses, potentially from age 45 or 50 years, based on individual capacity assessments; and
- longer term intergenerational financing makes adequate provision to appropriately fund the growing community needs for health, ageing and disability services, in view of the demographic ageing and the projected expansion in prevalence of people with chronic disease and disability.

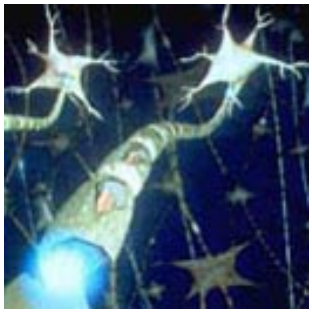
1. PREVALENCE AND SOCIOECONOMIC IMPACTS

1.1 EPIDEMIOLOGY AND AETIOLOGY[2]

1.1.1 WHAT IS MS?

Multiple Sclerosis (MS) is a chronic, relatively common and incurable disease that randomly attacks the central nervous system (brain and spinal cord).

MS is an inflammatory demyelinating condition. Myelin is a fatty material that insulates nerves, acting much like the covering of an electric wire and allowing the nerve to transmit its impulses rapidly. It is the speed and efficiency with which these impulses are conducted that permits smooth, rapid and coordinated movements to be performed with little conscious effort. In MS, the inflammation, breakdown and loss of myelin (demyelination) is accompanied by a disruption in the ability of the nerves to conduct electrical impulses to and from the brain and this produces the various symptoms of MS. The sites where myelin is lost (plaques or lesions) appear as hardened ('sclerotic' or scarred) areas: in people with MS these scars appear at different times and in different areas of the brain and spinal cord. The term 'multiple sclerosis' means, literally, **many scars**.



Symptoms of MS are unpredictable and vary greatly from person to person and from time to time in the same person. They may include: extreme tiredness (fatigue), tingling, numbness, impaired vision, loss of balance and muscle coordination, slurred speech, tremors, stiffness, bladder and bowel problems, difficulty walking, problems with memory and concentration, mood swings and, in severe cases, partial or complete paralysis.

Onset: 70% of cases begin between 20 and 40, with the average age being 30 and the peak incidence occurring in the mid-twenties, although rare individuals as young as 2 and as old as 75 have developed it.

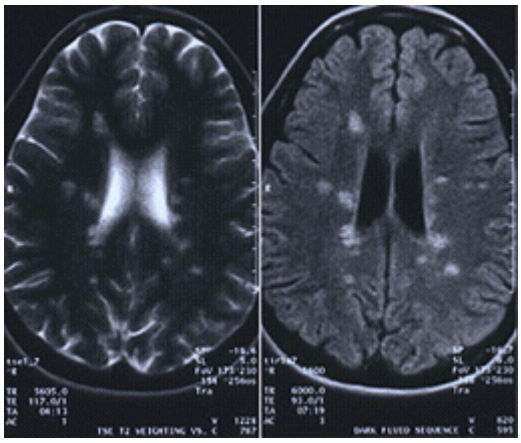
Progression: There are two distinct patterns of prognosis (Patwardhan et al, 2005):

- **Relapsing/remitting (RRMS):** About 80% of people with MS have a form in which neurological symptoms and signs typically evolve over a period of several days, stabilise, and then often improve spontaneously within weeks.
  - However, over time, signs and symptoms of central nervous system dysfunction persist after relapses, or progression occurs between relapses; this pattern is called **secondary progressive (SPMS)**.
- **Primary progressive (PPMS)**: In about 20% of patients, a progressive course is apparent from onset.

The progress, severity and specific symptoms of the disease cannot be predicted.

[2] Picture and epidemiological descriptions in this section are from the Multiple Sclerosis International Foundation, www.msif.org/en/ ms_the_disease/what_is_ms.html , unless alternatively sourced.

Diagnosis: The peculiar nature of MS makes the diagnostic process complex, requiring a combination of neurological exams, medical and laboratory tests and imaging to eliminate other possible disorders and confirm MS. Elusive symptoms that come and go might indicate any number of possible disorders and can be very difficult for general practitioners (GPs) to interpret. MS diagnosis should thus be made by a physician experienced in identification, and on objective evidence from two or more neurologic signs that occur in different parts of the central nervous system, last at least 24 hours, and are at least three months apart. As well as symptoms that indicate injury to more than one part of the central nervous system, laboratory tests can be helpful in showing abnormal findings consistent with a diagnosis of MS. **Magnetic resonance imaging** (MRI) with gadolinium contrast, especially during or following a first attack, can be helpful in providing evidence of lesions in the brain and spinal cord. A second MRI scan may be useful at least three months after the initial attack to identify new lesions and provide evidence of dissemination over time (Calabresi, 2004). Newer MRI technologies have added greatly to diagnostic capacity (see below).



MS diagnosis with advanced Open MR system, image courtesy of Siemens Medical Systems
T2 image on the left and new Turbo-FLAIR image on the right.[3]

Differential diagnosis: Other diseases that can mimic MS must be excluded, including vascular disease, spinal cord compression, vitamin B12 deficiency, central nervous system infection (eg, Lyme disease, syphilis), and other inflammatory conditions (eg, sarcoidosis, systemic lupus erythematosus, Sjögren's syndrome) (Calabresi, 2004).

Because of the frequent difficulty of diagnosing MS, in 2001 the International Panel on Diagnosis of MS formalised the inclusion of MRI and made other refinements to formulate what are now called the 'McDonald criteria' for diagnosis (McDonald et al, 2001). Since that time, the McDonald criteria have been widely used and tested in a variety of research settings.

1.1.2 AETIOLOGY

The overall cause of MS is still unknown. The body's immune system normally defends the body from attack by viruses or bacteria. However, in the case of MS, the body's immune system attacks its own myelin, causing disruption to nerve transmission. It is thought that genetic and environmental factors are involved – but

[3] Description and picture reproduced from www.imaginis.com/ multiple-sclerosis/mri-and-ms.asp

the actual trigger to the disease has not yet been discovered. Interestingly, some studies report a lower risk for MS in people with asthma and allergies, suggesting that the immune imbalances causing these conditions may protect against the immunological processes leading to MS.

Risk factors for MS include:

Gender: In Australia, about three times as many women as men have MS. This gender bias may be related to variation in a gene that controls a powerful immune messenger chemical called *interferon (IFN) gamma*.[4] There are also many demonstrated links between MS and the sex hormones – testosterone and oestrogen (eg, helping to explain why pregnant women with MS do not have relapses).

Genetic factors: Studies indicate that genetic factors may make certain individuals more susceptible to the disease, but there is no evidence that MS is directly inherited. New research continues to uncover genes involved in MS (Zhang et al, 2005). The risk for someone inheriting all the genetic factors contributing to MS is only about 2% to 4%. Nevertheless, when siblings have the disease, they are more likely to have the same degree of severity. Among identical twins the risk is about 25% to 30%.

Ethnicity: MS occurs more commonly among Caucasians, especially those of northern European ancestry, but people of African, Asian and Hispanic backgrounds are also affected.

Geography: MS prevalence increases with distance from the equator in both hemispheres. Specifically, prevalence is highest in northern and central Europe (except northern Scandinavia), Italy, southern Australia, and northern regions of North America. Middle-risk areas are southern Europe (except Italy), southern US, northern Australia, northern Scandinavia, the Caucasian sections of South Africa, and possibly Central America. Low-risk areas include tropical parts of Africa and Asia, the Caribbean, Mexico, and possibly northern South America. It is unclear whether this pattern is attributable to environmental factors – **sunlight (vitamin D, UV radiation)** – genetics, or both.

Smoking: A single new research study suggests that smoking may increase the risk of MS for those who do not yet have it, and increase the risk of converting to secondary progressive, versus a non-smoker with RRMS (Hernan et al, 2005).

Cow's milk during early infancy: Breast milk contains factors that may help regulate immune responses; there is some evidence that infants fed only on cow's milk may have higher risk for either MS or diabetes type 1 later in life. Studies on national differences in diabetes indicate risk may vary with different milk proteins, suggesting that not all cow's milk is identical and some proteins carry higher risks than others.

A large amount of research has been directed towards whether the geographical distribution of MS is due to environmental or genetic factors. Poser (1994) suggested

[4] Unlike interferon betas, which are used to treat MS, IFN gamma has been linked to immune attacks in MS, and preliminary findings suggest this variant may be more frequent or more active in women than men. IFN gamma appears to be a new key variable – perhaps one piece in a puzzle – in understanding who gets MS. People who have a gene that produces high levels of IFN gamma may be predisposed. This finding provides a possible target for further investigation (Jan. 27 online publication of *Genes and Immunity*).

that the geographic hypothesis is explained by the migration of ethnic groups with a particular susceptibility to MS. Migration studies have found that groups who migrate from a high prevalence area to one of low prevalence often exhibit higher rates of MS prevalence than the indigenous population (Compston and Robertson, 1998). In 1981 the prevalence of MS in English-born residents of Perth and Hobart was considerably higher than Australian-born residents (Hammond et al, 1988b) but not in Queensland (Hammond et al, 1987). However, this can depend on the age of migration. MS among people who migrated as children is usually much closer to that of the native-born population, suggesting that environmental factors can moderate the impact of a genetic susceptibility to MS. Australian studies into the difference in prevalence among Australian-born and overseas-born residents suggest these modifying factors may even extend well into adulthood (Hammond et al, 1987; Hammond et al, 1988b).

Miller et al (1990) found that while prevalence and mortality rates of MS in Australia and New Zealand were strongly correlated with latitude there was no statistically significant correlation of proportion of Mc/Macs in the phone book (a crude proxy for Scottish ancestry) or frequency of DL2 (an antigen most closely associated with MS) with latitude. They concluded that environmental factors were more likely to explain variations in MS prevalence across Australia.

Other authors commenting on the "place or race" debate conclude that both factors have a role to play in explaining MS prevalence (Sawcer et al, 1997).

The cause(s) of MS remains a mystery. Genetic factors play a role but no single gene is likely to be responsible for causing MS. Rather, the most popular current theory is that the disease occurs in people with a genetic susceptibility who are exposed to some environmental assault (a virus or a toxin) that disrupts the blood-brain barrier. Immune factors converge in the nerve cells and trigger inflammation and an autoimmune attack on myelin and axons. A number of disease patterns have been observed in MS patients leading some experts to believe that MS may represent several diseases with different causes.

Genetic factors probably play a role in making a person susceptible to the disease process leading to MS. But the risk for someone inheriting all the genetic factors contributing to MS is less than 5%. Advanced techniques called microarray technologies are now making it feasible to scan hundreds of genes and identify those most likely to be contributors to MS.

Infectious Agents, likely viruses, are the top suspects for triggering the autoimmune response in people genetically susceptible to MS. There are a number of reasons for this belief including clusters of historical MS outbreaks and the fact that some viruses are very similar to the myelin protein and may thus cause confusion in the immune system.

Infectious Agents Under Suspicion. Micro-organisms at the top of the suspect list are, or have been: herpes virus 6, Chlamydia Pneumoniae, Epstein-Barr virus, measles virus, adenovirus, polyomavirus, and the retroviruses (including HIV). Research has ruled out a link between vaccinations and relapses of MS.

Adapted from the University of Maryland Medical Centre site: "What causes MS?" **www.umm.edu/patiented/articles/what_causes_multiple_sclerosis_000017_4.htm**

1.1.3 MORTALITY AND CO-MORBIDITY

With modern medicine and technology, people with MS can be expected to live 90-95% of the normal life span (six or seven years less than average). However, in about half of MS cases, patients die from complications of the disease. MS also has significant negative emotional and physical consequences, and suicide rates are much higher than in the general population.

Women tend to have a better outlook than men. Factors that determine a higher risk for a severe condition include:

- being over 40 years old at the time of onset of symptoms;
- initial symptoms affecting either motor control, mental functioning, urinary control or multiple regions;
- frequent attacks in the first years or a short interval between the first two attacks; and
- remissions not complete; rapid progression of disability; or progressive MS from the beginning or shortly after onset.

MS mortality rates are higher in countries with a greater prevalence of MS (Kurtze 1997, p95). Several studies have looked at mortality rates associated with MS patients in Australia. Hammond et al (1989) showed that mortality rates also reflect the geographical prevalence of MS. Two methods are commonly used:

- the **indirect** method: based on ABS mortality figures, the method captures only those deaths where the main underlying cause of death was MS; and
- the **direct** method: based on recorded deaths from survey records (such as neurologists' records), the method captures all deaths of people with MS, whether due to MS or another co-morbidity.

The 1981 Queensland study (Hammond et al, 1987) found that mortality rates constructed using the indirect method were higher than those using the direct method, probably due to less comprehensive data collections for the latter. They also found a similar geographic pattern in mortality rates to those found in prevalence data, with higher mortality rates in the more southern areas of the State. Moreover, the study found a fall in ABS mortality rates from 1950-59 to 1971-80, which suggested that an increase in the survival rates from MS contributed to some of the increase in prevalence.

TABLE 1-1: MS MORTALITY RATES, QUEENSLAND 1981 (PER 100,000)

	Indirect	Direct
Above tropics	0.21	0.05 (0.06)
Below tropics	0.41	0.36 (0.35)
All of Queensland	0.34	0.29 (0.28)

Source: Hammond et al (1987), p.197, Table 12. Rates in parentheses are age-standardised to the 1981 Australian population.

Another study looked at patterns of co-morbidity in hospitalised patients with MS over the age of 65. Discharge diagnoses for urinary tract infection, pneumonia, septicaemia and cellulitus were more common for MS patients than an age and sex matched control group. MS patients were less likely to have discharge diagnoses of acute myocardial infarction, heart failure, hypertension, angina pectoris, cerebrovascular disease, diabetes mellitus and chronic obstructive pulmonary disease. Possible explanations given for this included under-reporting of certain co-morbid conditions, a protective effect of MS or its treatment, reduced prevalence of risk factors, disproportionate mortality in younger MS patients with co morbidity and the benefits of medical surveillance (Fleming and Blake, 1994).

Depression: Between 40% and 60% of MS patients suffer from depression at some point over the course of the illness, and studies have reported risks for suicide ranging from 3% to 15%. There is some evidence that depression in MS is not only due to the social and psychological impact of MS but to the disease process itself. Furthermore, in one study, depression had biological effects (increasing production of inflammatory cytokines) that could exacerbate MS. Treating depression thus may help reduce the disease process and suicide risk. People at highest risk for suicide are those who live alone, those with a history of an emotional disorder (e.g., depression, anxiety, alcohol abuse), a family history of mental illness, and people with high social stress (Fleming et al, 1994).

1.2 TREATMENT AND MANAGEMENT

1.2.1 PREVENTION AND EARLY INTERVENTION

Advances in understanding and treating MS are occurring and research to find a cure is encouraging. For example, Australian research (from the Menzies Centre for Population Health Research) suggests that sun exposure during childhood and early adolescence (particularly during winter) may reduce risk of MS, consistent with the recognised observation that MS is more common at latitudes with lower levels of ultraviolet radiation, vitamin D or both (Van der Mei et al, 2003). The study suggested that an additional one hour of winter sun may confer risk reduction for children aged six to 15 years, while noting issues related to skin cancer.[5] Vitamin D supplementation is also under investigation; Hayes (2000) recommends providing supplemental vitamin D to individuals who are at risk for MS.

Evidence now strongly suggests that the most destructive changes from MS in the brain occur very early on in the disease process and may cause considerable damage even before symptoms begin. Earlier diagnosis with new MRI technology, together with access to evolving treatments, offers the promise of more effective early intervention strategies for MS (Frohman et al, 2003). Many experts are now urging treatment after a first episode of relapsing MS (a clinically isolated syndrome) using disease-modifying agents, particularly where specific findings from advanced MRI techniques can help determine which patients are at highest risk for progression. Quality primary and specialist (neurologist) care are very important to comprehensive and effective management of MS. Many therapeutic and technological advances are helping people with MS lead more productive lives by modifying the underlying disease course as well as by providing learning strategies to help them cope with the many changes brought on by the disease. As such, treating patients early on can save money over time by preventing severe disability.

[5] Higher sun exposure for children aged 6-15 years in *summer* (average 2-3 hours or more a day during weekends and holidays) was also associated with a decreased risk of MS (adjusted odds ratio 0.31, 95% confidence interval 0.16 to 0.59), although not apparently as important as higher exposure in winter. Greater actinic (radiant) skin damage was also independently associated with a decreased risk of MS (0.32, 0.11 to 0.88).

1.2.2 PHARMACOLOGICAL MANAGEMENT

Maintenance Treatment for Relapsing-Remitting Multiple Sclerosis (RRMS)

Since 1996 four medications (Betaferon, Copaxone, Rebif and Avonex) have been approved in Australia and are available under the Pharmaceutical Benefit Scheme for relapsing forms of MS. They can help to lessen the frequency and severity of MS attacks, reduce the accumulation of lesions in the brain, and have also been shown to slow the progression of disability.

Interferons and other disease-modifying agents can have side effects and are expensive. Also, many patients have a mild course that can be managed with less toxic agents. However, strong evidence suggests that delaying treatment in most MS patients increases the risk for severe disability.

Corticosteroids may be used to treat an acute relapse and hasten recovery. Some research has reported benefits from the use of pulsed administration of intravenous methylprednisolone or intravenous immunoglobulin. Sometimes this is followed by oral prednisolone. Another agent showing promise is azathioprine, an immunosuppressant.

Treating Secondary Progressive Multiple Sclerosis (SPMS)

It is not clear if interferons and other standard treatments for RRMS help those whose condition has become continuously progressive. Mitoxantrone, an immunosuppressant, may delay relapse and progression in SPMS although side effects may sometimes be serious. Other immunosuppressants, such as cyclophosphamide, methotrexate and cladribine, may help some patients with SPMS. They can have toxic side effects, however, so there must be clear treatment indications.

Treating Primary Progressive Multiple Sclerosis (PPMS)

No treatments have been proven yet to slow primary progressive MS. Studies using interferons and glatiramer are underway.

In addition to the medications above, there is a wide range of therapies available to treat symptoms of MS such as spasticity, pain, fatigue and weakness, bladder dysfunction and depression.

Experimental Agents: Other agents under investigation for MS include monoclonal antibodies, aminopyridines, cannabinoids, oestrogen and statins.

1.2.3 PSYCHOSOCIAL AND OTHER HEALTH INTERVENTIONS

Psycho-social interventions: Diagnosis of MS can provoke a range of feelings – such as disbelief, anger, fear, depression, grief, loss and guilt. Appropriate counselling can be very helpful for the individual and the family to come to terms with emotions and to learn how to adjust and cope, retaining dignity and self-esteem. Psycho-education can help the person and their family learn to manage certain symptoms and can help prevent secondary morbidity such as depression or anxiety. Participation in support groups can also be very helpful, organised in each State and Territory by community organisations such as Multiple Sclerosis Australia. Peak community bodies meet a wide range of needs, including information and resources, support and education programs, referral services, family carer training and support (eg, through courses, seminars and respite) and advocacy.

Other health professionals: Physiotherapists, occupational therapists, speech therapists, mental health workers (eg, psychiatrists and psychologist), social workers, dieticians, continence advisers and urologists can all form part of a comprehensive case treatment plan for a person with MS, including for co-morbid conditions such as depression.

1.2.4 OTHER AND ALTERNATIVE INTERVENTIONS

Non-pharmacological experimental agents include:

Plasmapheresis: a procedure in which blood is removed from the body, blood cells are separated from plasma and mixed with replacement plasma, which is then returned to the body. The replacement plasma is thought to dilute antibodies and other immunologically active substances that may trigger MS.

Oligodendrocyte implants: a new minimally invasive method to transplant modified oligodendrocyte cells, which stimulate nerve and axon growth, directly into the brain.

Stem cell transplantation: stem cells are produced in the bone marrow and are the early forms for all blood cells in the body; adult stem cell transplantation may possibly slow progression.

Non-traditional treatments

Nearly 60% of MS patients try some form of alternative remedies[6] such as:

- relaxation and meditation such as music therapy and massage therapy;
- electromagnetic stimulation;
- the "Codi-Loder regimen" of vitamin B12, lofepramine (a tricyclic antidepressant), and L-phenylalanine (an amino acid available in health stores);
- linoleic acid (evening primrose oil), a polyunsaturated fatty acid; and
- oral enzymes (including bromelain, trypsin, papain and rutin) appear to reduce inflammation.

Research on any benefits is slim and there may be some danger with many remedies commonly used by MS patients:

- antioxidant vitamins or supplements (eg, A, E, C, Q10, pycnogenol, grape seed extract) can trigger T-cells and inflammatory components of the immune system;
- gingko – low but increased risk for bleeding and convulsion at high doses and interaction with other agents;
- bee venom – contains many chemicals, some of which can cause severe and sometimes deadly allergic reactions in some people; and
- other herbal or natural remedies (echinacea, ginseng, garlic, zinc, melatonin, borage seed oil, chaparral and comfrey) may exacerbate MS.

[6] For greater detail see **http://www.morehead.org/wellconnected/000017_9.htm**. 60% relates to lifetime 'prevalence' and is an American figure, in the absence of a current Australian alternative.

1.3 PREVALENCE

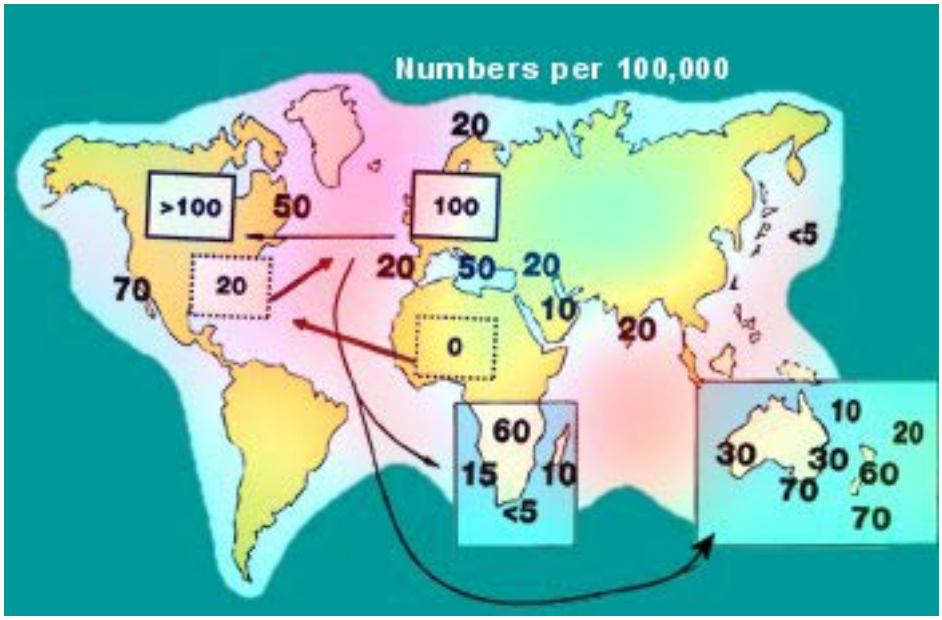
1.3.1 PREVALENCE RATES

An estimated 2.5 million people in the world have MS. There have been a large number of studies of the prevalence of MS around the world. Despite this, obtaining reliable and detailed estimates of the total number of people with MS in Australia today is very difficult. There are several reasons for this.

- MS is a low prevalence condition, so survey samples are often very small and hence more susceptible to sample error.
- There is no simple diagnostic test for MS, so even multiple case ascertainment methods may not fully capture all cases of MS in the study population.
- The increased prevalence of MS at latitudes further from the equator makes it difficult to extrapolate prevalence estimates for one region of Australia to other areas.
- In areas which have been repeatedly surveyed over the last 50 years, prevalence appears to be increasing, but the most recent published studies of prevalence in Australia are almost ten years old.

As Figure 1-1 shows, there is a general tendency for greater prevalence of MS at locations further from the equator. The possible explanations for this latitudinal gradient were discussed in Section 1.1.2 above.

FIGURE 1-1: WORLDWIDE PREVALENCE OF MS



Source: The Multiple Sclerosis Research Initiative world map, downloaded 18 April 2005 from **www.thisisfolkestone.co.uk/ms/maps/map.htm**

Throughout the world, the prevalence of MS also appears to be increasing over time. It appears that the observed increase in prevalence of MS may reflect a real increase in the incidence of the disease, as well as the impact of other factors such as better diagnostic testing (including MRI) and case ascertainment or increased survival rates. Studies in North America, Scandinavia and Sardinia have concluded that observed

increases in incidence are real, and not the result of methodological issues, but others in the UK rejected this hypothesis (Riise, 1997, p5-7). Noonan et al (2002) observed a particularly significant trend increase in incidence of MS for women.

Australian Studies

There has never been a nation-wide census of MS prevalence in Australia. However two large-scale prevalence studies have been undertaken in Australia. The first was in 1961, and the second 20 years later in 1981 (Hammond et al, 1987; Hammond et al, 1988b; McLeod et al, 1994). No published study appears to have been undertaken to coincide with the 2001 census date. Both of these studies looked at localised prevalence in various Australian towns and cities, with the primary aim to see if prevalence varied according to latitude and/or the ethnic background of the community. The surveys used a number of methods of case ascertainment, including the records of hospitals, specialists and general practitioners and the MS Society in each region.

More recent localised surveys were undertaken in August 1996 for the Australian Capital Territory (Simmons et al, 2001) and Newcastle (Barnett et al, 2003). Previous studies had suggested that prevalence in Newcastle could be used as a reliable proxy for prevalence throughout New South Wales, without the expense of a more comprehensive survey (McLeod et al, 1994). A longitudinal study of MS in Southern Tasmania was also commenced in 2002, although no results have yet been published.

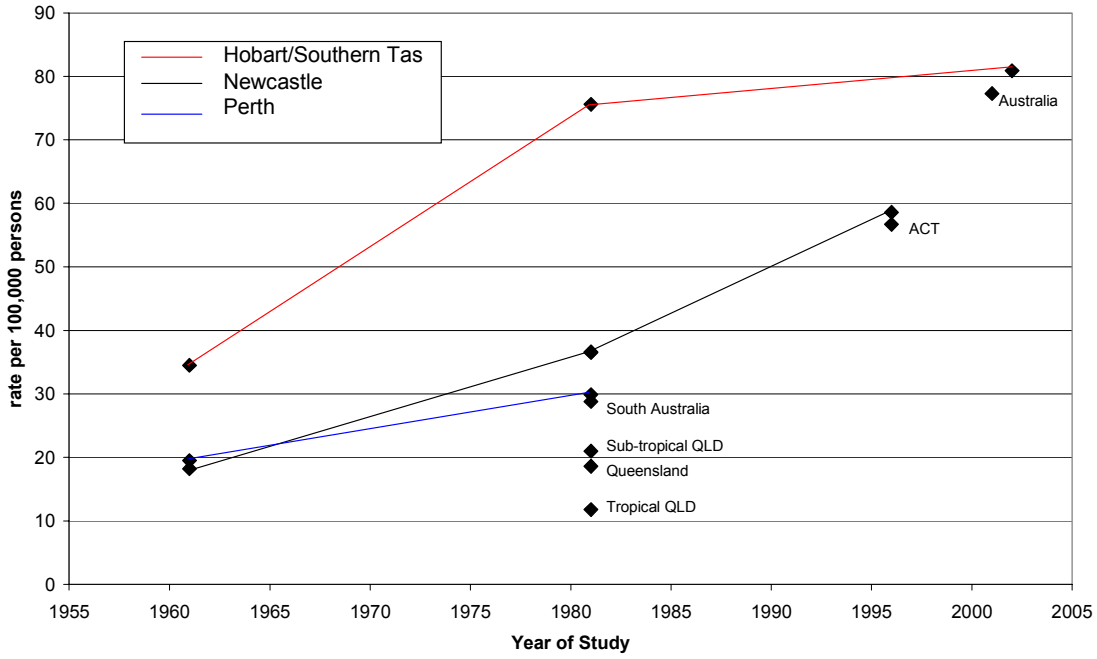
The 2001 ABS National Health Survey, a community based survey of self-reported prevalence, estimated there to be around 14,900 Australians with MS, equivalent to 0.08% of the Australian population in 2001, or 77.3 cases per 100,000 people. However, due to the very small sample size (n=23) it is not possible to disaggregate this total figure into age, gender or location specific prevalence rates.

Summarised results from the Australian studies are presented in Table 1-2 and Figure 1-2.

TABLE 1-2: MS PREVALENCE RATES FROM SELECTED AUSTRALIAN STUDIES

per 100,000 pop	Newcastle			Perth	Hobart	ACT	Australia	Southern Tasmania
	1961	1981	1996	1981	1981	1996	2001	2002
Males	16.5	24.6	33.1	16.0	52.6	29.6		
Females	19.9	48.1	83.4	43.6	96.4	72.1		
Persons	**18.2**	**36.5**	**58.6**	**29.9**	**75.6**	**51.1**	**77.3**	**80.9**

FIGURE 1-2: MS PREVALENCE RATES, AUSTRALIA, 1961 – 2002



These Australian studies have demonstrated the following trends.

- A latitudinal gradient with higher frequency of MS in southern areas. Populations located at latitudes greater than 40°S report prevalence rates more than twice those for people living in northern States (Miller et al, 1990).
- A significant increase in prevalence over time, although it is not clear the extent to which this reflects better case ascertainment or differential migration of people from high risk populations (Hammond et al, 1987; Hammond et al, 1988b).
  - Prevalence in Newcastle has risen by 272% for females and 74% for men from 1961 to 1996 (Barnett et al, 2003). The rise was attributed to increased incidence, particularly among females, and to increased survival rates.
  - The 1996 study of prevalence in the ACT found unexpectedly high levels of MS, compared to results then available (1981) of prevalence in Newcastle, a city of similar latitude. Subsequent publication of MS prevalence in Newcastle (Barnett et al, 2003) during 1996 in fact shows very similar results between the two cities at the later date.

Age-specific prevalence rates from the two 1996 surveys are set out in Table 1-3 below.

TABLE 1-3: AGE-SPECIFIC PREVALENCE RATES, 1996

	Newcastle, 1996						ACT, 1996					
	Male		Female		Person		Male		Female		Person	
	pht	n	pht	n	pht	n	pht	n	pht	n	pht	n
10-19		0		0		0	0	0	4.3	1	2.1	1
20-29	17	2	26	3	21.4	5	21.9	6	25.7	7	23.8	13
30-39	69.5	7	92.5	9	80.8	16	51.9	13	134.7	35	92.1	47
40-49	34.3	3	165.8	14	98.9	17	71	17	184.2	46	128.8	63
50-59	49	5	221.5	14	150.2	19	60.3	9	194.6	28	119.4	37
60-69	55.9	3	161.3	10	112.4	13	61	5	72.2	6	66.7	11
70+	31.3	2	71.9	7	55.8	9	0	0	34.3	3	28.2	3
Total	**33.7**	**22**	**83.7**	**57**	**59.1**	**79**	**32.2**	**50**	**82.5**	**126**	**57.1**	**176**
AS Total	***33.1***		***83.4***		***58.6***		***32.8***		***79.9***		***56.7***	
95% CI	20.6-50.2		62.9-108.4		46.3-73.2		22.7-46.2		63.4-99.2		43.1-74.1	

Source: Barnett et al (2003), Simmons et al (2001). 'AS Total'= age-standardised. 'pht' = per 100,000.

Taking a simple average of these two most recent detailed studies suggests a prevalence rate of 33.0 per 100,000 for men and 83.1 per 100,000 for women. Applying these average rates to the Australian population in 2001 would suggest around 11,480 people had MS – somewhat less than the number reported in the 2001 National Health Survey.

Because of the strong latitudinal gradient present in previous Australian studies, using the average from the 1996 studies may overstate prevalence in the northern States and understate prevalence in the more southern States. One possible way to induce differential prevalence rates for different States is to scale the 1996 Newcastle prevalence rates up or down in proportion to observed differences in prevalence in the 1981 studies. However it is not at all clear that these proportions would accurately represent differences in prevalence in 1996. Comparisons of the differentials in the 1961 and 1981 surveys are quite different, as shown in the table below. There are also missing data points. It is not clear whether Victoria, which is situated between 35°S and 40°S and accounts for around 24% of the total Australian population, should have an imputed prevalence rate closer to that of Perth and Newcastle (30°S to 35°S) or of Hobart (40°S to 45°S).

TABLE 1-4: GEOGRAPHIC VARIATIONS IN MS PREVALENCE, AUSTRALIA, INDEX RELATIVE TO NEWCASTLE

Location	1961	1981
Newcastle	1.00	1.00
Perth	1.01	0.82
Hobart	1.63	2.07
Queensland	0.44	0.51
NSW	-	1.00
SA*	1.85	0.79

For this study, Access Economics has generated imputed age-specific prevalence rates for the Australian population as a whole for the year 2001 (see Table 1-5). These prevalence rates are based on the two 1996 studies which surveyed Australians living in the middle latitude areas but several adjustments have been made.

- The first adjustment was to remove the fluctuating pattern in prevalence among middle aged males (20-29 to 40-49 cohorts). This was necessary to remove the fluctuations present in the 1996 Newcastle prevalence estimates which are most likely a result of small sample size. In this study prevalence for men peaks in the 30-39 age group, and then falls over 50% among 40-49 year olds. This would suggest that men are dying or recovering from MS in middle age, which is not likely to represent a true approximation of disease progression.
- Secondly, prevalence rates for each age-gender cohort were scaled up by a factor of 1.312 so that, when applied to the 2001 Australian population, the total number of Australians with MS equalled that reported in the 2001 National Health Survey (14,900). The implicit assumption being made here is that between 1996 and 2001 the prevalence of MS has increased due to some combination of increased incidence, better diagnostic techniques and longer survival rates for people with MS. This scaling also accounts for the greater concentration of Australia's population in urban areas south of Newcastle, where prevalence is likely to be higher following the North-South gradient.

TABLE 1-5: PREVALENCE RATES FOR COSTING PURPOSES

Age Group	Male per 100,000 pop	Female per 100,000 pop
10-19	0.0	5.6
20-29	25.5	33.9
30-39	68.1	149.0
40-49	69.1	229.6
50-59	71.7	273.0
60-69	76.7	153.2
70+	20.5	69.7

The difference between prevalence rates in the original 1996 studies and Access Economics' imputed rates for 2001 can be seen in Figure 1-3 (females) and Figure 1-4 (males), taking into account the increased prevalence trends over time.

FIGURE 1-3: COMPARISON OF AGE-SPECIFIC PREVALENCE RATES, FEMALES

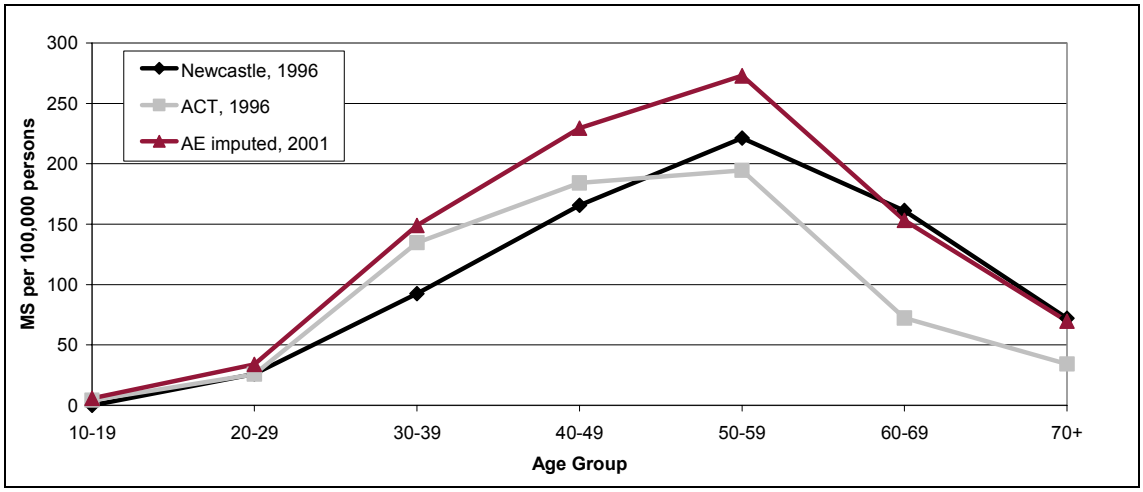
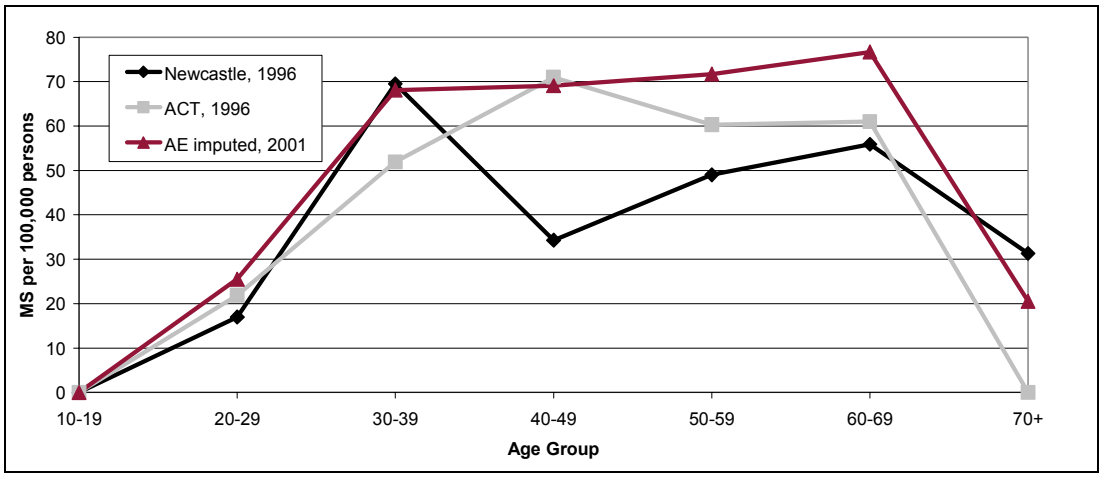


FIGURE 1-4: COMPARISON OF AGE-SPECIFIC PREVALENCE RATES, MALES



1.3.2 PREVALENCE ESTIMATES AND PROJECTIONS

Estimates of MS prevalence in 2005 and projected prevalence in 2010 and 2020 are made on the basis of the imputed age-specific prevalence rates set out in Table 1-5 above and presented in Table 1-6.

TABLE 1-6: MS PREVALENCE BY AGE AND GENDER, AUSTRALIA, 2005, 2010, 2020

	2005	2010	2020
Male			
0-19	-	-	-
20-29	359	377	391
30-39	1,009	1,010	1,072
40-49	1,029	1,050	1,069
50-59	925	989	1,087
60-69	660	822	1,021
70+	167	193	285
Total	**4,150**	**4,441**	**4,925**
per 100,000	***41.14***	***41.94***	***42.76***
Female			
0-19	147	145	140
20-29	469	491	505
30-39	2,246	2,236	2,345
40-49	3,462	3,524	3,574
50-59	3,539	3,840	4,197
60-69	1,316	1,651	2,122
70+	752	833	1,143
Total	**11,931**	**12,721**	**14,026**
per 100,000	***116.52***	***118.43***	***120.17***
Persons			
0-19	147	145	140
20-29	829	868	896
30-39	3,256	3,247	3,417
40-49	4,491	4,574	4,643
50-59	4,464	4,828	5,284
60-69	1,976	2,474	3,143
70+	919	1,026	1,428
Total	**16,081**	**17,162**	**18,952**
per 100,000	***79.12***	***80.45***	***81.72***

- **There are estimated to be 16,081 people with MS in 2005, increasing to 17,162 people (up 6.7%) by 2010 and to 18,952 people (up 10.4% from today) by 2020**.
- **74% of all Australians with MS are female**.
- **87% of Australians with MS are of working age** (15-64 years), which is projected to decline a little to 84% by 2020.
  - Over half of Australians with MS are aged 40-59 (56% now falling to 52% by 2020).
  - Senior Australians (aged 60 and over) with MS will increase from 18% to 24% of the total in the next 15 years, while the share of younger people (under 40) with MS will decline from 26% to 24%.

It should be noted that these estimates only allow for changes in the demographic makeup of the Australian population over the next 15 years; the imputed age-gender prevalence rates from 2001 are thus assumed to remain constant thereafter.

The age-gender distribution in 2005 is illustrated in Figure 1-5, while the change in the age distribution is highlighted in Figure 1-6.

- There will be more than 50% growth in the number of people with MS aged over 60, over the next 15 years.
- In contrast, the number of people aged 0-19 is projected to fall over the forecast horizon.

FIGURE 1-5: MS PREVALENCE BY AGE AND GENDER, 2005

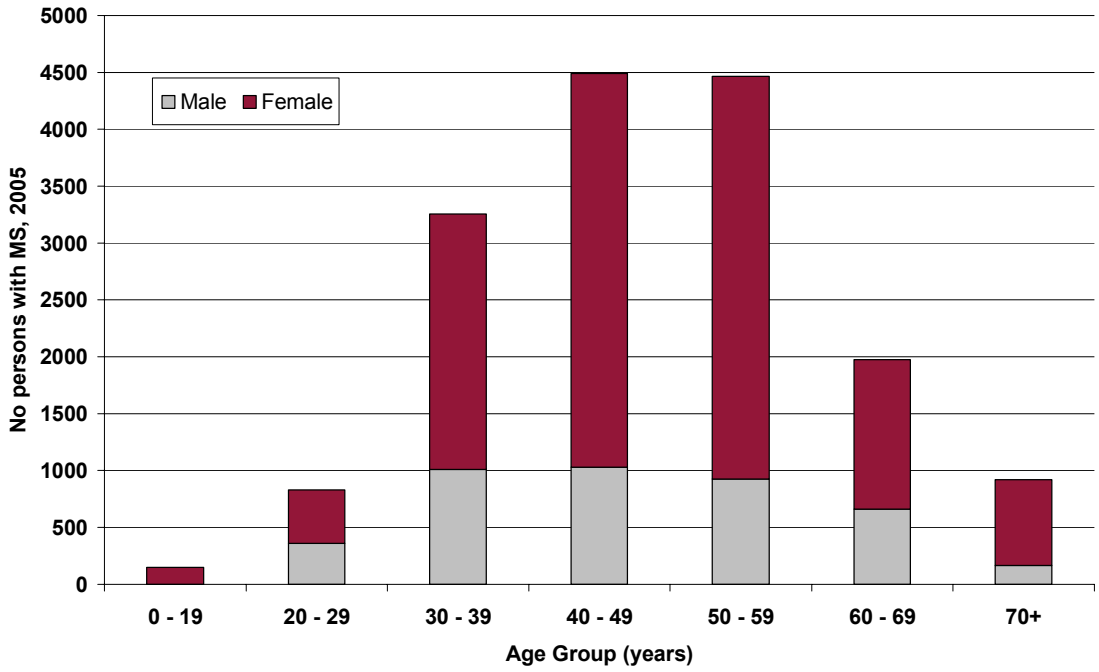
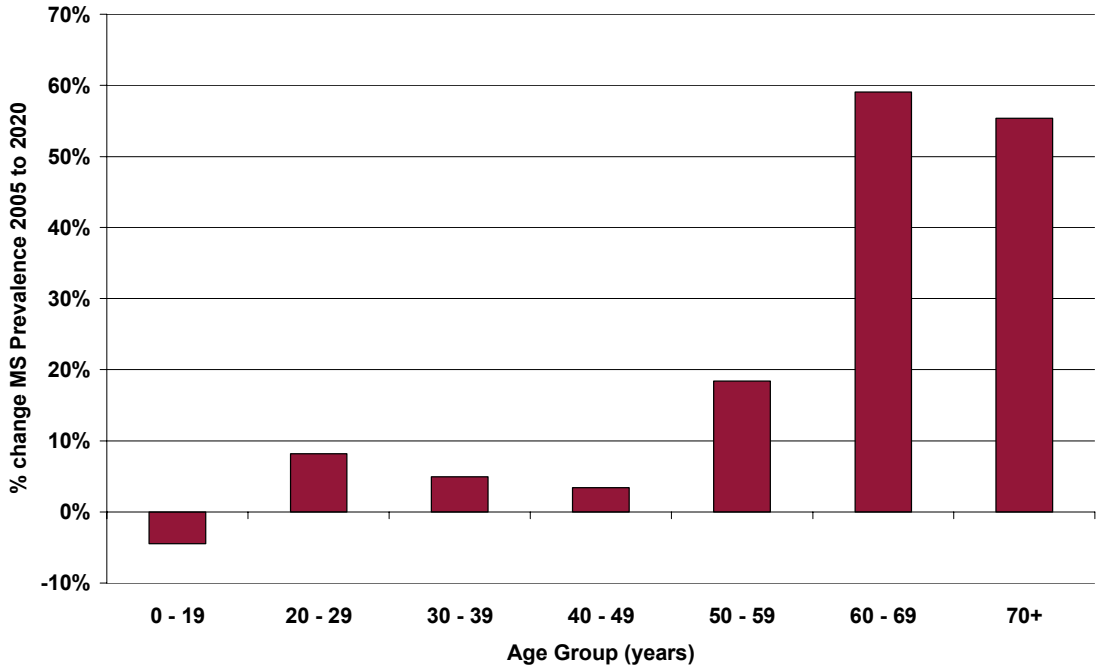
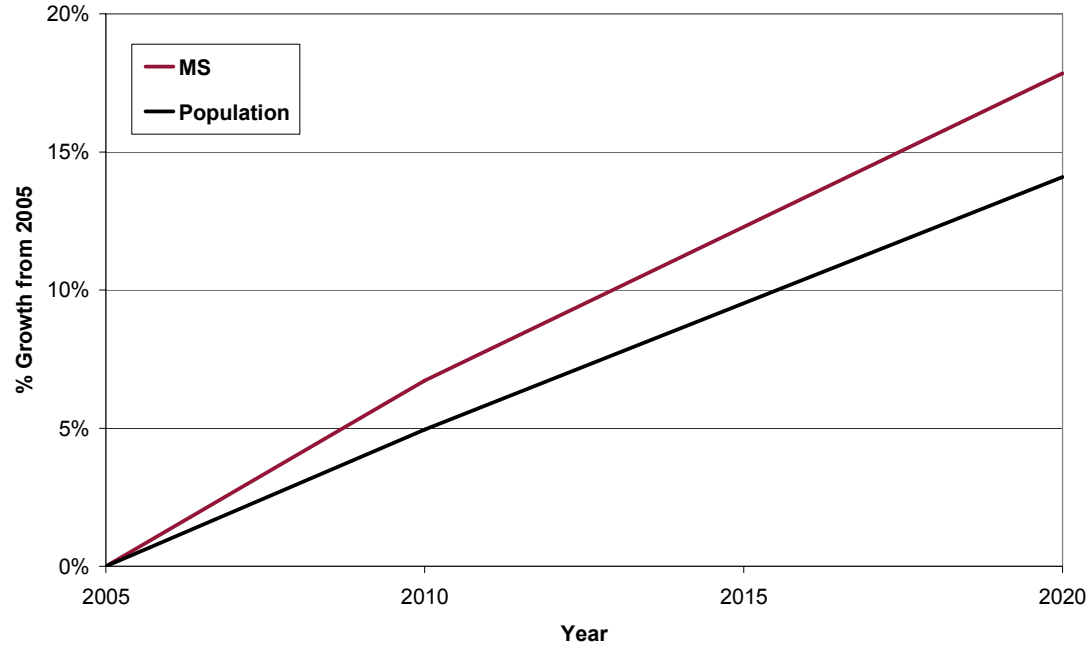


FIGURE 1-6: MS PREVALENCE, % CHANGE BY AGE GROUP, 2005 TO 2020



The growth in MS prevalence relative to (slower) population growth is illustrated in Figure 1-7.

FIGURE 1-7: GROWTH IN MS PREVALENCE RELATIVE TO POPULATION, 2005-2020



1.4 HEALTH AND SOCIOECONOMIC IMPACTS

Information in this section draws significantly on data from the Australian Multiple Sclerosis Longitudinal Study (AMSLS), a national research database owned by MS Australia. The AMSLS includes an initial sample of 2,000 people with MS randomly selected from the membership lists of Australian State and Territory MS Societies and other people diagnosed with MS after 30 June 2002 who have volunteered to enrol with the AMSLS. The AMSLS records both demographic information and clinical information provided by the participant's neurologist or treating physician including diagnostic classification using the McDonald criteria (see Section 1.1.1), the type of MS and disease stages.

The AMSLS Economic Impact of MS Working Party is currently undertaking a comprehensive nation-wide sub-study of the cost of MS in Australia, known as the Economic Impact Study (EIS). In August 2003 the AMSLS EIS obtained 1,134 responses to:

- a **Baseline Questionnaire** covering time since first symptom, time of diagnosis, place of residence, number of dependents, employment, unpaid assistance, health insurance and health-related quality of life (measured against the SF-36 index); and
- a prospective **Cost Diary** completed over one month covering the resource use and costs of MS.

The AMSLS EIS survey sample has been found to be generally representative of people with MS in Australia, as shown by comparison with data on people with MS from other existing Australian studies (Hendrie et al, 2004).

Detailed analysis of the AMSLS EIS will be forthcoming over time, but preliminary results of the costing exercise were released in November 2004 (Simmons et al, 2004).

1.4.1 DISABILITY

The majority of people with MS do not become severely disabled. Longitudinal studies have shown that around half of people with MS are independently mobile after 15 years and can live normal and productive lives.

Physicians and researchers often use a scale called the Kurtzke Disability Status Scale to assess and predict future disability (Kurtzke, 1997). The system uses a score of 1 to 10 to rate the degree of disability. Experts have used the scale to attempt to predict average times for progression from one MS stage to the next depending on whether they have relapsing-remitting or chronic progressive disease (Table 1-7).

TABLE 1-7 MS DISABILITY SCORE AND DISEASE PROGRESSION

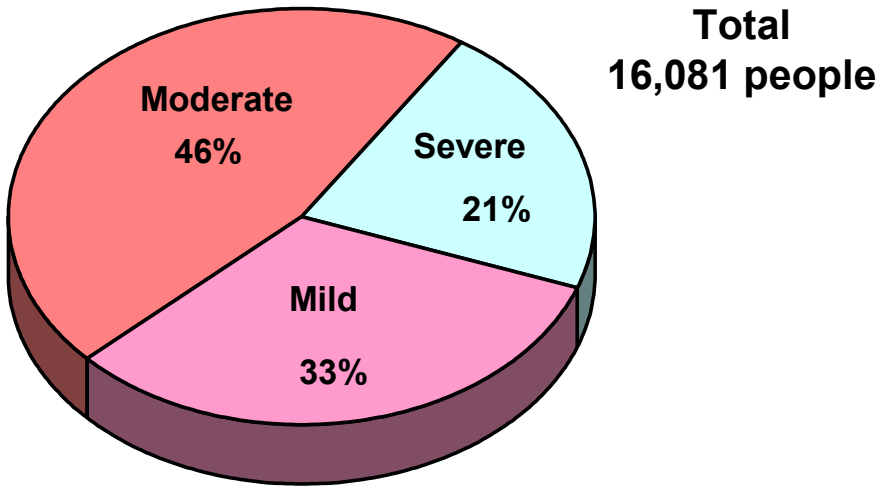
Score	Disability Description	Relapsing-Remitting MS: Average time until onset of symptoms	Chronic Progressive MS: Average time until onset of symptoms
1	No disability and minimal neurologic symptoms.	11.4 years from Score 1 to Score 4	0 years from Score 1 to Score 4
2	Minimal disability in one or two functional areas. Slight weakness or stiffness, mild walking impairment or visual disturbances		
3	Moderate disability in one functional area, such as vision or the urinary tract, and possibly more than one minimal disability in several others. Either a part or one of the limbs or a whole side can be partially paralyzed. May stagger at times.		
4	Disability is relatively severe but there is full ability to walk without aid. Patients are self sufficient and can be active 12 hours a day and carry on normal activities. Can walk without aid or rest for 300 to 500 meters.		
5	Disability is severe enough to impair or even preclude a full day's activities. Able to walk unaided and without rest for 100 to 200 meters.	23.1 years from Score 1 to Score 6	7.1 years from Score 1 to Score 6
6	Can walk unaided for about 100 meters only with assistance or devices, such as two canes, crutches, or braces.		
7	Mostly restricted to wheelchair, although can manage the wheelchair and leave it unassisted. Can walk with aids no further than about five meters.	33.1 years from Score 1 to Score 7	13.4 years from Score 1 to Score 7
8	Mostly restricted to wheelchair or even bed but still has effective use of arms remains and able to perform many self-care functions.	(data not available)	(data not available)
9	Bedridden. Patient can communicate or eat.		
10	Fatality occurs from complications.		

Source: Confavreux et al (2000).

Classification of mild, moderate and severe disability from MS in the most recent AMSLS patient self-report "Six-monthly Survey of MS and Medication" (1,740 responses, around an 80% response rate), were:

- Mild (Disease Steps 1, 2) = 560/1740 = 32.2% or 5,232 Australians in 2005;
- Moderate (Steps 3, 4, 5) = 796/1740 = 45.7% (7,403 people);
- Severe (Steps 6, 7, 8) = 367/1740 = 21.1% (3,447 people); and
- Missing data = 17/1740 = 1.0%, distributed equally across groups in Figure 1-8.

FIGURE 1-8: MILD, MODERATE AND SEVERE DISABILITY FROM MS (% OF TOTAL), 2005



Source: AMSLS

1.4.2 SOCIOECONOMIC STATUS AND RURALITY

Socioeconomic factors

Many chronic illnesses, including MS, have an inverse correlation with income and financial wellbeing – in part since people with lower incomes may have a greater predisposition to chronic illness. Possibly more important in the case of MS is that chronic illness has a negative impact on earning capacity as well as increasing medical and indirect expenses, which reduce disposable income. In one English study, 37% of respondents claimed that their overall standards of living had declined since MS was diagnosed, due to either a loss of employment or additional expenditure incurred as a result of disability (Hakim et al, 2000).

Preliminary published results from the AMSLS EIS (Simmons et al, 2004) suggest that Australians with MS often have lower income levels than the general Australian population. Age and gender standardised data from the AMSLS EIS show that a significantly greater proportion of people with MS – 48.2% compared to 38.8% – have low gross personal incomes (less than $16,000 per annum) compared to the general Australian population (ABS, 2005b). The general Australian population comparators are based on 2001 Australian Bureau of Statistics Census of Population and Housing Expanded Community Profile data for Australia, based on place of remuneration.

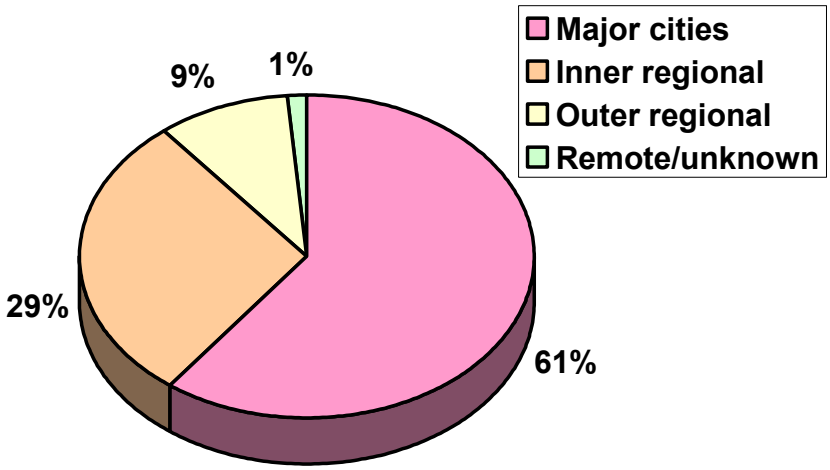
Financial problems, whether imposed by MS or already present, limit the ability for people with MS to access health services that are not provided through funded programs. Physiotherapy is one such service (often privately purchased) that is required to maintain mobilisation of the musculature and where disability can be compounded by lack of regular treatment.

Rurality

The AMSLS database enables calculation of prevalence by Accessibility Remote Index of Australia (ARIA) code. The results are presented in Figure 1-9, with 61% of people with MS in major cities (fewer than the 66% Australia-wide; ABS, 2004b), 29% in inner

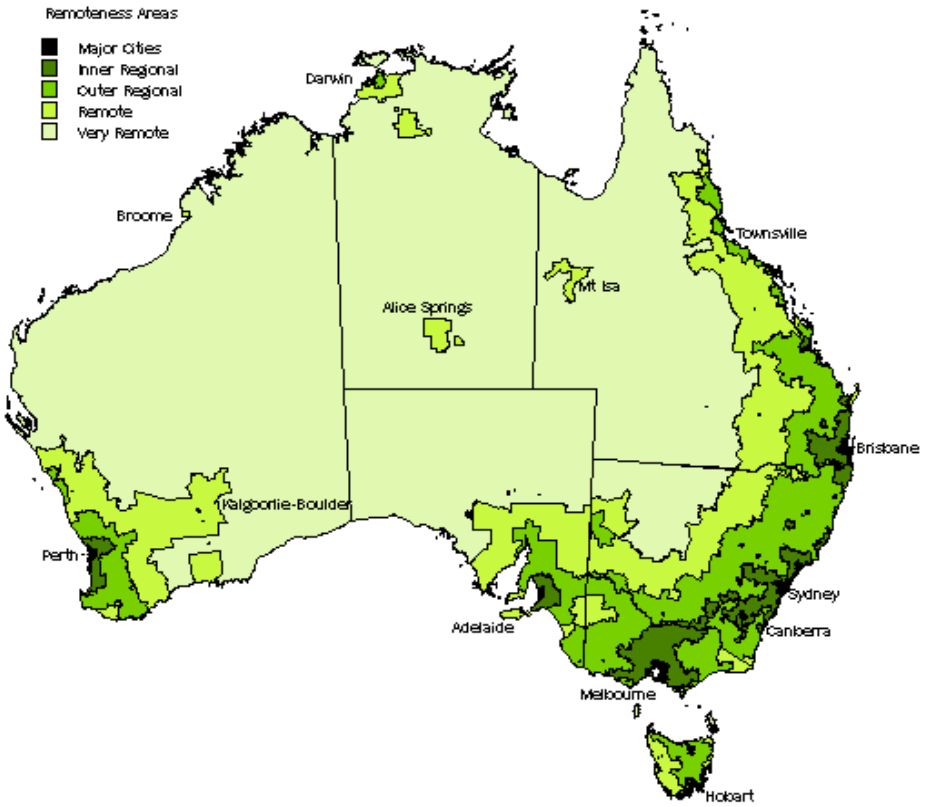
regional areas (compared to 21%), and 10% in outer regional and remote areas (13%). This may reflect latitude issues (Figure 1-10) as well as possible sampling issues for outer regional and remote areas. It could also be that people with MS moved to inner regional areas for access and economic reasons. There is a lower representation in the major cities – possibly due to high costs of housing, particularly open ones allowing for easy access. Additionally, outer regional and remote areas may have lower representation due to wanting to be closer to services and decrease the fatigue associated with travel. The AMSLS EIS did not specifically collect this data, however, people did report in written accounts that travel and access were issues, as were affordable housing.

FIGURE 1-9: MS PREVALENCE BY RURALITY (% OF TOTAL), 2005



Source: AMSLS

FIGURE 1-10: REMOTENESS ACROSS AUSTRALIA



Source: ABS (2004b)

1.4.3 EMPLOYMENT

The AMSLS EIS collected data on the number of people in full-time and part-time employment, those unemployed, and those not participating in the workforce for the year to August 2003. The AMSLS EIS preliminary published results (Simmons et al, 2004) summarise some effects of MS on employment.

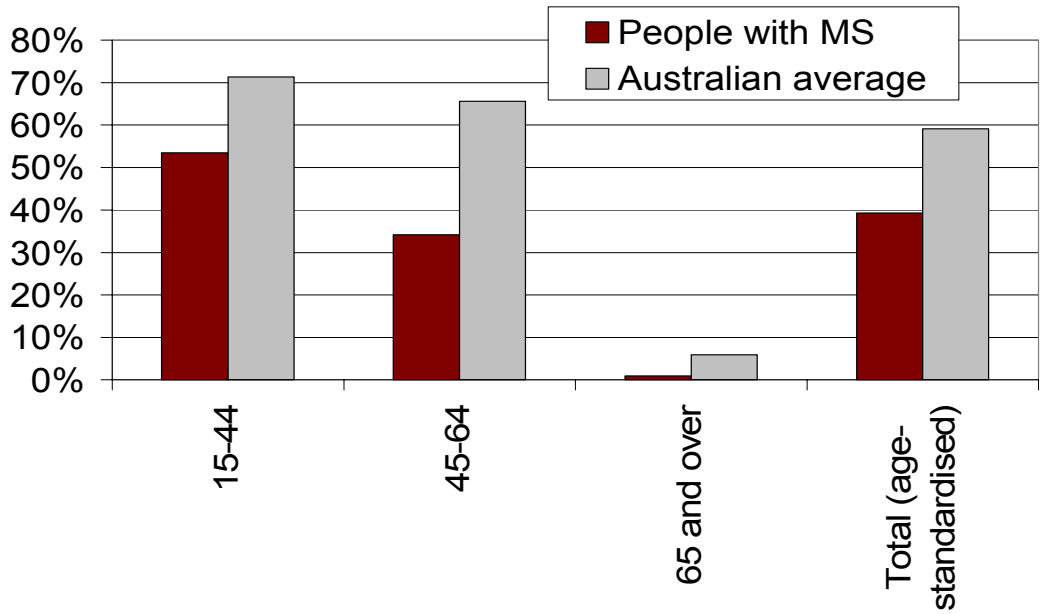
- People with MS are far less likely to be in full-time employment, but have similar levels of part-time employment to the general population.
- Almost half of the study sample had left their paid employment due to MS.
- The impact of physical symptoms is the most common reason stated for leaving paid employment due to MS. Workplace unsuitability was also frequently cited.
- Another third of people felt their current employment was at risk.
- People with MS in employment tended to be in higher skilled jobs than the general population.

Figure 1-11 illustrates the lower rates of employment at each age level and across the age-standardised population (ie assuming that the sample of people with MS were distributed in the same way as those in the Australian population sample).

- 39.3% of people with MS (age-standardised) are employed compared to 59.1% of the Australian population, on average.

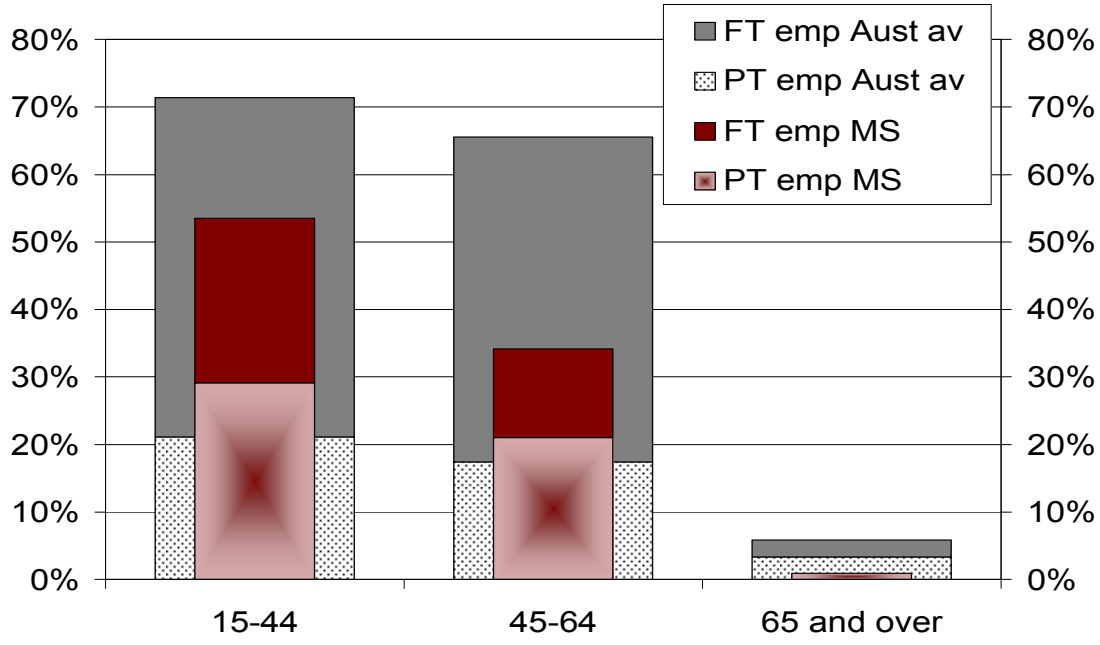
- The difference is 19.9%, or 3,195 people not in the workforce in 2005 due to their MS.

FIGURE 1-11: MS EMPLOYMENT RATES RELATIVE TO AUSTRALIAN AVERAGES, 2003



Source: AMSLS EIS.

FIGURE 1-12: MS FULL-TIME AND PART-TIME EMPLOYMENT RATES RELATIVE TO AUSTRALIAN AVERAGES, 2003



Source: AMSLS EIS.

Figure 1-12 shows the difference in full-time and part-time employment rates.

- Part-time employment rates are higher in the 15-44 and 45-64 age groups. Employment losses derive mainly from people with MS being unable to work full time, and thus to be employed less overall.

The unemployment rate among people with MS is estimated from AMSLS EIS data as 4.3%, lower than the 5.7% across the Australian population, noting the small sample size (n=19 people with MS unemployed).

Case studies

Ten years ago I had a budding career as a chef. I used to work 60 to 80 hours a week, and I loved it.

Ten years ago I was diagnosed with MS. The diagnosis came suddenly; I was extremely tired, started cutting myself and found that I needed to pull myself up stairs by using the banister, as my legs were tired and weak. It was a huge shock, not only for me but for my family and friends.

MS is unpredictable by nature, no two people will experience the same road; it's a personal journey… There is no pattern, no reason, and sometimes it can be downright scary, to say the least. MS can affect any body function you can think of; personally for me it seems to have taken a liking to my legs. I have sensory issues from the waist down, been in a wheel chair having to learn to walk again, been blind, had double vision, incontinence and a myriad of other things… But most of all it affects our stamina, our ability to do anywhere near what a normal person considers physically ordinary…

A month ago I was hospitalised on intravenous steroids, 1000mg a day for 4 days as my leg decided not to work. Needless to say I had to take time off work to recover. I have a very understanding boss, which I am thankful for. And again only last week I had vertigo and needed more time off work…

There is also the question of discrimination in the work place; having MS can make getting a job harder. Potential employers don't deliberately practice discrimination because of MS. Rather, it is our unpredictability in being able to work that throws out their schedules… Part time work is also a key as people with MS experience fatigue and in many cases cannot work full time… **In my case, working part time enables me to have a normal life outside of work; my episodes are decreased as the stress and fatigue are easier to manage.**

Having a disability also has its issues, an example being transport... Even temporary loss of the use of an arm, leg, or sight causes us difficulty in driving so the expense of taxis becomes an issue. Public transport is not an option; getting to the station or tram stop would be hard enough let alone getting on the tram, bus or train and by the time that we got to our destination we would be worn out.

[There is also the cost of] medication, doctor's bills, equipment like wheel chairs, and changing of equipment in the home to help with everyday tasks like bathing and going to the toilet that would otherwise be taken for granted.

People with MS want to work, we want to be part of society and valued by society, even if that means a part time role in a completely different capacity to the training and profession that was chosen originally. In my case, cooking. I am lucky that I have found working on the phones or dealing with people in what I like to call a "sit down job" is what I like to do.

From a speech by Rachelle Pynt, New South Wales, 35 years, 9 March 2005

I was 46 years old when I was diagnosed with MS and was in a high-powered management job. At 46 I was too young to retire and still had the ability to perform the job I was employed to do.

Then there was the question of disclosure – should I tell my employer I had been diagnosed with this unpredictable illness, not knowing what my future was – would I be wheelchair bound, lose my sight or suffer other disabilities that come with this cruel illness? I did, however, make the mistake of telling one of my work colleagues – a person that I regarded as a friend – that I had been diagnosed with MS. Unbeknownst to me he went straight to the managing director of the company I worked for and told him I had been diagnosed with MS.

After 30 years in the workforce – I had been head-hunted by other employers – I was now being head-hunted by a neurological disease with no known cause or as yet no cure.

Work had always been a great part of life. I was fortunate in that I had worked in senior positions within the printing industry and had the respect of my colleagues and suppliers. The hours were long but the personal and financial rewards were satisfying. This was about to change.

My employer, on being told of my diagnosis by my work colleague, had started to consult with an employer body and other senior staff members to find a way to get me to resign my position. The first thing they did was relocate me from my downstairs office to an office upstairs, where it was hot as opposed to my original office that was air conditioned… One of the major effects [of MS] on me is fatigue, which is exacerbated by heat – and for me to walk up a flight of stairs even in those early days was not easy. It was not unusual for me to actually have to sit down whilst ascending the stairs and even complete the climb on all fours.

Eventually the position I had was made redundant and I was offered another position with less money and no company car. What followed was another stressful period, another relapse and eventually the new position was also made redundant…

I tried to find other employment but could not hide the fact that I had MS, and found that no-one was prepared to employ me. Now, since my illness has progressed, I know I cannot work full time – in fact, some days I cannot get out of bed…

As a person under retirement age I do not get the benefits that those on senior cards do, something I believe is wrong as we, in most cases, still have mortgages and school fees to pay. When I lost my job I was not at the stage of life where I was financially independent. I still had a child at school and I was the main breadwinner in our home…

Discrimination is out there in the workforce – for those [with MS] who can still work, there are so many obstacles put in their way that it is almost impossible to work. Yes, I do have a potentially disabling disease, but I can't help wonder if intolerance and lack of understanding are more of a disability.

Financial loss is a symptom [of MS]. You will not find it in any textbook, but it can be one of the most debilitating.

From a speech by Robert Pask, Victoria, 55 years, 9 March 2005

1.4.4 USE OF MEDICAL, WELFARE AND OTHER SERVICES

The AMSLS EIS collected a variety of data on service utilisation and expense items across a range of areas where MS has health and socioeconomic impacts. The AMSLS EIS provides particularly valuable source data in relation to use of:

- aids and equipment (see Section 2.2.4);
- informal care (Section 2.2.2); and
- welfare payments (Section 2.2.3) received by:
  - 513 of 1020 people with MS under 65 (50%); and
  - 95 of 113 people aged 65 years and over (84%).

Table 1-8 presents the categories in the AMSLS EIS, together with preliminary estimates of total and per person costs, based on the authors' assumption of 15,000 people with MS in Australia.

- The preliminary estimate of total costs is $659.3m, including 40% indirect costs (production losses), 36% 'direct' costs, 15% informal care and 9% high care residential care.

TABLE 1-8: COST CATEGORIES IN THE AMSLS EIS AND PRELIMINARY ESTIMATES

Cost category	Explanation	$m	% of total	$ per person
Direct costs – personal	People with MS living in the community – includes medications, medical services, support services, medical tests, hospital stays, assistive and medical aids, medical products, and home and car alterations	58.4	9%	3,893
Direct costs – community/ government	As above	178.1	27%	11,873
Nursing home and equivalent high support care costs		60.2	9%	4,013
Informal care	People with MS living in the community – includes unpaid care and estimated as 15% of total cost of MS	98.9	15%	6,593
Indirect costs	Includes sickness absence and early retirement estimated as 40% of total cost of MS	263.7	40%	17,580
Total cost		**659.3**	**100%**	**43,953**

Source: Simmons et al (2004).

It should be noted that the definitions and methodology in the AMSLS EIS study are quite different from those in this Access Economics report. The key differences are:

- this report defines direct costs as health system expenditures in accordance with official categories, while the AMSLS EIS has a broader definition, for example including home and car modifications as direct costs;

- the AMSLS EIS adopts a "bottom-up" approach throughout, while this report adopts a 'top-down' approach for direct costs and a bottom-up approach for indirect financial costs; and
- this analysis includes an estimate of the 'burden of disease' due to suffering and premature death from MS.

The impacts of the need for aids and modifications, carers, and welfare services are explored in much greater detail when utilised in the indirect costings in Section 2.2 of this report.

2. THE COST BURDEN OF MS IN AUSTRALIA

2.1 DIRECT HEALTH SYSTEM COSTS

There are two main methods for estimating direct health system costs.

- Top-down disease cost data are derived in Australia by the Australian Institute for Health and Welfare (AIHW) from an extensive process developed in collaboration with the National Centre for Health Program Evaluation for the Disease Costs and Impact Study (DCIS). The approach measures health services utilisation and expenditure (private and public) for specific diseases and disease groups in Australia. The DCIS methodology has been gradually refined over the 1990s to now estimate a range of direct health costs from hospital morbidity data, case mix data, Bettering the Evaluation and Care of Health (BEACH) data, the National Health Survey and other sources. AIHW (2005) provides a summary of the main results of estimates of health expenditure by disease and injury for the year 2000-01.
- Bottom-up cost estimates use a process of data-gathering (possibly supplemented by targeted surveying) for specific cost items – prescriptions, GP appointments, radiology, hospitals, and so on. In Australia, this approach has been adopted in the AMSLS EIS conducted by Dr Rex Simmons and his team.

The advantage of top-down methodology is that cost estimates for various diseases will be consistent, enhancing comparisons and ensuring that the sum of the parts does not exceed the whole (total health expenditure in Australia). The advantage of bottom-up methodology is that it can provide greater detail in relation to specific cost elements and can capture indirect cost elements as well as direct cost elements.

In this study we have utilised top-down data primarily, while triangulating against preliminary data from the AMSLS EIS.

2.1.1 METHODOLOGICAL BASIS

Data for MS were purchased by special request from the AIHW for MS for the top-down analysis of direct costs. Younger age groups have been combined (0-24 years) to enhance the reliability of estimates.

- Admitted patient (**inpatient**) costs were based on 3,345 separations for MS in 2000-01 (0.5% of total separations).
- Unreferred (**GP**) costs are based on 150 statistical encounters with patients with MS from three years of BEACH data.
- The age-gender breakdown for other out-of hospital medical services (**specialists, imaging and pathology**) is based on that of the unreferred encounters, noting that for imaging and pathology the numbers are quite small, so care should be taken in using the age-gender estimates, although the sub-totals are quite robust.
- Total expenditure for **non-admitted** patients and **over-the-counter medications** is estimated using 1993-94 DCIS proportions for MS, with the age-gender distribution based on the GP distribution. There is thus less certainty with these estimates.

- For **other health professionals**, the estimate is based on referrals from GPs, which seems to happen rarely on the basis of the BEACH data. This is likely to be a very conservative estimate since a large proportion of allied health services are unreferred.
- **High care residential accommodation** costs are based on the 1998 Survey of Disability Ageing and Carers, which reveals that 0.5% of high care expenditure in aged care homes was for residents who had MS as their main problem.[7] The age-gender distribution was derived by Access Economics by averaging two possible distributions.
  - The first distribution was based on prevalence of MS plus 20 years. This could be expected to indicate the number of people with progressed MS and thus disability.
  - The second distribution is that of aged care expenditure from AIHW (2001) for people with diseases of the nervous system and sense organs, which is likely to be an older distribution than those people with MS in aged care homes.
  - In averaging these estimates we are likely to have a more valid approximation of the age-gender split of people with MS in aged care facilities. However, we note that, **since admission to care facilities for the elderly may be inappropriate for younger people with disability from MS, it is important that better data in this area are collected to enhance future policy making in relation to the high care needs of people with MS**.

The AIHW include only 86% of total recurrent health expenditure in their estimates of expenditure by disease and injury, referred to as 'allocated' health expenditure. The 'unallocated' remainder includes capital expenditures, expenditure on community health (excluding mental health), public health programs (except cancer screening), health administration and health aids and appliances. Allowance is made for the unallocated component after presentation of the allocated components in Section 2.1.2.

The AIHW 2000-01 data were used as the base for Access Economics' estimates for spending on MS in 2005. Two factors contributed to the extrapolation.

- Health cost inflation (AIHW, 2004a) measured 3.5% in 2000/01-01/02 and 4.2% in 2001/02-02/03 and is assumed to measure 2.9% (the average rate for the ten-year period to 2002–03) till the end of 2005 – 17.5% overall for the whole period - as detailed in Table 2-1; and
- estimated growth in the population from 2001 to 2005, derived from ABS demographic data for each age-gender group.

[7] Similar data from the 2003 Survey of Disability Ageing and Carers are not yet available. The Survey has a separate 'cared accommodation' component, completed by nursing staff at the facility, from which the 0.5% estimate is derived. This estimate is quite robust and unlikely to change much in the 2003 survey.

TABLE 2-1: HEALTH COST INFLATION, % PER ANNUM, AUSTRALIA, 1992-93 TO 2002-03

Period	Health inflation	General inflation
2000–01 to 2001–02	3.5	2.5
2001–02 to 2002–03	4.2	2.5
Average annual rates of inflation		
1992–93 to 1997–98	2.6	1.5
1997–98 to 2002–03	3.2	2.4
1992–93 to 2002–03	2.9	1.9

Source: AIHW (2004a).

2.1.2 HEALTH COSTS IN 2005

In 2005, the allocated health costs of MS are estimated as **$117.1m**.

- Two thirds of this expenditure is for women with MS ($79.1m) and one third for men with MS ($38.0m).
- More than half of health costs are incurred by people aged 35-54 (Figure 2-1).
- Average allocated health cost per person with MS is $7,279 per annum.
  - Cost per person with MS is lowest in the 25-44 age group, and highest in the 75 and over group, where residential care becomes the dominant cost element.

Table 2-2 over the page provides further detail.

FIGURE 2-1: ALLOCATED HEALTH COSTS, MS, BY AGE AND GENDER, 2005 ($M)

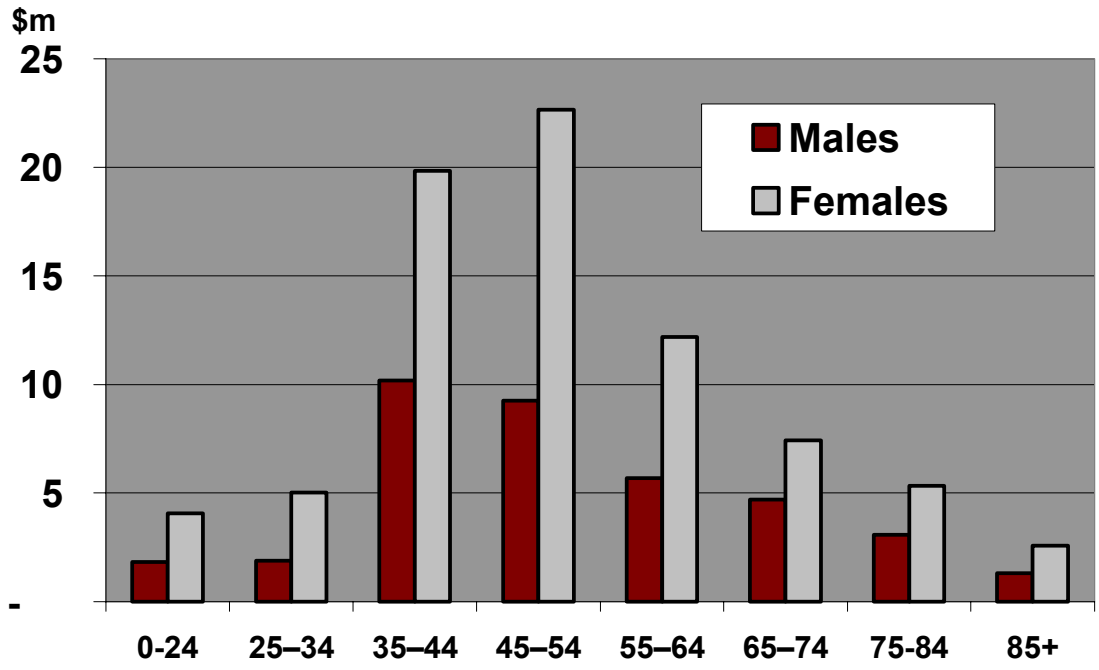


TABLE 2-2: ALLOCATED HEALTH COSTS, MS, BY COST TYPE, AGE AND GENDER, 2005 ($M)

	Hospitals				Medical services					Pharmaceuticals					
Age group	Inpatients	Outpatients	Total hospital	Aged care homes	Unreferred attend-ances	Imaging	Pathology	Other medical	Total out-of-hospital medical	Pre-scription	Over-the-counter	Total	Other health pro-fessionals	Research	**Total including aged care**
Male															
0-24	0.2	0.0	0.2	0.1	0.0	0.0	0.0	0.0	0.0	1.5	0.0	1.5	0.0	0.0	1.8
25–34	0.4	0.0	0.4	0.0	0.1	0.0	0.0	0.0	0.1	1.2	0.0	1.3	0.1	0.0	1.9
35–44	1.1	0.0	1.1	1.0	0.2	0.1	0.0	0.0	0.3	7.6	0.0	7.6	0.1	0.1	10.2
45–54	0.8	0.0	0.8	1.1	0.2	0.1	0.0	0.0	0.3	6.8	0.0	6.8	0.1	0.1	9.3
55–64	0.7	0.0	0.7	1.3	0.1	0.0	0.0	0.0	0.2	3.3	0.0	3.3	0.1	0.1	5.7
65–74	0.3	0.0	0.3	2.1	0.1	0.0	0.0	0.0	0.1	2.1	0.0	2.1	0.0	0.1	4.7
75-84	0.1	0.0	0.1	2.4	0.0	0.0	0.0	0.0	0.0	0.4	0.0	0.4	0.0	0.2	3.1
85+	0.0	-	0.0	1.2	-	-	-	-	-	0.1	-	0.1	-	0.1	1.3
Total M	**3.5**	**0.0**	**3.6**	**9.2**	**0.7**	**0.2**	**0.1**	**0.0**	**1.1**	**22.8**	**0.1**	**22.9**	**0.5**	**0.7**	**38.0**
Female	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
0-24	0.3	0.1	0.3	0.1	0.2	0.0	0.0	0.1	0.3	3.2	0.0	3.2	0.1	0.0	4.1
25–34	1.5	0.1	1.6	0.0	0.1	0.0	0.0	0.1	0.3	2.9	0.0	3.0	0.1	0.1	5.0
35–44	2.3	0.2	2.5	0.8	0.5	0.0	0.1	0.4	1.0	14.8	0.0	14.8	0.4	0.2	19.8
45–54	3.4	0.2	3.7	1.6	0.5	0.0	0.1	0.4	1.0	15.6	0.0	15.7	0.4	0.3	22.7
55–64	1.5	0.1	1.6	2.1	0.2	0.0	0.0	0.2	0.4	7.8	0.0	7.8	0.2	0.1	12.2
65–74	0.8	0.0	0.8	2.0	0.1	0.0	0.0	0.1	0.1	4.2	0.0	4.2	0.1	0.1	7.4
75-84	0.2	-	0.2	4.3	-	-	-	-	-	0.5	-	0.5	-	0.3	5.3
85+	0.0	0.0	0.0	2.0	0.0	0.0	0.0	0.0	0.0	0.3	0.0	0.3	0.0	0.2	2.6
Total F	**10.1**	**0.7**	**10.8**	**13.0**	**1.6**	**0.0**	**0.2**	**1.2**	**3.1**	**49.3**	**0.1**	**49.5**	**1.2**	**1.5**	**79.1**
Person	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
0-24	0.4	0.1	0.5	0.2	0.2	0.0	0.0	0.1	0.4	4.7	0.0	4.7	0.1	0.1	5.9
25–34	1.9	0.1	2.0	0.1	0.2	0.0	0.0	0.1	0.4	4.2	0.0	4.2	0.2	0.1	6.9
35–44	3.3	0.2	3.6	1.9	0.7	0.1	0.1	0.4	1.3	22.4	0.1	22.4	0.5	0.3	30.0
45–54	4.3	0.2	4.5	2.7	0.7	0.1	0.1	0.4	1.3	22.4	0.1	22.5	0.5	0.4	31.9
55–64	2.3	0.1	2.4	3.4	0.3	0.1	0.1	0.2	0.6	11.0	0.0	11.1	0.3	0.2	17.9
65–74	1.1	0.0	1.1	4.1	0.1	0.0	0.0	0.1	0.2	6.3	0.0	6.3	0.1	0.3	12.1
75-84	0.3	0.0	0.3	6.7	0.0	0.0	0.0	0.0	0.0	0.9	0.0	0.9	0.0	0.5	8.4
85+	0.0	0.0	0.0	3.2	0.0	0.0	0.0	0.0	0.0	0.4	0.0	0.4	0.0	0.3	3.9
Total	**13.7**	**0.7**	**14.4**	**22.2**	**2.3**	**0.3**	**0.4**	**1.3**	**4.2**	**72.2**	**0.2**	**72.4**	**1.8**	**2.2**	**117.1**

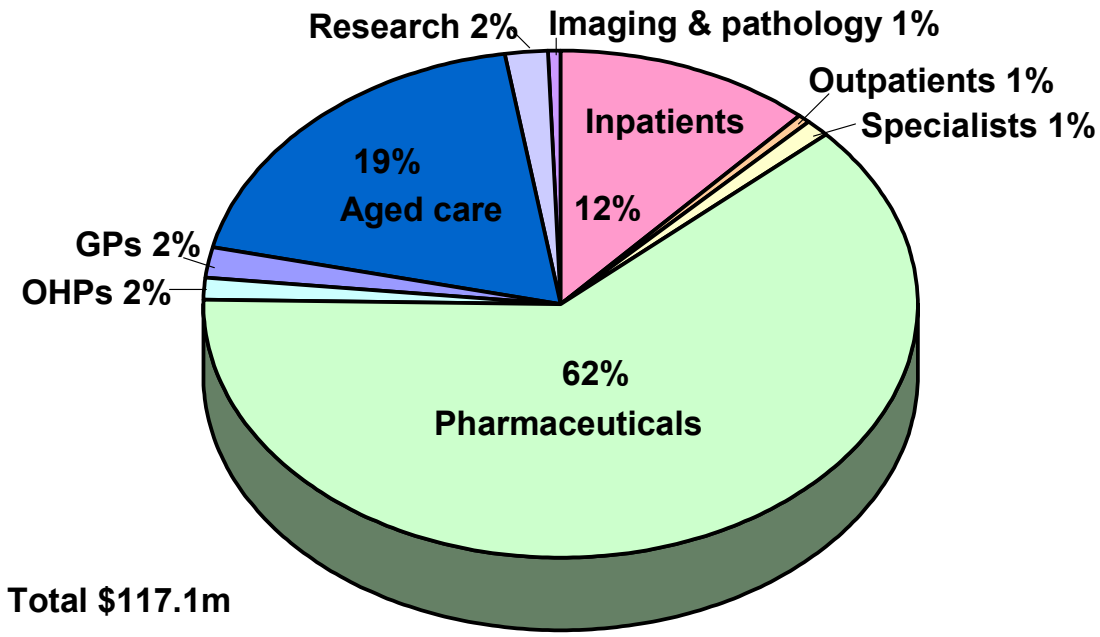
Note: Numbers may not sum due to rounding.

The health cost profile for MS is dominated by pharmaceuticals – $72.4m (61.8%).

The second largest cost component for MS is high care residential accommodation or 'aged care' (18.9% of total costs in 2005 or $22.2m).

- Inpatient hospital costs are the third largest component at $13.7m (11.7% of the total), while outpatient costs are only 0.6% of the total ($0.7m).
- Unreferred attendances (GPs) are $2.3m (2.0%); other (allied) health practitioners $1.8m (1.5%) and other out-of-hospital medical (specialists) are $1.3m (1.1%); imaging and pathology costs an estimated $0.6m (0.5%).
- Research into MS is estimated as $2.2m in 2005 (1.9% of total health expenditure on MS). The average research share for all health conditions, of total allocated health expenditure, is higher at 2.4% (AIHW, 2005).

FIGURE 2-2: ALLOCATED HEALTH COSTS, MS, BY COST TYPE, 2005 (% SHARE)



Note: Numbers may not sum due to rounding.

FIGURE 2-3: ALLOCATED HEALTH COSTS, MS, BY COST TYPE AND AGE, 2005 ($M)

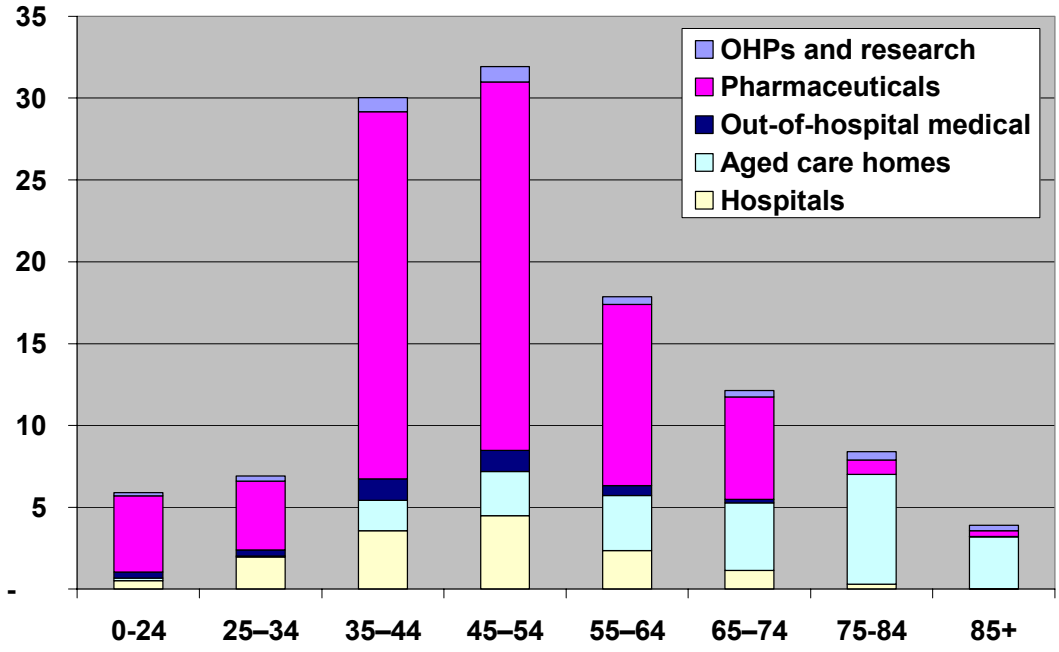


Figure 2-3 illustrates how pharmaceuticals dominate the expenditure profile early on, but aged care becomes the largest cost component for people with MS as they age, with the shares for hospital, pharmaceutical and other health elements diminishing in the older age groups.

The chart also illustrates that many younger people are, somewhat inappropriately, accommodated in facilities for the frail aged. If allocated recurrent aged care costs are a little over $30,000 per person per annum[8] this implies there are around 730 people with MS in aged care facilities in 2005, or around 4.5% of people with MS. Of those with MS who are 75 and over, an estimated 71% are in nursing homes. However, an estimated 136 people with MS aged 65-74 are in residential aged care and an **estimated 268 people with MS aged under 65 are in residential aged care. An estimated 69 people with MS aged under 45 are in residential aged care.**

TABLE 2-3: PEOPLE WITH MS IN NURSING HOMES, NUMBER AND % TOTAL, 2005

	People with MS	People with MS in homes	% of people with MS in homes
under 45	6,476	69	1.1%
45–54	4,477	89	2.0%
55–64	3,220	111	3.4%
65–74	1,448	136	9.4%
75+	460	326	71.0%
Total	16,081	730	4.5%

[8] In 2001 there were 144,013 operational residential aged care places (AIHW, 2004b) and total expenditure on residential aged care was $3,899m (AIHW, 2005) implying an average cost per person per annum of $27,074. Inflating this by the health cost inflator (2.9%) for four years gives an estimated cost per person per annum in 2005 of $30,354.

Unallocated health costs: As noted in the preamble to Section 2.1, the AIHW include only 86% of total recurrent health expenditure in their estimates of expenditure by disease and injury, referred to as 'allocated' health expenditure. The 'unallocated' remainder includes capital expenditures, expenditure on community health (excluding mental health), public health programs (except cancer screening), health administration and health aids and appliances. For MS then, these unallocated cost elements are estimated by grossing up the allocated health expenditure by 100/86. **Unallocated cost elements are thus estimated as $19.1m in 2005, bringing total health costs in 2005 to $136.1m.**

2.1.3 PROJECTIONS OF DIRECT COSTS

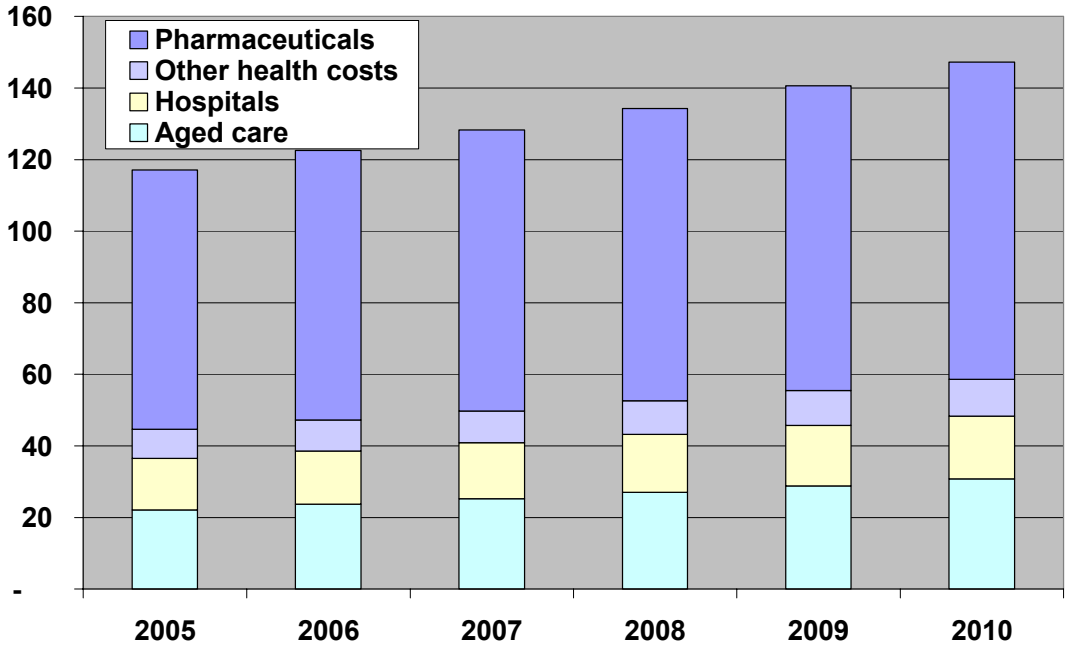
Health expenditure on MS is projected to the year 2010 based on demographic ageing (projected population change by age gender cohort) and health cost inflation (15.4% over the five-year period).

Again, the analysis is conducted in terms of the allocated health costs, with the unallocated component discussed at the end of the section.

- **By 2010, allocated health costs are estimated to rise by 27% to $147.2m**.
- Aged care costs grow fastest (39% over the period to $31m), reflecting the ageing of the sub-population of people with MS.
  - The share of aged care is thus projected to increase from 18.9% to 20.9% in the next five years.
- Pharmaceutical expenditure is projected to increase by 22%, with a fall in share from 61.8% to 60.2%.
- Hospital expenditure is projected to increase by 23%, with a fall in share from 12.3% to 12.0%.
- Other health cost items rise by 24% with share fairly constant.

Figure 2-4 illustrates the projected increases.

FIGURE 2-4: ALLOCATED HEALTH COST PROJECTIONS, MS, BY COST TYPE, 2005-2010

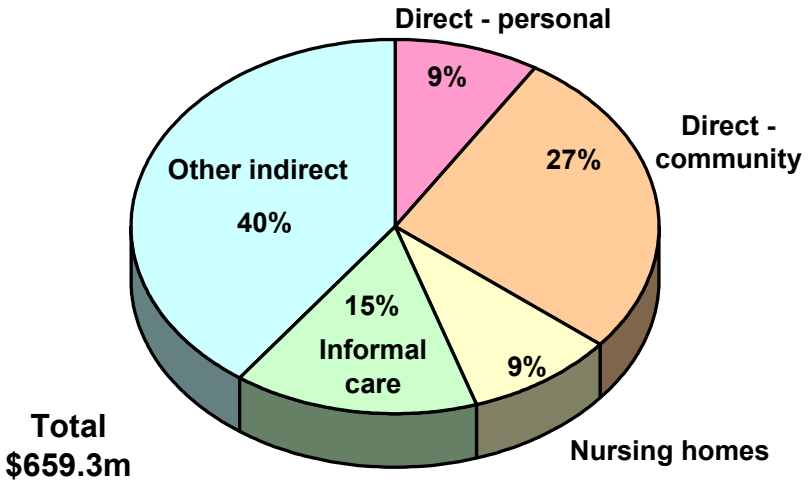


Unallocated cost elements are estimated as $24m in 2010, bringing total projected health costs in 2010 to $171.1m.

2.1.4 COMPARISON WITH BOTTOM-UP DATA

This section briefly compares preliminary results from the AMSLS EIS with Access Economics direct cost estimates and attempts to reconcile differences. Table 1-8 in Section 1.4.4 summarised the AMSLS EIS preliminary cost elements, illustrated below in Figure 2-5.

FIGURE 2-5: AMSLS EIS MS PRELIMINARY ESTIMATES OF COST COMPONENTS



Source: Simmons et al (2004).

Nursing home care: The AMSLS EIS estimates these as $60.2m per annum, more than double the Access Economics estimate of $25.8m (including $22.2m allocated and $3.6m unallocated) in 2005 dollars. The AIHW data and methodology are very reliable here. A possible reason for the difference is the large impact of comorbidity, for which no allowance is made in the AMSLS EIS. The AMSLS EIS counts the costs of all people with MS who are admitted to nursing homes, while the AIHW/Access Economics approach includes only the *attributable fraction* of nursing home care that is due to the MS. In other words, elderly people who have MS may have other chronic conditions – vision disorders, cardiovascular and musculoskeletal diseases, for example, which may also contribute in varying degrees to their admission. Failure to account for comorbidity over-estimates aged care costs and represents a danger in bottom-up methodology where the total would be much smaller than the sum of the parts so estimated.

Other direct costs: The AMSLS EIS estimates these as $236.5m compared to the Access Economics estimate of $94.9m. The key difference here is that the AMSLS EIS includes a number of costs that Access Economics incorporates as indirect rather than direct – notably support services, assistive aids and home and car alterations. The AMSLS EIS also includes some elements not included by Access Economics (eg, alternative therapies such as vitamin/mineral supplements).

Other costs: The AMSLS EIS and Access Economics both treat production losses and informal care as indirect costs (see Section 2.2). Neither study is able at present to separately identify Commonwealth and State/Territory disability funding for people with MS, which includes in home attendant care, therapy, case management and like services that are funded by State Governments. However, this element is likely to be small relative to total costs and a minimum estimate is included.

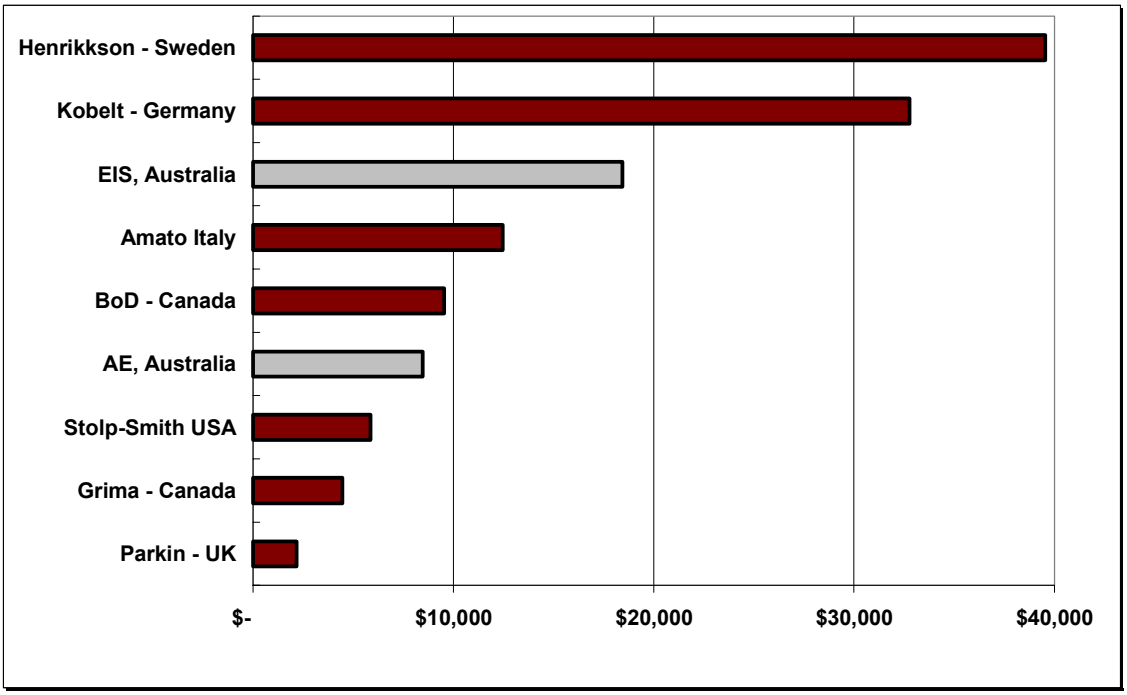
Divergence in direct costs per person is highlighted when comparing with direct cost components in other international studies. Patwardhan et al (2005) identified just under 200 English language articles which satisfied the search criteria "multiple sclerosis" and "costs and cost analysis", "economics", or "fees and charges". Of these, ten studies were found that compared costs, both direct and indirect, to the level of disability of the person with MS. Although the studies exhibited significant variation in categories of costs included and the grouping of disability steps, Patwardhan et al (2005) drew the following conclusions.

- Variations in the studies were primarily due to different categories of costs included. The highest cost studies had tried to quantify less tangible costs such as costs to health status brought about by health care intervention or the value of caregiver and foregone leisure time. The lowest cost studies focus more narrowly on the costs of hospitalisation.
- Both direct and indirect costs rise with increasing severity category, the rise in cost is qualitatively exponential and the rise in indirect costs appears at lower severity scores than direct costs.

Costs in northern European countries might be expected to be higher because of greater MS severity due to latitude, as well as more socialist health systems. Although different items are included in each of the studies and varying methodologies are utilised, as well as divergent international health systems and policies, the results are presented for interest on a per capita basis (converted to 2005 Australian dollars at purchasing power parity), in Figure 2-6. The Access Economics direct cost estimate is higher than the UK, USA and one Canadian study, while the AMSLS EIS is third highest behind the Swedish and German studies.

- Average health cost per person with MS in Australia is $8,464 per annum.
- The international range of estimates is from $2,179 to $39,541 per person per annum.

FIGURE 2-6: MS DIRECT COSTS PER PERSON, 9 INTERNATIONAL STUDY RESULTS, 2005 $A



Source: Access Economics based on Patwardhan et al(2005).

2.2 INDIRECT FINANCIAL COSTS

The World Health Organization and cost of illness studies in the past have typically classed indirect costs as all those costs that are not direct health system costs, the approach adopted here. More recently, the importance of making the economic distinction between real and transfer costs has become recognised.

- **Real costs** use up real resources, such as capital or labour, or reduce the economy's overall capacity to produce goods and services.
- **Transfer payments** involve payments from one economic agent to another that do not use up real resources, for example, a disability support pension, or taxation revenue.

Transfer costs are important when adopting a whole-of-government approach to policy formulation and budgeting. Measurement of indirect costs remains a matter of some debate and controversy. In this report, we estimate **two types of indirect costs of MS**.

- **Financial costs** (this section) include lost production from MS-related morbidity and premature mortality (and the associated deadweight taxation losses), and other financial costs eg, carers, aids and home modifications for those disabled.
- **Non-financial costs** (Section 2.3) derive from loss of healthy life—the pain, premature death and loss of life quality that result from MS. These are more difficult to measure, but can be analysed in terms of the years of healthy life lost,

both quantitatively and qualitatively, known as the 'burden of disease', with an imputed value of a 'statistical' life so as to compare these costs with financial costs of MS.

2.2.1 LOWER WORKFORCE PARTICIPATION FOR PEOPLE WITH MS

As discussed in Section 1.4.3, MS can have a significant impact on a person's capacity to work. Studies in both Australia and overseas have found that 50% to 80% of people with MS no longer remain in paid employment ten years after diagnosis. This loss in productivity represents a real cost to the economy.

Access Economics measures the lost earnings and production due to both illness and premature death using a 'human capital' approach. The lower end of such estimates includes only the 'friction' period until the worker can be replaced, which would be highly dependent on labour market conditions and un(der)employment levels. In an economy operating at near full capacity, as Australia is at present, a better estimate includes costs of temporary work absences plus the discounted stream of lifetime earnings lost due to early retirement from the workforce, reduced working hours (part-time rather than full-time) and premature mortality. In this case, it is likely that, in the absence of illness, people with MS would participate in the labour force and obtain employment at the same rate as other Australians, and earn the same average weekly earnings. The implicit and probable economic assumption is that the numbers of such people would not be of sufficient magnitude to substantially influence the overall clearing of the labour market.

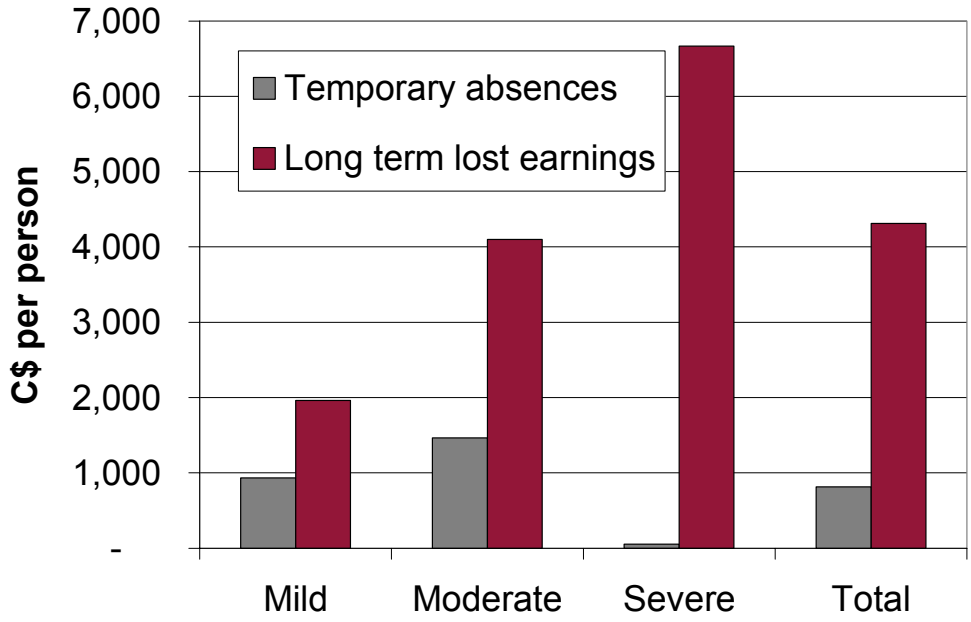
Premature workforce separation

Based on unpublished data from the AMSLS EIS, Access Economics estimates that the employment rate for people with MS is 19.9% lower than the age-standardised rate for all Australians (Section 1.4.3). This implies that, if people with MS were employed at the same rate as average Australians of the same age, then an additional 3,195 people would be employed in 2005. We can assume that, on average, each person would receive a salary equal to the current average weekly wage for all Australians (ABS, 2005a) based on full-time and part-time earnings. Under these assumptions, **the annual cost of lost earnings due to workplace separation and early retirement from MS is $127.9m**.

Temporary absences

Auty et al (1997), in a Canadian study of the annual and lifetime costs of MS, measured costs from absenteeism (missed days of work for employed people with MS due to illness) as well as foregone work income (from people with MS who worked less as a result of the disease). The results showed that the proportion of losses from temporary absences relative to those from long term lost earnings fell (as would be expected) as severity of MS increased, from 48% for mild disease to 36% for moderate disease and 1% for severe MS (Figure 2-7). Overall the (weighted) average loss from temporary absences was 18.9% of total lost earnings.

FIGURE 2-7: LOST PRODUCTION, TEMPORARY AND LONG-TERM, MS, CANADA



Source: Based on data from Auty et al (1997).

Amato et al (2002) also estimate the overall proportion – as 22.6%, in a larger study (n=566 compared to n=198 in the Canadian study). The weighted average is thus 21.7%.

Access Economics utilises the 21.7% parameter from these European studies to estimate the costs of lost productivity from temporary absences associated with MS relative to the production losses from workforce separation.

- Lost production from absenteeism and for Australians with MS is thus estimated as a further **$24.2m**.

Premature mortality

As described in Section 1.1.3, life expectancy for people with MS is around 7 years less than for the general population, representing a loss of 8.7% of lifespan on average. Based on prevalence of MS, this equates to 1,288 missing Australians in 2005, due to MS.

If these people had not died, they would be likely to be represented in the workforce in the same proportion as other people with MS aged over 65 (0.9%), so there are an estimated 11 missing workers due to premature death. The present value of their work is estimated as $263,604 in 2005 dollars:

$$PV = SUM\ [Y/(1+r)^t]$$

where the discount rate (r) is 1.55% (Section 2.3.3), the timeframe (t) is 7 years and the average income (Y) based on average weekly earnings is $40,028 per annum.

So the **production losses from premature death from MS are estimated as $3.0m.**

Taxation revenue foregone

Reduced earnings due to reduced workforce participation, absenteeism and premature death will also have an effect on taxation revenue collected by the Government. As well as foregone income (personal) taxation, there will also be a fall in indirect (consumption) tax, as those with lower incomes spend less on the consumption of goods and services.

Personal income tax foregone is a product of the average personal income tax rate and the foregone income. With MS and lower income, there will be less consumption of goods and services, estimated up to the level of the disability pension. Without MS, it is conservatively assumed that consumption would comprise 90% of income (the savings rate may well be lower than this). The indirect tax foregone is estimated as a product of the foregone consumption and the average indirect tax rate, derived from the Access Economics macroeconomic model. This estimation is conservative since the average tax rate of people with MS is likely to be less than the average tax rate of people across Australia, since more of them work part time and their average incomes (and hence marginal tax rates) are likely to be lower.

Access Economics estimates that in 2005, **$45.1m of potential taxation revenue** will be lost due to the reduced participation of people with MS in the paid workforce. Of this, **$32.7 (72.5%) is lost income tax and $12.4m (27.5%) is lost consumption tax**.

As noted in the preamble to Section 2.2, lost taxation revenue is considered a transfer payment, rather than an economic cost. However, raising additional taxation revenue does impose real efficiency costs on the Australian economy, known as **deadweight losses**. Administration of the taxation system costs around 1.25% of revenue raised (derived from total amounts spent and revenue raised in 2000-01, relative to Commonwealth department running costs). Even larger deadweight losses also arise from the distortionary impact of taxes on workers' work and consumption choices. These distortionary impacts are estimated to be 27.5% of each extra tax dollar collected (Lattimore, 1997 and used in Productivity Commission, 2003, p6.15-6.16, with rationale).

Access Economics estimates that **$13.0m in additional deadweight loss is incurred** in 2005, due to the additional taxation required to replace that foregone due to the lost productivity of people with MS (Table 2-4).

Welfare payments made to people with MS who are no longer working must, in a budget-neutral setting, also be funded by additional taxation. The deadweight losses associated with welfare transfers are calculated in Section 2.2.3.

TABLE 2-4: LOST EARNINGS AND TAXATION REVENUE DUE TO MS, 2005, AUSTRALIA

Potential earnings lost	$158.6 million
Average personal income tax rate*	20.60%
Potential personal income tax lost	$32.7 million
Average indirect tax rate*	15.30%
Potential indirect tax lost	$12.4 million
Total potential tax revenue lost	$44.1 million
Deadweight loss from additional taxation	**$13.0 million**

* Source: Access Economics (2005).

2.2.2 FAMILY AND CARER COSTS

Informal community care is provided by family and friends of the patient at no monetary cost. However, informal care still has an economic cost, as the caregiver cannot spend that time doing other activities, including paid work or other leisure activities. It is noted that this analysis is partial (rather than a general equilibrium approach) and that, as with the approach to production losses, an implicit principle is that the economy is operating at full capacity (and therefore household tasks are a net resource cost). In this context, there are several possible methods for valuing the time foregone by caregivers including:

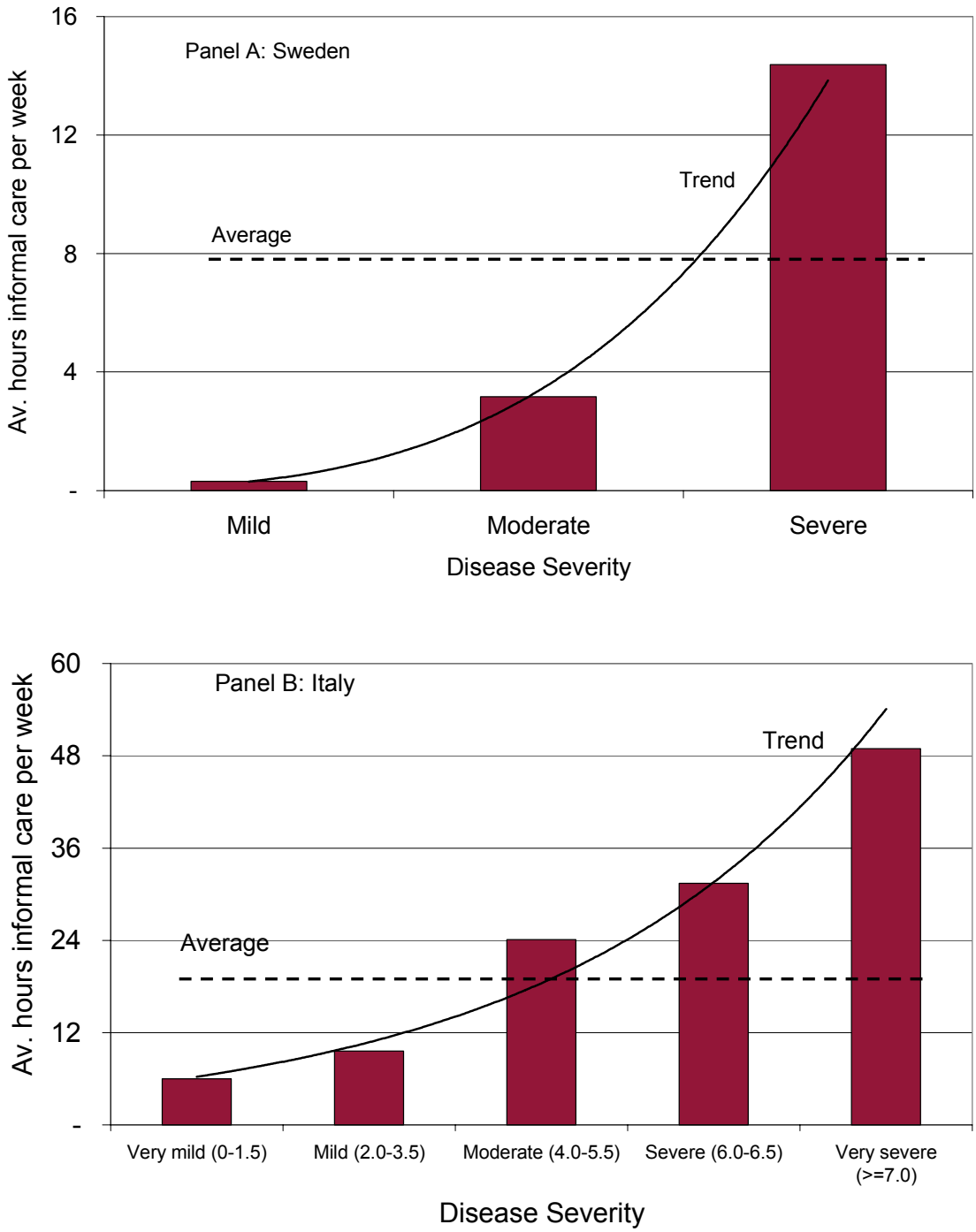
- **Opportunity cost**: the value of lost wages foregone;
- **Replacement valuation**: the cost of buying a similar amount of services from the formal care sector; and
- **Self-valuation**: what carers themselves feel they should be paid.

Access Economics has adopted the replacement valuation approach in this report, due to the lack of information about the demographic characteristics of carers of Australians with MS, noting that replacement valuation will generally give higher results than the other two methods, for which data are not available.

Many studies have found that the need for informal care rises exponentially with disability level (Patwardhan et al, 2005). A cross-sectional study of people with MS in France, Germany and the UK found that, in all three countries, both the number of people receiving informal care and the amount of care provided per day increased with greater disease severity. People with severe MS received at least twice as much care as patients with moderate MS (Murphy et al, 1998).

The average hours of informal care from two European studies (in Sweden and Italy) showed informal care hours of 7.9 and 22.1 per person per week respectively for people with MS (Henriksson et al, 2001; Amato et al, 2002). Both studies found the hours of care increased with severity of MS, from 0.2 hours of care per week for mild MS to around 3.7 hours per week for moderate disease and 17.2 hours for people with severe MS (see Figure 2-8, Panel A). In Italy the range was from 6.0 to 48.9 hours per week of care for very severe MS (Panel B).

FIGURE 2-8: INFORMAL CARE, AVERAGE HOURS PER WEEK, BY LEVEL OF DISABILITY



Source: Henriksson et al (2001) and Amato et al (2002).

Australian data from the AMSLS EIS show that the average number of hours of unpaid assistance that people in the AMSLS EIS received because of MS was 12.3 hours per week. This average is across the total sample, not just those who received assistance. The assistance was related to activities of daily living (personal care, meal preparation, physical access to or within the home), home and garden activities (essential household tasks such as putting out the garbage bin, house maintenance and repairs, managing bills and household paperwork, maintenance or outside and garden area),

and other activities (essential transport, child care). The providers of this unpaid assistance included partner/spouse, other relative, friend, volunteer, MS Society or other service provider, and refers to those living in the community. Splits by severity of the MS are not yet available.

Applying these average care needs to the Australian MS population, as shown in Table 2-6, suggests that a total of almost 10.3m hours of informal care are provided to Australians with MS annually.

The estimate of the replacement value of informal community care is sensitive to changes in the estimate of the wage parameter for alternate formal sector care. In this analysis, the unit cost used has been based on the wage of moderately skilled formal sector carers (supervised employees). In May 2004, full-time carers and aides employed in the formal sector received an average wage of $17.20 per hour, or $650.30 for a 37.8 hour week (ABS 2005c). This average includes payment of overtime for after hours work. However, the hourly rate received by employees does not account for on-costs such as superannuation incurred by employers, the wages of supervisors, managers or administrative support staff or other capital overheads. Loadings are added for each of these additional costs, and for average wage growth between May 2004 (when the survey was last undertaken) and February 2005 (the most recent period for which estimates of average weekly earnings across all employees are available).

TABLE 2-5: REPLACEMENT VALUATION OF INFORMAL CARE, UNIT COST COMPONENTS

	% Loading	Hourly rate
Base rate per hour – May 2004		$17.20
Loading for growth in AWE May 2004 to Feb 2005	4.9%	$0.85
Loading for on-costs	15.6%	$2.82
Loading for capital	3.6%	$0.75
Loading for supervision and administration	16.3%	$3.40
Total hourly rate inc. overheads		**$25.01**

The 15.6% loading of on-costs comprises superannuation, workers compensation, payroll and Fringe Benefits Taxation allowances (ABS 2004a). Loadings for capital (3.6%) and administrative (16.3%) overheads are based on the relative shares of capital expenditure and administration costs to other areas of recurrent spending in Australia's formal health sector (AIHW 2004a, 2005). When all these loadings are added, the hourly cost of employing a carer in the formal sector to replace an informal carer is $25.01 in 2005 (Table 2-5).

Based on this rate, **the total value of family and other informal carer provided to Australians with MS is $257.7m in 2005** (Table 2-6).

TABLE 2-6: COST OF INFORMAL CARE BY AUSTRALIANS WITH MS, 2005

	Av. hours informal care per week, per person	Total hours per annum (m)	Replacement cost per annum ($m
People with MS	**12.3**	**10.3**	**$257.7**

Source: Access Economics from AMSLS EIS data.

Community care

AMSLS EIS data also permit an estimate of the cost of formal community care services provided to people with MS (home services including help with home tasks and activities of daily living). This came to $432 per person per year, of which the individual paid $372 and the government or non-government organisation paid $60. The latter is likely to be an underestimate as participants self-reported the amount and would be unlikely to have known the full cost to service providers in all cases. A better estimate may be possible from the hours of formal care provided, which will be available when the full AMSLS EIS findings are published.

At this unit cost, the estimate for formal sector community care for people with MS in 2005 is $7.0m of which $6.0m (86%) is estimated to be borne by the individual.

ABS (2005d) enables an alternative conservative ballpark estimate of the cost of community care, by using the ratio of Australian Government expenditure for 2003-04 on community care relative to residential care. In that year the ratio was 1,056.9m relative to $5,110.8m, or 21%, suggesting an estimate for community care in 2005 of $5.3m for Australians with MS. This is likely to be a conservative estimate as, because of their younger demographic relative to the overall distribution of residential and community care services, people with MS are likely to use a relatively greater proportion of community services relative to residential services.

Individual data for State/Territory disability services expenditure on people with MS are not available. People with MS also access services funded through the Commonwealth State and Territory Disability Agreement (CSTDA). MS Australia estimates (personal correspondence) that:

> *Accommodation, attendant care, respite, therapy and employment support programs are funded through State and Federal Government to the approximate value of $17m. People with MS are under-represented in many services in the CSTDA due to the fact that the service types are based around people with more stable disabilities, and are primarily facility based, whereas people with MS require services at home and at work. Long waiting lists in each State and Territory are a feature of disability services systems, and work against people with progressive conditions who cannot wait long periods for services. The mismatch of the need for immediate services (such as equipment or attendant care) when required and the waiting list allocation process is one factor that encourages inappropriate hospital or nursing home admission.*

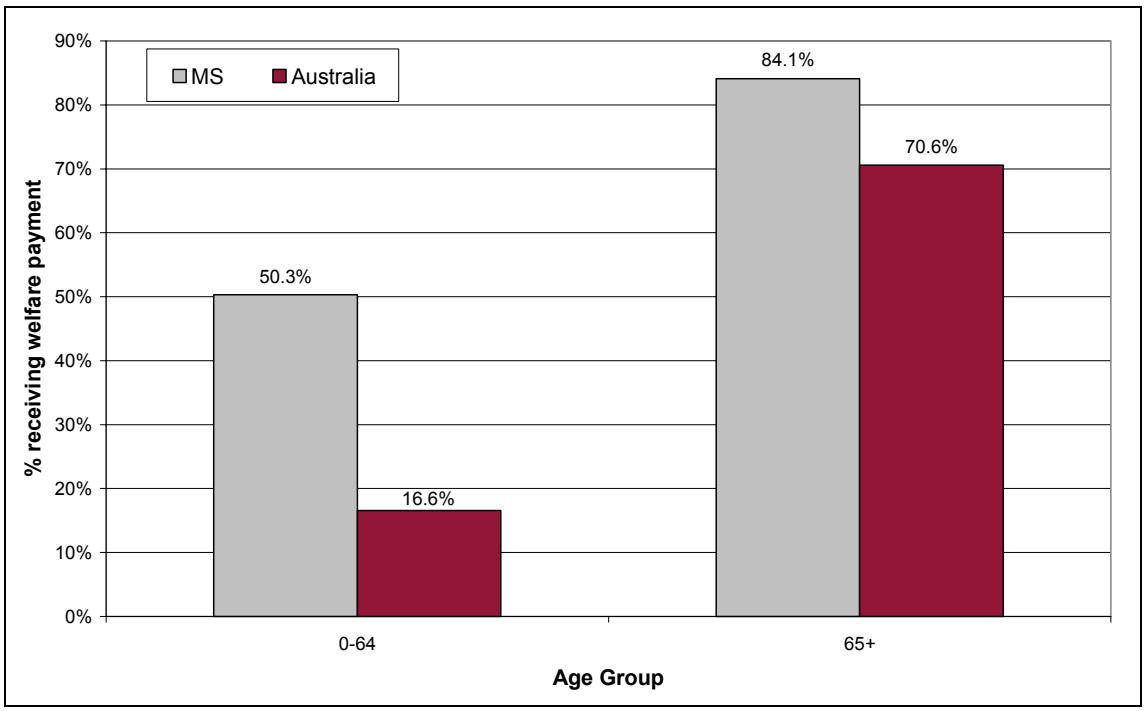
2.2.3 COST OF WELFARE PAYMENTS

Pre-published data from the AMSLS EIS suggest that 53.7% of all people with MS receive some form of welfare payment. While some of these may be the means-tested age pension (84.1% of people with MS aged 65 and over receive a Government

benefit), which is paid to all eligible people regardless of disability, over 50% of MS patients under the age of 65 are also receiving income support.[9]

These are significantly higher rates of reliance than for the Australian population as a whole, as shown in Figure 2-9. In 2003 when the AMSLS EIS was undertaken, only 16.6% of the general population under 64 and 70.6% of those aged 65 and over received some form of income support payment (Centrelink, special data request).

FIGURE 2-9: PROPORTION OF PEOPLE RECEIVING A WELFARE PAYMENT, AUSTRALIA 2003



The difference in rates of reliance on income support payments between the two groups (33.7% and 13.5% respectively) can be thought of as the additional amount of welfare 'attributable to' a person having MS. Hence in 2005, 5,054 additional people received some form of welfare payment, due to MS. For the 244 people over 65 years of age this is most likely to be the Age Pension, and for the 4,810 people under 65 it is likely to mainly be the Disability Support Pension. People with MS may also receive Sickness Allowance, Newstart, Mobility Allowance and Rent Assistance, depending on their level of disability and personal situation. The average amount payable per fortnight for each payment in 2003-04, and maximum current payment is set out in Table 2-7 below, along with a brief summary of each payment.

[9] Respondents were asked whether they received Unemployment Allowance/Newstart, Age Pension, Disability Support Pension, Mature Age Allowance, Invalid, Austudy/Abstudy, Parenting Payment – Single, Parenting Payment – partnered, Sickness Allowance, Special Benefit, Carer Pension, Department of Veteran's Affairs income support.

TABLE 2-7: AVERAGE AND MAXIMUM PAYMENT FOR SELECTED INCOME SUPPORT PAYMENTS

Payment Type	Number of recipients Qtr1 2003-04	Av payment per fortnight 2003-04*	Max payment per fortnight 20 March 2005
Age Pension	28,325	$404.32	$476.30 single $397.70 couple (each)
Disability Support Pension	696,795	$422.63	As for Age Pension
Sickness Allowance	8,189	$380.68	As for Newstart
Mobility Allowance	47,402	$68.00	$69.70
Newstart	483,093	$329.00	$399.30 single, no children $432.00 single, dependent child(ren) $360.30 couple (each)
Rent Assistance	949,698	n/a – included in appropriations for primary payment	$65.33 to $130.06 depending on household situation
Any Income Support Payment	4,673,000	n/a	n/a

Source: Access Economics estimates based on FACS (2005), www.centrelink.gov.au and special data request from Centrelink. *Rate includes Rent Assistance where paid.

The **Age Pension** is paid to people of qualifying age (65 years of age for men and 62.5 years of age for women – rising to 65 by 2014) who cannot support themselves fully in retirement. It is subject to an income and assets test.

The **Disability Support Pension** (DSP) is a means-tested payment for people permanently unable to work due to physical, intellectual or psychiatric impairments, or for those who are permanently blind.

Sickness Allowance is a means-tested payment for people who are temporarily unable to work or study due to illness and have a job or course of study to return to.

Mobility Allowance is a non-means tested allowance for people who are working (paid or unpaid), training or seeking work and are unable to use public transport without substantial assistance.

Newstart Allowance provides income support to people aged between 21 and Age Pension Age who are unemployed. To be eligible, recipients must meet an activity test by seeking work or undertaking other activities designed to improve their employment prospects. Recipients must also accept suitable employment opportunities.

Rent Assistance is a non-taxable income supplement payable to persons who receive an income support payment (other than Austudy), and assists people to meet the cost of renting in the private housing market.

Data limitations make it difficult to accurately calculate the value of welfare payments paid to people with MS. While people may not be working due to MS, they may be claiming one of a number of benefit payments, and the amount payable will depend on the income and assets of the person with MS and of the people with whom they live.

For people over 65, Access Economics has used the average payment made under the Age Pension for 2003-04, indexed by CPI to 2005 - $414.71 per fortnight. For those under 65, an average payment of $394.71 per fortnight is used. This is constructed by weighting the average payments for DSP, Newstart, Sickness Allowance and Mobility Allowance by the number of people receiving each type of benefit, and indexing the value by CPI to 2005. As a relatively equal number of people under 65 receive DSP and Newstart, the imputed rate lies about halfway between the two payment rates. This may be a conservative rate if more people with MS receive DSP rather than Newstart.

Table 2-8 summarises the total annual cost of welfare payments to people with MS. People with MS will receive around $3.46 million in income support payments during 2005. Of this, $2.0 million or 57.7% represent payments attributable to MS (ie in excess of what would be expected based on rates for the general population). These payments themselves are not economic costs, but a financial transfer from taxpayers to income support recipients. The economic cost of these transfer payments is only the deadweight loss caused by the taxation needed to finance the payments. As previously, the deadweight loss is assumed to be 28.75 cents for each dollar of taxation required. In this case, a deadweight loss of $0.57 million per annum will be incurred to finance additional income support payments to people with MS.

TABLE 2-8: COST OF WELFARE PAYMENTS TO PEOPLE WITH MS, AUSTRALIA 2005

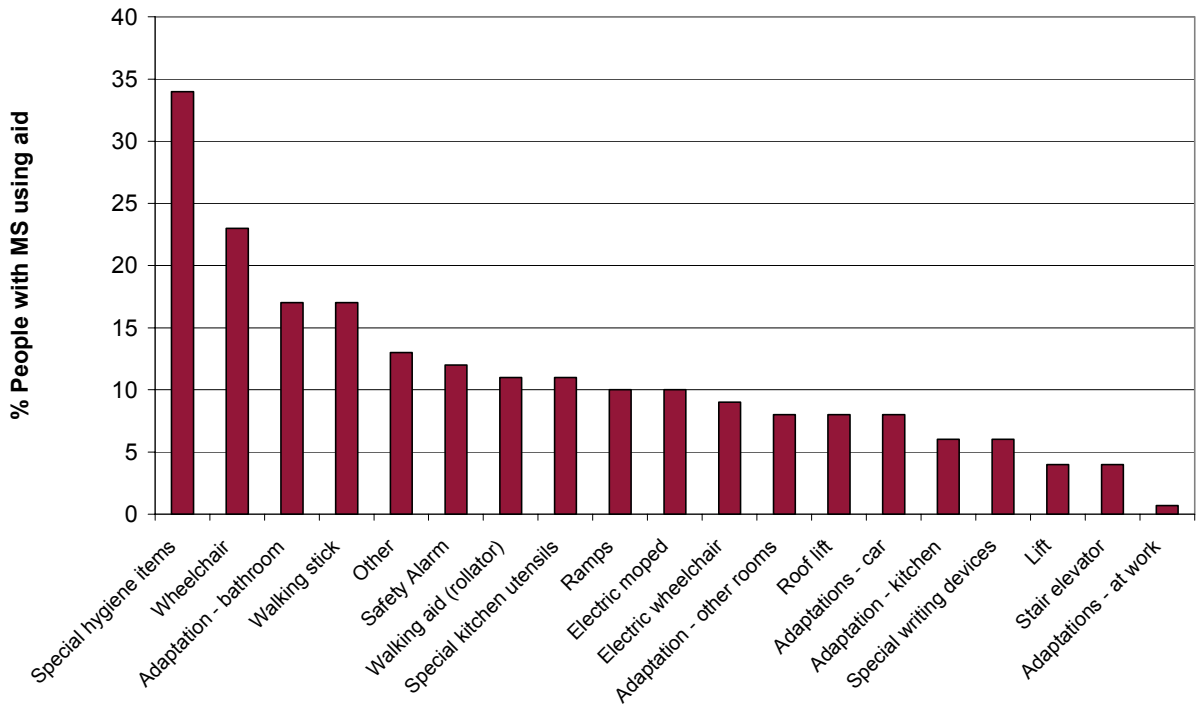
2005, $M	0-64	65+	Total
Total value welfare payments to people with MS	2.83	0.63	3.46
Component attributable to MS	1.90	0.10	2.00
Deadweight loss	**0.55**	**0.29**	**0.57**

2.2.4 MODIFICATIONS AND AIDS

Patients with MS in the later stage of progression are highly dependent on medical equipment and supplies, with almost 100% of patients with severe MS in a European study requiring some form of aid (Murphy et al, 1998).

Overseas studies (Henriksson et al, 2001) suggest the most common aids used are special hygiene items (over 30%) and mobility aids (over 40%).

FIGURE 2-10: MODIFICATIONS AND AIDS FOR PEOPLE WITH MS, SWEDEN



Source: Henriksson et al (2001).

In Australia, the AMSLS has estimated the cost of such modifications and aids for people with MS as $1,646 per person per annum, based on expenditure over the five years to August 2003. Inflating this to 2005 prices ($1,729 per person per annum) and multiplying by the prevalence of MS provides an estimate of the **total cost of modifications and aids of $27.8m in 2005**. Of this, 85.7% ($23.8m) is estimated to be borne by the individual and 14.3% by governments (Table 2-9).

TABLE 2-9: COST OF MODIFICATIONS AND AIDS FOR AUSTRALIANS WITH MS, 2005

	Average cost per person ($)			Total $m
	5 years to August 2003	Average per annum	2005 prices	
Costs, individuals	7,054	1,411	1,482	$23.8
Total costs*	8,229	1,646	1,729	**$27.8**

Source: AMSLS EIS. * Includes government contributions through community programs.

2.2.5 SUMMARY OF FINANCIAL COSTS

The total real financial costs of MS are thus estimated as $601m in 2005, summarised in Table 2-10 and Figure 2-11.

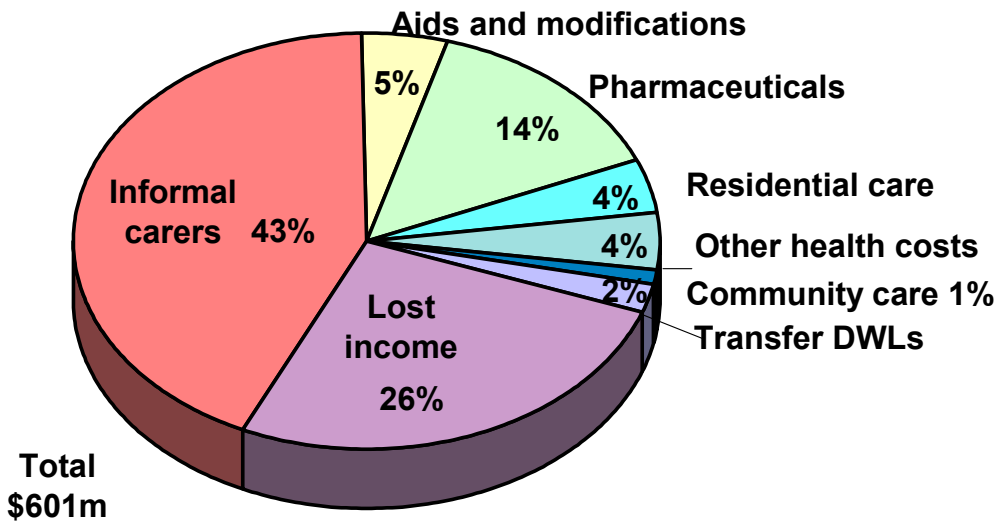
- Informal sector care is the greatest cost, 43% of the total, with lost earnings second at 26½% and pharmaceutical costs third largest at 14%.
- Aids and home modifications represent 5% of total costs, while residential care and other health costs are each about 4% of total costs.

- Other financial costs (community care and the deadweight costs of welfare and taxation transfers) comprise the remaining 3½%.
- Indirect costs outweigh direct health costs over 3 to 1.
- **Annual costs per person with MS are $37,333, $30 for every Australian and 0.07% of GDP in total**.

TABLE 2-10: MS, FINANCIAL COST SUMMARY, 2005, $M

Cost element	Real cost	Transfer payment
Allocated health costs	**$117.1**	
Pharmaceuticals	$72.4	
Aged Care	$22.2	
Other allocated health	$22.5	
Unallocated health costs	$19.1	
Total health costs	**$136.1**	
Indirect financial costs		
Lost earnings (people with MS)	$158.6	
Tax foregone (people with MS)	$13.0	$45.1
Value of carers	$257.7	
Welfare payments	$0.6	$2.0
Aids and other indirect costs	$27.8	
Community care	$7.0	
Total indirect financial	**$464.6**	
Subtotal, financial costs	**$600.7**	**$47.1**
Per person with MS	$37,333	$2,925
Per capita (population)	$29.55	$2.32
% GDP	**0.07%**	**0.01%**

FIGURE 2-11: MS, FINANCIAL COST SUMMARY, 2005, % TOTAL



Note: Numbers may not sum due to rounding.

Access Economics' findings regarding cost shares concord well with recent international studies, which note that indirect costs (informal carers and lost productivity) dominate costs and that pharmaceutical costs are much higher than a decade ago due to the new biological disease-modifying treatments now available (Kobelt et al, 2004).

2.3 THE 'BURDEN OF DISEASE'

To those experiencing MS, less tangible costs such as loss of quality of life, loss of leisure, physical pain and disability are often as or more important than the health system costs or other financial losses. This chapter measures the burden of suffering and premature death from MS.

2.3.1 VALUING LIFE AND HEALTH

Since Schelling's (1968) discussion of the economics of life saving, the economic literature has properly focused on **willingness to pay** (willingness to accept) measures of mortality and morbidity risk. Using evidence of market trade-offs between risk and money, including numerous labour market and other studies (such as installing smoke detectors, wearing seatbelts or bike helmets etc), economists have developed estimates of the **value of a 'statistical' life (VSL).**

> The willingness to pay approach estimates the value of life in terms of the amounts that individuals are prepared to pay to reduce risks to their lives. It uses stated or revealed preferences to ascertain the value people place on reducing risk to life and reflects the value of intangible elements such as quality of life, health and leisure. While it overcomes the theoretical difficulties of the human capital approach, it involves more empirical difficulties in measurement (BTE, 2000, pp20-21).

Viscusi and Aldy (2002) summarise the extensive literature in this field, most of which has used econometric analysis to value mortality risk and the 'hedonic wage' by estimating compensating differentials for on-the-job risk exposure in labour markets, in other words, determining what dollar amount would be accepted by an individual to induce him/her to increase the possibility of death or morbidity by x%. They find the VSL ranges between US$4 million and US$9 million with a median of US$7 million (in year 2000 US dollars), similar but marginally higher than the VSL derived from US product and housing markets, and also marginally higher than non-US studies, although all in the same order of magnitude. They also review a parallel literature on the implicit value of the risk of non-fatal injuries.

> A particular life may be regarded as priceless, yet relatively low implicit values may be assigned to life because of the distinction between identified and anonymous (or 'statistical') lives. When a 'value of life' estimate is derived, it is not any particular person's life that is valued, but that of an unknown or statistical individual (Bureau of Transport and Regional Economics, 2002, p19).

Weaknesses in this approach, as with human capital, are that there can be substantial variation between individuals. Extraneous influences in labour markets such as

imperfect information, income/wealth or power asymmetries can cause difficulty in correctly perceiving the risk or in negotiating an acceptably higher wage.

Viscusi and Aldy (2002) include some Australian studies in their meta-analysis, notably Kniesner and Leeth (1991) of the Australian Bureau of Statistics (ABS) with VSL of US2000 $4.2 million and Miller et al (1997) of the National Occupational Health and Safety Commission (NOHSC) with quite a high VSL of US2000$11.3m-19.1 million (Viscusi and Aldy, 2002, Table 4, pp92-93). Since there are relatively few Australian studies, there is also the issue of converting foreign (US) data to Australian dollars using either exchange rates or purchasing power parity and choosing a period.

Access Economics (2003b) presents outcomes of studies from Yale University (Nordhaus, 1999) – where VSL is estimated as $US2.66m; University of Chicago (Murphy and Topel, 1999) – US$5m; Cutler and Richardson (1998) – who model a common range from US$3m to US$7m, noting a literature range of $US0.6m to $US13.5m per fatality prevented (1998 US dollars). These eminent researchers apply discount rates of 0% and 3% (favouring 3%) to the common range to derive an equivalent of $US 75,000 to $US 150,000 for a year of life gained.

2.3.2 DALYs AND QALYs

In an attempt to overcome some of the issues in relation to placing a dollar value on a human life, in the last decade an alternative approach to valuing human life has been derived. The approach is non-financial, where pain, suffering and premature mortality are measured in terms of Disability Adjusted Life Years (DALYs), with 0 representing a year of perfect health and 1 representing death (the converse of a QALY or "quality-adjusted life year" where 1 represents perfect health). This approach was developed by the World Health Organization, the World Bank and Harvard University and provides a comprehensive assessment of mortality and disability from diseases, injuries and risk factors in 1990, projected to 2020 (Murray and Lopez, 1996). Methods and data sources are detailed further in Murray et al (2001).

The DALY approach has been adopted and applied in Australia by the Australian Institute for Health and Welfare (AIHW) with a separate comprehensive application in Victoria. Mathers et al (1999) from the AIHW estimate the burden of disease and injury in 1996, including separate identification of premature mortality (YLL) and morbidity (YLD) components. In any year, the disability weight of a disease (for example, 0.18 for a broken wrist) reflects a relative health state. In this example, 0.18 would represent losing 18% of a year of healthy life because of the inflicted injury.

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

The main problem with the DALY approach is that it is not financial and is thus not directly comparable with most other cost measures. In public policy making, therefore, there is always the temptation to re-apply a financial measure conversion to ascertain the cost of an injury or fatality or the value of a preventive health intervention. Such financial conversions tend to utilise "willingness to pay" or risk-based labour market studies described above.

The Department of Health and Ageing (based on work by Applied Economics) adopted a very conservative approach to this issue, placing the value of a human life year at around A$60,000 per annum, which is lower than most international lower bounds on the estimate.

> *"In order to convert DALYs into economic benefits, a dollar value per DALY is required. In this study, we follow the standard approach in the economics literature and derive the value of a healthy year from the value of life. For example, if the estimated value of life is A$2 million, the average loss of healthy life is 40 years, and the discount rate is 5 per cent per annum, the value of a healthy year would be $118,000.[10] Tolley, Kenkel and Fabian (1994) review the literature on valuing life and life years and conclude that a range of US$70,000 to US$175,000 per life year is reasonable. In a major study of the value of health of the US population, Cutler and Richardson (1997) adopt an average value of US$100,000 in 1990 dollars for a healthy year.*
>
> *Although there is an extensive international literature on the value of life (Viscusi, 1993), there is little Australian research on this subject. As the Bureau of Transport Economics (BTE) (in BTE, 2000) notes, international research using willingness to pay values usually places the value of life at somewhere between A$1.8 and A$4.3 million. On the other hand, values of life that reflect the present value of output lost (the human capital approach) are usually under $1 million.*
>
> *The BTE (2000) adopts estimates of $1 million to $1.4 million per fatality, reflecting a 7 per cent and 4 per cent discount rate respectively. The higher figure of $1.4 million is made up of loss of workforce productivity of $540,000, loss of household productivity of $500,000 and loss of quality of life of $319,000. This is an unusual approach that combines human capital and willingness to pay concepts and adds household output to workforce output.*
>
> *For this study, a value of $1 million and an equivalent value of $60,000 for a healthy year are assumed.[11] In other words, the cost of a DALY is $60,000. This represents a conservative valuation of the estimated willingness to pay values for human life that are used most often in similar studies.[12]" (DHA, 2003, pp11-12)."*

As the citation concludes, the estimate of $60,000 per DALY is very low. The Viscusi (1993) meta-analysis referred to reviewed 24 studies with values of a human life ranging between $US 0.5 million and $US 16m, all in pre-1993 US dollars. Even the lowest of these converted to 2003 Australian dollars at current exchange rates,

[10] *In round numbers, $2,000,000 = $118,000/1.05 + $118,000/(1.05)^2 + … + $118,000/(1.05).^{40}* [Access Economics comment: The actual value should be $116,556, not $118,000 even in round numbers.]

[11] The equivalent value of $60,000 assumes, in broad terms, 40 years of lost life and a discount rate of 5 per cent. [Access Economics comment: More accurately the figure should be $58,278.]

[12] In addition to the cited references in the text, see for example Murphy and Topel's study (1999) on the economic value of medical research. [Access Economics comment. Identical reference to our Murphy and Topel (1999).]

exceeds the estimate adopted ($1m) by nearly 25%. The BTE study tends to disregard the literature at the higher end and also adopts a range (A$1-$1.4m) below the lower bound of the international range that it identifies (A$1.8-$4.3m).

The rationale for adopting these very low estimates is not provided explicitly. Certainly it is in the interests of fiscal restraint to present as low an estimate as possible.

In contrast, the majority of the literature as detailed above appears to support a higher estimate for VSL, as presented in Table 2-11, which Access Economics believes is important to consider in disease costing applications and decisions. The US dollar values of the lower bound, midrange and upper bound are shown at left. The 'average' estimate is the average of the range excluding the high NOHSC outlier. Equal weightings are used for each study as the:

- Viscusi and Aldy meta-analysis summarises 60 recent studies;
- ABS study is Australian; and
- Yale and Harvard studies are based on the conclusions of eminent researchers in the field after conducting literature analysis.

Where there is no low or high US dollar estimate for a study, the midrange estimate is used to calculate the average. The midrange estimates are converted to Australian dollars at purchasing power parity (as this is less volatile than exchange rates) of USD=0.7281AUD for 2003 as estimated by the OECD.

Access Economics concludes the VSL range in Australia lies between $3.7m and $9.6m[13], with a mid-range estimate of $6.5m. These estimates have conservatively not been inflated to 2004 prices, given the uncertainty levels.

TABLE 2-11: INTERNATIONAL ESTIMATES OF VSL, VARIOUS YEARS

	US$m			A$m
	Lower	**Midrange**	**Upper**	**0.7281**
Viscusi and Aldy meta-analysis 2002	4	7	9	**9.6**
Australian: ABS 1991		4.2		5.8
NOHSC 1997	11.3		19.1	
Yale (Nordhaus) 1999		2.66		**3.7**
Harvard (Cutler and Richardson) 1998	0.6	5	13.7	6.9
Average*	2.9	**4.7**	7.4	**6.5**

* Average of range excluding high NOHSC outlier, using midrange if no data; conservatively not inflated.
A$m conversions are at the OECD 2003 PPP rate.

2.3.3 DISCOUNT RATES

Choosing an appropriate discount rate for present valuations in cost analysis is a subject of some debate, and can vary depending on which future income or cost stream is being considered. There is a substantial body of literature, which often

[13] Calculated from the non-indexed studies themselves. Converting the Access Economics average estimates from USD to AUD at PPP would provide slightly higher estimates - $3.9 million and $10.2m, with the same midrange estimate.

provides conflicting advice, on the appropriate mechanism by which costs should be discounted over time, properly taking into account risks, inflation, positive time preference and expected productivity gains.

The absolute minimum option that one can adopt in discounting future income and costs is to set future values in current day dollar terms on the basis of a risk free assessment about the future (that is, assume the future flows are similar to the certain flows attaching to a long term Government bond).

Wages should be assumed to grow in dollar terms according to best estimates for inflation and productivity growth. In selecting discount rates for this project, we have thus settled upon the following as the preferred approach.

- **Positive time preference**: We use the long term nominal bond rate of 5.8% pa (from recent history) as the parameter for this aspect of the discount rate. (If there were no positive time preference, people would be indifferent between having something now or a long way off in the future, so this applies to all flows of goods and services.)
- **Inflation:** The Reserve Bank has a clear mandate to pursue a monetary policy that delivers 2 to 3% inflation over the course of the economic cycle. This is a realistic longer run goal and we therefore endorse the assumption of 2.5% pa for this variable. (It is important to allow for inflation in order to derive a real (rather than nominal) rate.)
- **Productivity growth**: The Commonwealth Government's Intergenerational report assumed productivity growth of 1.7% in the decade to 2010 and 1.75% thereafter. We suggest 1.75% for the purposes of this analysis.

There are then two different discount rates that should be applied:

- To discount income streams of future earnings, the discount rate is:
  5.8 - 2.5 - 1.75 = 1.55%.
- To discount other future streams (healthy life, health services, legal costs, accommodation services and so on) the discount rate is:
  5.8 – 2.5 = 3.3%

While there may be sensible debate about whether health services (or other costs with a high labour component in their costs) should also deduct productivity growth from their discount rate, we argue that these costs grow in real terms over time significantly as a result of other factors such as new technologies and improved quality, and we could reasonably expect this to continue in the future.

Discounting the VSL of $3.7m from Table 2-11 by the discount rate of 3.3% over an average 40 years expected life span (the average from the meta-analysis of wage-risk studies) provides an estimate of the value of a life year of $162,561.

2.3.4 ESTIMATING THE BURDEN OF DISEASE FROM MS IN 2005

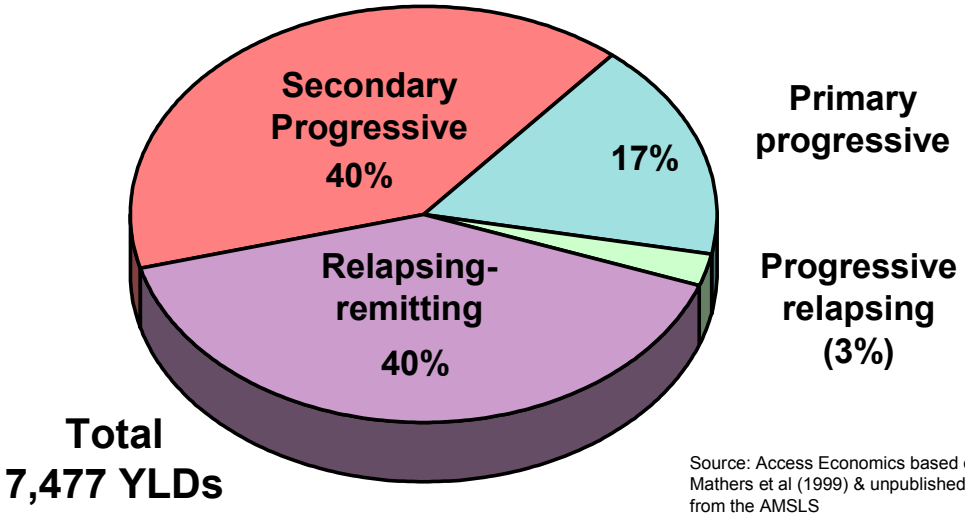
The mortality burden (YLL) estimate for 2005 is based on the burden estimated by Mathers et al (1999) for 1996, inflated on the basis of the growth in MS prevalence over the period 1996 to 2005. The YLL component is thus estimated as 3,056 DALYs.

Since we are adopting a prevalence approach (the burden in the year 2005 of people with MS in that year), the morbidity burden can be estimated in one of two ways:

- by extrapolating the 1996 burden in line with prevalence growth of MS, which provides a low estimate – 4,346 DALYs; or
- by re-estimating the 2005 burden based on data from the AMSLS EIS about the relative shares of relapsing-remitting and progressive MS (Figure 2-12) and multiplying the prevalence of each by their disability weights from Mathers et al (1999), which provides a higher estimate – 7,477 DALYs.

Access Economics calculates YLD using each method and takes the average (5,912) as the base case, with high and low scenario analyses. The burden of disease estimate (YLD plus YLL) is thus 8,968 DALYs in the base case.

FIGURE 2-12: BURDEN OF DISEASE BY MS TYPE, 2005

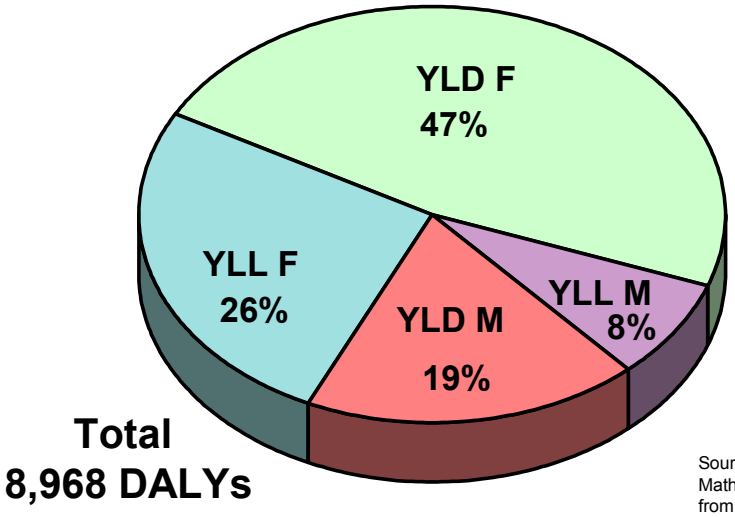


Source: Access Economics based on Mathers et al (1999) & unpublished data from the AMSLS

The compositional share of the disease burden is illustrated in Figure 2-13, with women bearing 73% (6,602 DALYs) and men 27% (2,366 DALYs) in the base case.

- Around one third of the disease burden is from premature mortality (34%) and two thirds (66%) from disability associated with MS.
- Nearly half the disease burden is disability burden borne by women with MS.

FIGURE 2-13: BURDEN OF DISEASE BY YLD/YLL AND GENDER, 2005



Source: Access Economics based on Mathers et al (1999) & unpublished data from the AMSLS

FIGURE 2-14: BURDEN OF DISEASE, MS, BY AGE AND YLD/YLL, 2005

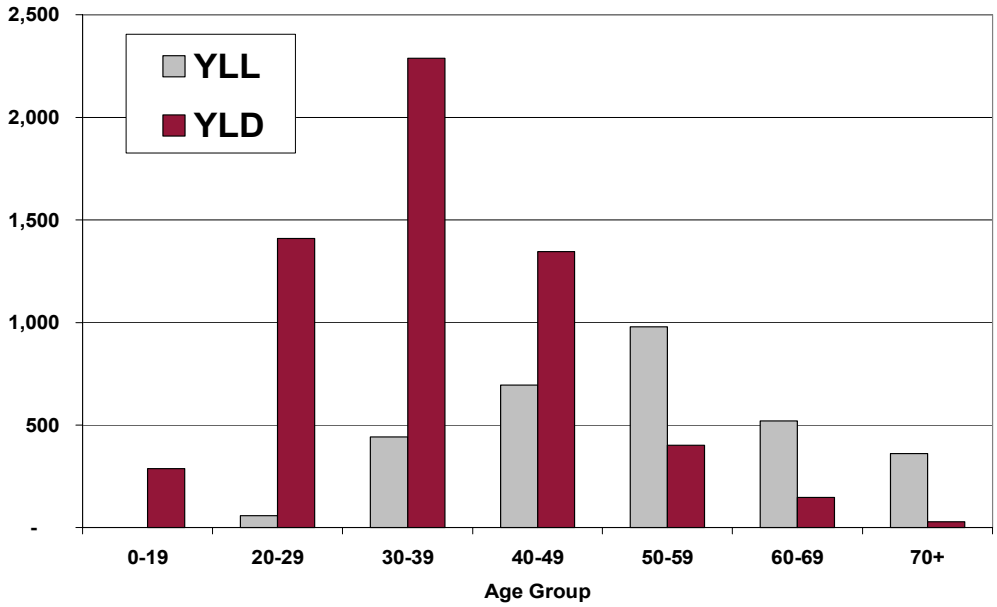


Figure 2-14 illustrates the shifting burden of disease, with the disability burden dominating the younger age-groups and the premature mortality burden becoming relatively more significant with age, also reflected in the underlying data in Table 2-12.

TABLE 2-12: MS DISEASE BURDEN BY AGE, GENDER AND YLD/YLL, AUSTRALIA, 2005

	YLL	YLD	DALYs
Male			
0-19	-	-	-
20-29	-	441	441
30-39	90	605	695
40-49	196	431	628
50-59	211	139	349
60-69	111	37	148
70+	98	7	105
Total	**706**	**1,660**	**2,366**
Female			
0-19	-	288	288
20-29	59	969	1,028
30-39	352	1,683	2,035
40-49	499	916	1,414
50-59	769	264	1,032
60-69	408	111	520
70+	263	22	285
Total	**2,350**	**4,252**	**6,602**
Persons			
0-19	-	288	288
20-29	59	1,410	1,469
30-39	442	2,288	2,730
40-49	695	1,347	2,042
50-59	979	402	1,382
60-69	519	149	668
70+	362	29	391
Total	**3,056**	**5,912**	**8,968**

2.3.5 VALUING THE BURDEN OF DISEASE

Multiplying the burden of disease in DALYs as derived in the preceding section by the value of a life year of $162,561 derived in Section 2.3.3 provides a monetary measure of the gross disability and premature mortality burden of MS. The low, base and high scenarios are illustrated in Figure 2-15 below with the underlying data presented in Table 2-13.

- **The gross cost of disability and premature death from MS is estimated as $1.46 billion ($1.20bn to $1.71bn)**.

FIGURE 2-15 GROSS COST OF DISABILITY AND PREMATURE DEATH SCENARIOS, MS, 2005 ($M)

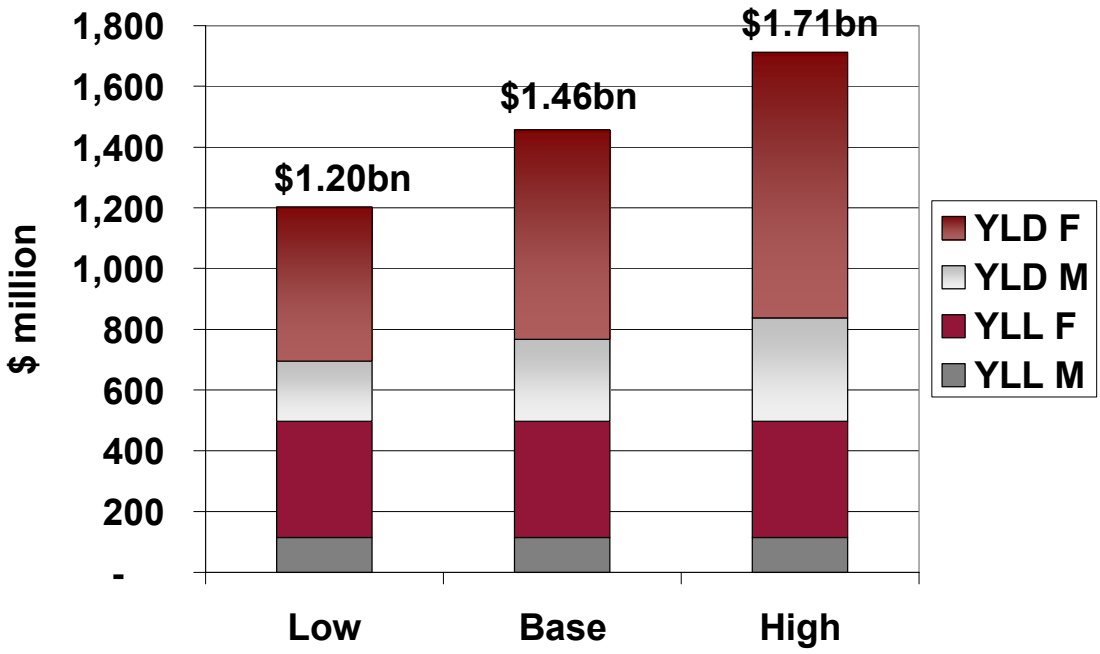


TABLE 2-13: GROSS COST OF DISABILITY AND PREMATURE DEATH SCENARIOS, MS, 2005, ($M)

	Scenarios		
DALY element	**Low**	**Base**	**High**
YLL male	115	115	115
YLL female	382	382	382
YLD male	198	270	341
YLD female	508	691	874
Total	**1,203**	**1,458**	**1,712**

Bearing in mind that the wage-risk studies underlying the calculation of the VSL take into account all known personal impacts – suffering and premature death, lost wages/income, out-of-pocket personal health costs and so on – this base case estimate of $1.5 billion should be treated as a 'gross' figure. However, costs specific to MS that are unlikely to have entered into the thinking of people in the source wage/risk studies should *not* be netted out (eg, publicly financed health spending, care provided voluntarily). The results after netting out are presented in Table 2-14.

TABLE 2-14: NET COST OF DISABILITY AND PREMATURE DEATH, MS, $M, 2005

	Individual	Government	Other	Total
Base Case				
Gross cost of suffering	1,458			1,458
minus health costs	11	39	7	57
minus production losses	70	56	33	159
minus aids	24			
minus welfare receipts	2			
Net cost of suffering	**1,335**			
Low scenario				
Gross cost of suffering	1,203			1,203
Net cost of suffering	**1,081**			
High scenario				
Gross cost of suffering	1,712			1,712
Net cost of suffering	**1,590**			

The net cost of suffering in the base case is thus $1.34bn in 2005.

3. COMPARISONS, CONSTRAINTS AND CHALLENGES

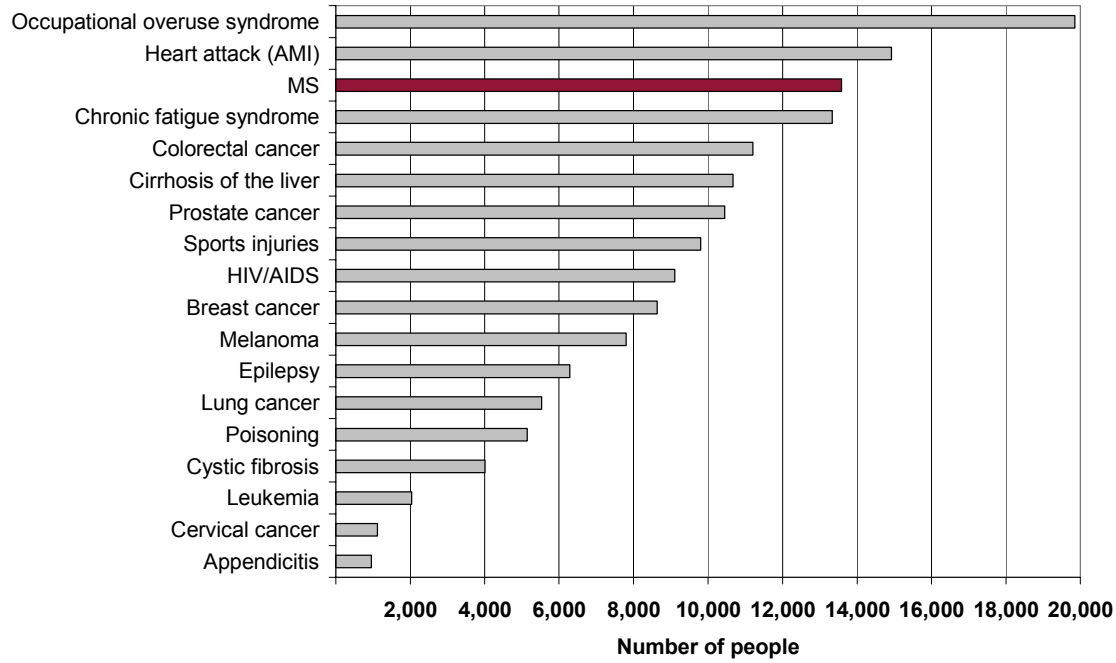
3.1 COMPARISONS WITH OTHER DISEASES

3.1.1 PREVALENCE

MS is a surprisingly prevalent condition – with higher one-year prevalence than breast cancer, bowel cancer[14], sports injuries or poisoning (Figure 3-1).

- MS is of similar prevalence to heart attack and chronic fatigue syndrome.
  - That said, all the National Health Priority conditions are more prevalent – namely, all cancers, diabetes mellitus, asthma, mental health (including depression), injuries, cardiovascular disease, musculoskeletal disease (including arthritis) and dementia, newly listed as a NHP.
  - The use of select comparators, however, enables more relevant comparison for policy makers of similar magnitude disorders.
- These comparators are based on Mathers et al (1999) data from the year 1996 (MS prevalence is estimated as around 13,585 Australians in that year).

FIGURE 3-1: COMPARISON OF MS PREVALENCE, ANNUAL, SELECT COMPARATORS



[14] It is noted that the lifetime prevalence of cancers (as opposed to the one-year prevalence) is higher than for MS, since cancer results relatively rapidly in either mortality or treatment and subsequent healing.

3.1.2 HEALTH SYSTEM EXPENDITURE COMPARISONS

MS and its health impacts do not rank high in health spending priorities. In 2000-01, the estimated allocated expenditure was $93.2 million, only 15% of asthma, the smallest of the National Health Priority areas. Table 3-1 presents other health priorities and conditions. There may be good reason to correct this underspend through investment in cost-effective therapies to reduce the huge disease burden of MS.

TABLE 3-1: COMPARISON OF ALLOCATED HEALTH SPENDING, 2000-01, $M

Condition	$m	% Total
MS	**93**	**0.2%**
Asthma*	615	1.3%
Diabetes*	836	1.7%
Stroke	922	1.9%
Depression	1,042	2.1%
Infectious and parasitic diseases	1,251	2.5%
Maternal conditions	1,318	2.7%
Skin diseases	1,392	2.8%
Arthritis*	1,436	2.9%
Ischaemic heart disease	1,488	3.0%
Cancer*	2,764	5.6%
Digestive system	2,821	5.7%
Mental disorders*	3,018	6.1%
Injuries*	4,061	8.3%
Musculoskeletal*	4,725	9.6%
Cardiovascular disease*	5,393	11.0%
Total	49,174	100.0%

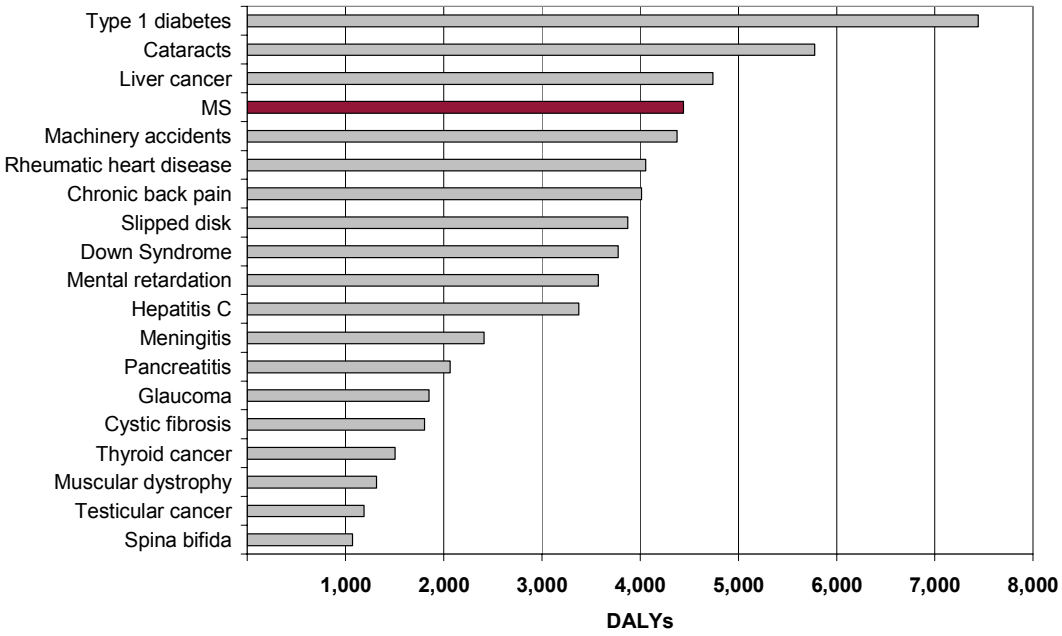
* National Health Priority areas. Source: AIHW (2005). Special data request for MS.

3.1.3 BURDEN OF DISEASE

Figure 3-2 compares the burden of disease of MS and its impacts (4,443 DALYs in 1996, 0.2% of total DALYs) with other selected conditions.

- Again, although not as burdensome as any of the eight National Health Priorities, **MS causes more disability and loss of life than all chronic back pain, slipped disks, machinery accidents, rheumatic heart disease or mental retardation**, and is similar in disease burden to liver cancer or visual impairment from highly prevalent cataracts.

FIGURE 3-2: COMPARISON OF DISEASE BURDEN, 1996, DALYS

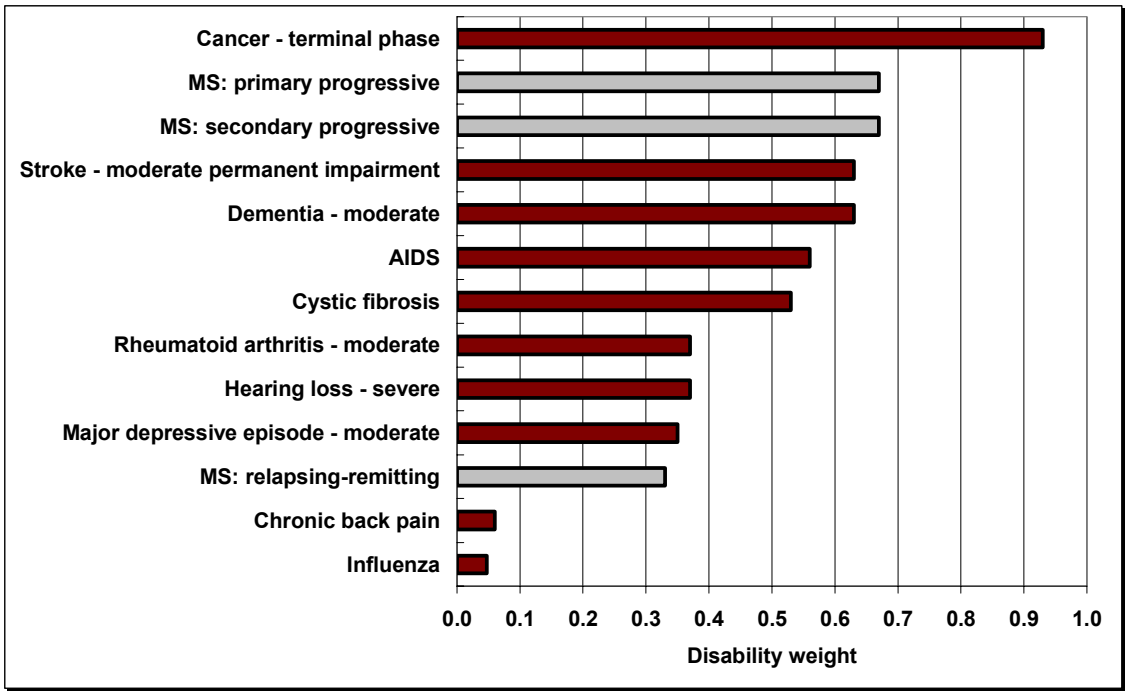


* National Health Priority areas. Source: Mathers et al (1999).

Perhaps more telling than aggregate comparisons of DALYs, which are largely determined by prevalence, is the disability associated with MS as revealed in disability weights for YLDs.

Figure 3-3 illustrates that progressive MS has a higher disability weight than most of the national health priority areas, approaching that of terminal phase cancer. Having relapsing-remitting MS is similar to the disability associated with a major depressive episode.

FIGURE 3-3: DISABILITY WEIGHTS, MS AND SELECTED COMPARATORS



3.2 CONSTRAINTS AND CHALLENGES

The analysis in this report underscores the potential to change the age profile and composition of the costs of MS. Three general principles must be borne in mind, given the cost profile.

- Interventions that enhance employment retention and opportunities have great capacity to reduce production losses and thus overall costs of MS.
- Early interventions that are appropriate to the life cycle and wellbeing of people with MS and support their informal sector carers are vital to delay costly institutionalisations.
- Timely and cost-effective interventions and research have the potential to retard growth in future direct and indirect costs of MS and enhance the quality of life of people with MS in Australia over the longer term.

3.2.1 EMPLOYMENT SUPPORT

The age of onset of MS is generally in early adulthood and means that a significant number of people with MS are working, studying, starting families, or financially committed (eg, buying their first home) at diagnosis. The maintenance of employment is thus a critical factor for people with MS to retain maximum independence and normality in the face of a progressive disease where employment continuity is under continuing threat.

The first best solution from an economic and equity perspective involves policies that enable people with MS to retain employment where possible, while recognising the

need to have a solid welfare response for those that cannot maintain employment due to health and mobility restrictions.

Section 1.4.3 and 2.2.1 of this report have highlighted the substantial impact of the current situation where 80% of people with MS lose their employment within ten years of diagnosis (AMSLS EIS data), often in their thirties or forties, with inadequate retirement savings, risks of social isolation and disadvantage in re-entering the labour market. Key risk factors for employment loss identified by MS Australia (2005) are:

- the effect of symptoms, particularly fatigue, vision disturbance and unstable health;
- poor employment protection and workplace accommodation
  - despite welcome reforms in recent years, current employment support programs in Australia for people with disabilities still tend not to emphasise retention and protection of existing jobs (rather, finding 'new' jobs for the unemployed);
  - historically, poor workplace adaptation and job redesign (including the selective use of adaptive technology, such as voice recognition software and modified equipment) have resulted in workplaces becoming inaccessible for people with MS as their conditions change, contributing to the loss of skilled workers as people are forced out of work prematurely;
  - small workplace modifications can sometimes make enormous differences (eg, through the federal Workplace Modification Scheme[15] or Work Based Personal Assistance measures – FACS, 2003) which have been expanded in the 2005 Federal Budget, although previously there were access difficulties; and
- poor information and support for employees and employers about MS prognosis.

Many workers report discrimination in their employment once their diagnosis becomes known, although with supportive work environments, challenges can be overcome and the benefits realised (see the case studies Section 1.4.3). Once a job has been lost, finding alternative employment that will accommodate disabilities can be extremely problematic.

- Many prospective employers require details of pre-existing disabilities with consequent reluctance to take on those whose capacity to perform a full range of employment duties is doubted.
- Employers may also have concerns about workers compensation liability in the case of hiring workers with a chronic illness.
- The lack of an existing employment relationship and knowledge of the individual also makes it difficult for people with MS to break into new jobs.

[15] Under the Department of Family and Community Services Workplace Modifications Scheme, employers are assisted to provide employment opportunities to eligible job seekers with disabilities through the provision of financial assistance for specific workplace modifications or purchase of specialist equipment. The primary aim of the Scheme is to provide assistance with the cost of workplace modifications, or special or adaptive equipment for eligible new workers with a disability. Assistance may be extended to some existing workers and to some eligible self-employed persons with disabilities who are participants of the New Enterprise Incentives Scheme.

Accordingly, many people with MS and similar chronic illnesses have fractured working lives or are unable to maximise their earning capabilities by not being able to advance their employment status or by being limited in overtime capacity. An additional obstacle for people with MS can be the additional time, effort and cost commuting to work, negotiating traffic or public transport. Work-from-home arrangements can be advantageous where possible in such situations.

A key challenge is in introducing seamless employment support programs that involve innovative strategies such as workplace environment adaptation, job restructuring or tailoring, part-time and flexible work-from-home options, and transport assistance, as appropriate. Workers compensation 'return to work' or rehabilitation models can be useful – these can determine work capacity on an individual basis. Incentive regimes are also possible that recognise efforts made by both parties in adapting and maintaining employment arrangements. Such schemes should:

- include specialist advice (medical, allied health and specific experts eg, the Chronic Illness Alliance) for capacity reviews and in relation to the individual's workplace accommodation, routines, situation and capacity/ limitations in taking on additional work;
- not be a 'point in time' assessment but be cognisant of diagnosis, prognosis and disease progression over time, especially for RRMS, and allow for regular re-reviews if the individual's health or employment status changes suddenly;
- recognise the individual's health maintenance regime and how this can be preserved in combination with work (eg intermittent days off/job sharing);
- interact on a case-management basis with State funded disability and health services working with the person;
- consider how the individual's eligibility for Superannuation disability insurance may be affected by the timing of a return to work; and
- contain a thorough and independent appeals mechanism.

The linking of managing chronic illness with the workers compensation management of workplace injuries is worthy of further investigation. The methodology involved in modifying duties and workplaces for injured workers returning to work is one that would very much apply to workers with chronic illnesses. Currently there is the anomalous situation where injured workers are taken back because of a statutory obligation, but employers are in no way bound to make any provision for an existing employee who develops a health problem.

In the context of the long term need for greater workforce participation, the cause of injury/disease or the locus of responsibility for providing the support should not be a defining factor. If there is the opportunity for the worker to remain at work with modified duties or work place, then it should be mandatory for the employer to take reasonable steps, particularly if adaptive resources are available from DEWR, disability services or other sources.

One idea is for Government contribution to workers' compensation premiums for those employers who take on workers with a disability. More could be done in negotiation with workers compensation jurisdictions to link requirements for employers to support workers with a chronic illness in the same ways as they do injured workers. All that would be different is that the Federal Government would indemnify employers for costs of modifications for workers with chronic illness and disabilities.

Education and awareness strategies are also needed to counter workplace misperceptions and discrimination against people with disabilities (particularly MS), and that induce culture change among employers and employees to identify and implement positive long term solutions. These should cultivate 'success factors', namely:

- a positive relationship between employee and employer;
- basic employer knowledge of MS (including the impact of invisible symptoms like fatigue and memory problems) and sensitivity to the employee's needs;
- worker's knowledge of employment rights frameworks such as discrimination and Equal Opportunity legislation;
- options for workplace and job modification/flexibility, including working from home and being able to work outside normal hours;
- effective management of symptoms to facilitate longevity in work; and
- availability of responsive support services into workplaces to assist in workplace accommodation, information provision and disclosure issues.

> *"Job Network and Open Employment services also need substantial education about MS and chronic illness if their services are to be useful and relevant to this target group." (MS Australia, 2005, p14)*

Finally, job support programs for people with MS need to be fully integrated into the range of core services provided for people with disabilities through State and Federal networks, as well as with welfare payment systems and incentives, particularly the nexus with the Disability Support Pension.

The combination of part time employment and part time DSP is common for people with MS who want to continue working as much as possible for as long as possible to retain their independence[16]. MS Australia (2005) concludes:

> *"Any changes to DEWR policy must recognise that for people with complex conditions such as MS, employment is just one element in managing a difficult life. There is no single, simple policy response that can achieve a sustainable outcome. It requires flexibility, linkages and quality decision making…*
>
> *"The MS Societies are keen to work with the provider sector to improve their capabilities… An improved regime for employers would perhaps make it easier for providers to work with clients with chronic illnesses. In this sense a closer link between State funded disability services and DEWR funded services is desirable, because in many cases people in receipt of the DSP are clients of these services, and coordination of effort in the provision of support services is desirable."*

3.2.2 EARLY INTERVENTION

There is much that continues to be needed in relation to early health promotion and awareness interventions for people with MS. **The evidence basis demonstrates the**

[16] Less than 10% of DSP recipients in Australia have earnings, the lowest employment rate of OECD countries (FACS, 2004). Incentives must exist that support working as much as possible.

efficacy and cost-effectiveness for early diagnosis and intervention through patient and carer education and support, and through pharmacological and other therapies. In particular, there remains the challenge to change attitudes away from some remaining community perceptions that early symptoms of MS mean the pronouncement of a 'lifetime in a wheelchair'. To the contrary, much can and should be done, as early as possible, to delay disability from MS and maximise functionality and quality of life.

On the pharmacological side, numerous studies now note the efficacy of the new immunomodulatory drugs, interferon beta and glatiramer acetate, that have been shown to reduce relapse rates and slow progression of MS in several large multicentre, randomised controlled trials such as CHAMPS (Controlled High risk Avonex MultiPle Scelerosis) and ETOMS (Early Treatment Of MS). A review of the available evidence is provided in Jeffery (2002) concluding that there is an argument for early intervention in the treatment of MS. Kidd (2001) is more strongly supportive concluding that:

> *"Early intervention with integrative modalities has the potential to make MS a truly manageable disease".*

Furthermore, early IFNbeta treatment of patients with clinically isolated syndromes suggestive of MS has been shown to lengthen time to conversion into definite MS (Flachenecker and Rieckmann, 2003). On this issue Montalban (2004) provides the aetiological link:

> *"Cerebral axonal damage and brain atrophy begin at the earliest stage of MS. Progressive neuronal degeneration contributes to irreversible neurological deficit and ultimately disability. Axonal loss, which seems to be related to the inflammatory process, occurs much more rapidly in the early than later phases of disease, providing additional impetus for early intervention… Studies show that fewer patients with a first demyelinating event and abnormal MRI had a second clinical attack within 2 years if once-weekly treatment with interferon beta-1a was started at the time of the first episode."*

Modern studies with appropriate economic modelling suggest that treatment with IFNbeta may also be cost-effective in a variety of settings. For example, Kobelt et al (2000) found that treatment with interferon beta-1b versus no treatment in patients with secondary progressive multiple sclerosis cost US$43,000/QALY, which is in the cost-effective range.[17]

- World Health Organisation advice suggests that interventions are cost-effective if they cost less than three times GDP per capita (A$124,000) to avert one lost DALY (equivalent to purchasing a QALY) and **very cost-effective if they cost less than GDP per capita (A$41,000, US$30,000) per DALY averted (QALY gained)**.

Early psychosocial interventions are also highly beneficial. Courts et al (2005) found in a focus group study of young adults with a recent diagnosis of MS that four major themes emerged – caregiver roles, the need for information, relationship

[17] Other studies have shown greater or lesser cost-effectiveness – for example, Parkin et al (2000) found interferon beta-1b versus standard management in patients with RRMS cost US$410,000/QALY-US$1,500,000/QALY. Other cost effectiveness analysis examples are provided in the Harvard registry **www.hsph.harvard.edu/cearegistry/data/1976-2001_CEratios_comprehensive_4-7-2004.pdf**

changes and barriers. Young couples and families need information, education and support in order to enhance their ability to cope with the MS diagnosis and its inherent adjustments, in particular advocacy in the workplace to tailor and/or retain employment and thus minimise potential productivity losses and enhance wellbeing. Early information and intervention assists in these transition and maintenance processes and can thus reduce the costs of MS in the medium term.

Information, education and support can take a variety of forms – for example, Mills and Allen (2000) found that training in mindfulness of movement resulted in improved symptom management for people with MS in a pilot study, and recommended a larger study. A coping skills program was compared with a peer support program (Schwartz, 1999) to discover that the coping skills intervention yielded greater gains in psychosocial role performance, coping behaviour and numerous aspects of wellbeing, while the peer support intervention had less impact on wellbeing but was particularly useful for a subgroup of people with affective problems. Other interventions include cognitive behavioural therapies and aerobic endurance exercise and energy conservation strategies for management of fatigue in MS.

3.2.3 PHARMACEUTICALS

Section 3.2.2 summarises the value of enhancing awareness of the efficacy of early access to interferon pharmacotherapies, which are already listed for pubic subsidy through the Pharmaceutical Benefits Scheme (PBS). This section explores the appropriateness of expanding the indications of anti-fatigue and anti-convulsant therapies on the PBS to include treatment for people with MS, for whom these drugs are currently not accessible or prescribed off-label, although there is evidence they may be beneficial in reducing fatigue and enhancing quality of life. Internationally (through North America and Europe) there is variation on the listing and off-label prescription of these drugs for people with MS.

Anti-fatigue therapies: *Modafinil* is a psycho-stimulant (wake-promoting agent) currently included in the PBS for the "initial treatment, by a qualified sleep medicine practitioner, of patients with narcolepsy" under a range of criteria. Modafinil has been shown to be effective and well-tolerated in low doses in a number of clinical studies to manage fatigue for people with MS, as has *amantadine* (Krupp, 2003; Rammohan et al, 2002; Zifko et al, 2002). Zifko (2004) concludes:

> *"Fatigue is the most common symptom of MS and is associated with a reduced quality of life. It is described as the worst symptom of their disease by 50-60% of patients… Primary fatigue syndrome can be alleviated with drug treatment in many cases."*

Currently Modafinil costs around $130 per 30 tablets in Australia, which are reported to last people with MS for up to three weeks.

Anti-convulsant therapies: *Neurontin* is currently included in the PBS for the "treatment of refractory neuropathic pain not controlled by other drugs" and for the "treatment of partial epileptic seizures which are not controlled satisfactorily by other anti-epileptic drugs". Neurontin and other anti-convulsant drugs (eg, *Gabapentin, Tizanidine, Levetiracetam, Baclofen*) have been shown to be well-tolerated and effective for treating neurological pain, paroxysmal symptoms and spasticity in MS (D'aleo, 2000; Cutter et al, 2000; Dunevsky and Perel, 1998; Rushton et al, 2002; Schapiro, 2001; Finnerup et al, 2002).

Currently Neurontin costs around $120 per 100 tablets in Australia, which are reported to last people with MS for up to one month.

3.2.4 RESIDENTIAL AND COMMUNITY CARE

Continuity and quality of care

People with MS commonly experience restrictions in mobility and activities of daily living (ADL), with a wide range of physical, psychological, environmental and economic factors contributing to outcomes. Typically, their needs can change and become more inter-related and numerous as the disease evolves, necessitating assessment and intervention from a variety of different perspectives using a coordinated multidisciplinary management approach. Freeman (2001) concludes that:

> *"Management needs to be considered from a long term perspective rather than as a fragmented series of isolated 'quick-fixes'."*

Too often at present, services are provided that are neither timely nor consistent with the person's stage of progression of MS (see example below).

> Peter has had MS for 14 years, and now permanently uses a wheelchair for mobility. In 2004 Peter was assessed as being at high risk of developing pressure ulcers that involve prolonged treatment and care.
>
> He has already had one prolonged hospital stay (four months) in a rehabilitation bed in hospital because of difficulties managing his care and skin integrity, at a cost of around $45,000. His family currently provide all but seven hours per week of regular care, with Peter attending a community program one day per fortnight.
>
> He has been prescribed a replacement pressure relieving mattress to manage his pressure ulcer risk, at a cost of $7,650. The State Disability Equipment program has a funding limit of $800 every two years for pressure care equipment, based on the cost of a wheelchair cushion. This program, that funds all disability equipment, has no provision for pressure mattresses and Peter is unable to meet the $6,850 shortfall.
>
> His care regime, operated by his family, has adapted to a less optimal option to protect his skin, while on a waiting list for an attendant care package of 34 hours per week to share the care.
>
> If Peter experiences further skin problems he faces further long stay admissions to hospital for treatment of pressure ulcer. In addition, if his family care arrangements falter without adequate attendant care support, he risks a high care permanent nursing home placement, for perhaps 30 or more years.
>
> The provision of the pressure mattress and care program when required may well be the most cost-effective (and compassionate) response.
>
> *Peter, 51years, Melbourne.*

These problems arise in part from the nature of service provision in State and Federal 'care silos'. People with MS require services across the spectrum of health, disability services and residential accommodation, with the ability to access seamless, flexible, multidisciplinary models of service provision.

People with MS, like others with chronic progressive conditions, do not fit easily into any single jurisdictional program. At various times, and sometimes concurrently, they will need services from HACC, acute health and disability services. As things stand, there is no formal connection between these services and when services are not properly coordinated, inefficiencies and crises of care often occur. While attempts have been made at the Commonwealth level to better coordinate services (eg, *A New Strategy for Community Care - The Way Forward*, Department of Health and Ageing)[18] more needs to be done connecting Commonwealth and State disability services. The failure of these connections is resulting in relatively young people with MS being admitted into nursing homes.

Challenges in ensuring the quality of care include:

- skilled workforce shortages in allied health, community health and general practice, particularly in certain areas;
- insufficient appropriate education and training in the formal health care sector or to adapt/adopt more effective models of care for young people with disabilities;
- the need for a special type of carer (as with palliative care), who has the training and capacity to cope with the chronic progressive illness compared to acute illness with a 'cure';
- differentials in comparative rates of pay
  - disability service awards are lower than hospital awards for the same class of workers, leading to higher turnover and more junior staff than desirable in disability services
- episodic case mix funding does not take into account the progressive nature of MS.

Moreover, because of the younger age profile of people with MS, aged care services are seldom appropriate. The goal and benefit of tailored service provision is thus avoidance or delay of costly and inappropriate institutionalisation. An alternative and more appropriate model of care would be HACC-type annex services that are age-appropriate and flexible, to grow as the needs of people with MS grow, without having to change systems as the disease progresses. A number of lifestyle and age-appropriate accommodation models exist already in disability services, and are provided by MS Societies that are worthy of duplication for those people who can no longer remain at home.

Young people in nursing homes

Section 2.1.2 identified that hundreds of people with MS aged under 65 are accommodated in residential aged care, because the accommodation and support they need for their disability does not exist, or community care packages were not available. This problem has become endemic in Australia and not just for people with MS – 5% of aged care beds are occupied by people aged under 65 with demand accelerating (AIHW, 2002):

[18] See www.health.gov.au/internet/wcms/publishing.nsf/Content/A+New+Strategy+for+Community+Care+-+The+Way+Forward-1

"Between 2000 and 2006, it has been estimated that those aged under 65 years will grow by 9%, those aged 15–64 years by 12%, and the group aged 45–64 years will grow by 19.3% or 59,500 people."

Aged care is inappropriate for younger people because:

- therapeutic input is required to maintain a person's physical, cognitive and social functioning, but aged care facilities have a lack of rehabilitation orientation;
- staff do not have the requisite skills and knowledge to care for younger people with MS, acquired brain injuries, Muscular Dystrophy or Parkinson's Disease and staffing levels are insufficient to maintain and promote independence for these people;
- the resources needed to purchase appropriate equipment to support the complex care needs of young people do not exist within this framework; and
- it can substantially reduce wellbeing for younger people to be placed in a restrictive and morbid environment with little or no community involvement or peer support.

In contrast, the National Alliance of Young People in Nursing Homes (2004) proposes a strategy to work with government and non-government agencies to develop sustainable funding and organisational alternatives that deliver a 'life worth living' to younger people living in residential care, through:

- developing alternative housing and support options for younger people wishing to move out of nursing homes;
- reducing further admission of younger people into nursing homes through the provision of flexible care packages to ensure they are able to access choices about where they live;
- developing and implementing research designed to complement the commitment to action, which is underpinned by the needs and experiences of young people and their families/friends, to identify **models of care, extent of need, costs and resources** required to provide alternative accommodation and support for younger people with disabilities needing a high level of care;
- building measures and resource allocation into the Commonwealth State Disability Agreement; including performance targets for the States regarding the creation of alternative services;
  - add this cohort to the measurement of unmet demand in the calculation of growth funds; and
  - establish a Commonwealth State Working Group to resolve the funding responsibilities and ensure sustainable service delivery;
- initiating leadership through the Commonwealth to resolve responsibilities and resources so that:
  - State/Territory Departments must define and clarify areas of discrete fiscal responsibility for younger people in nursing homes;
  - there is recognition that the resources available to meet these needs have not been adequate in the past; and
  - there is revision of current policy regarding admission of younger people to residential aged care.

To this end, the National Alliance of Young People in Nursing Homes (2004) called on Commonwealth and State Governments to:

- establish a national body for young people in nursing homes comprising representatives from the Commonwealth and State Governments and all stakeholder groups, including those directly affected, to oversight the implementation of the agreed strategies and
- establish a National Young People in Nursing Homes Advocacy Alliance to coordinate lobbying efforts, form partnerships with and across health and community service sectors and ensure action occurs on the agreed strategies.

3.2.5 SUPPORT FOR INFORMAL CARERS AND RESPITE

Given the profile of costs, with informal care 43% of the costs of MS, support for informal carers will remain a key issue in order to avoid the additional real resource cost and poorer quality outcome of care being institutionalised. There is an extensive literature on the lower costs and improved outcomes of informal sector care that has led to a policy orientation supporting such care for people with disabilities and the frail aged (called 'ageing in place' for the latter group).

In this study, for the 15,361 people with MS estimated to be living in the community, the average cost of care per person (including the replacement valuation of informal care, aids and modifications and support services from the formal sector) is $19,041. Costs for the 730 people in high care residential care are an estimated $30,354 per person – some 60% higher.

In 2003, data from the ABS Survey for Disability Ageing and Carers showed that around 37.2% of all primary carers felt they needed more support in their caring activities (ABS, 2004c). Even with the welcome support measure of recent Federal Budgets, there remains more to be done, particularly for carers in rural and remote areas. Most primary carers are of working age, have lower rates of employment because of their caring duties, and as a consequence have lower average incomes (ABS, 2004c). Informal care is most often provided by close family members who, as a result of caring, suffer from generally worse physical health, tiredness, stress, back/muscle problems, depression, anxiety, isolation and lack of respite. Many provide long hours of care because of the lack of other choices. The propensity to provide care may well be lower in the future with inter-generational changes, while the number of people requiring care will grow with demographic ageing and the rising prevalence of chronic disabling conditions.

The core issue for carers of people with MS, as with the general population of Australian informal carers, is the need for support services to grow in line with care needs. The constraint in this area is primarily budgetary. The May 2005 Budget announced a new initiative, *Respite care to assist employed carers.* Carers in paid employment and carers re-entering the workforce will benefit from an increase in the number of respite services available through funding of $95.5 million over four years. This will include increasing the funding to Commonwealth Carer Respite Centres, enabling day respite centres for older Australians to extend their hours of operation. This will enable up to 5,000 employed carers each to access an average of 480 extra hours of respite in a full working year.[19]

[19] www.health.gov.au/internet/budget/publishing.nsf/Content/health-budget2005-abudget-afact2.htm

Adequate ongoing funding injections are required to increase services to carers, in particular for education, peer support and respite. Access Economics (2003a) showed that programs that provide these services to carers can have seven-fold returns in terms of improving the quality of life of carers and the people they care for and delaying costly institutionalisations.

Respite for people with MS and their carers suffers from the same inherent problems as residential care for people with MS – frequently the care is not age-appropriate, respite carers are inadequately trained, availability is not flexible and thus services may not be useable. Unlike aged care and dementia respite services, the respite can be as important for the person with MS as for the carer.

The nature and course of MS means that individuals and families have to adapt to changed circumstances and capacity. Through the progress of the disease, most people with MS continue to have an engagement with the community both in terms of work, family and recreation. The imperative of policy must be to protect and encourage this engagement through education, community support and adaptation, and not force people, eve short term, into unsuitable facility based health or disability services.

An inherent flaw is that respite services have arisen from the aged care system, and are not designed for younger people who need to be able to continue their normal activities during respite periods – the respite care thus needs to be **lifestyle-friendly and age-appropriate**. Moreover, more flexible models of respite care are needed, including overnight and weekend support, cottage style accommodation, extended hours at day centres and extension in many areas where there are access problems nd service gaps.

3.2.6 RESEARCH

Section 2.1.2 noted the relative under-funding of research for MS as 1.9% of total health expenditure compared to 2.4% across all health conditions. The returns to investment in medical research in Australia are estimated at 2.4:1 in terms of the value of gains in healthy life (Access Economics, 2003). There is a need to address the relative under-funding by building on catalysing processes already taking place within the Australian MS and research community.

MS Research Australia is an initiative of MS Australia that brings together laboratories and research groups in Australia's premier academic institutions to form five major research centres, each focused on a key theme of MS research. Within the research centres are a total of 34 research laboratories and more than 150 scientists and clinical researchers, with MS Australia playing the coordinating role. MS Research Australia (2005) outlines the MS Australia strategy to achieve a nationally coordinated research structure with substantial interdisciplinary collaboration, by providing a partnership between the MS community and the research community through a virtual research institute. The aims of MS Research Australia are to:

- eliminate the effects of MS by funding research into the causes, treatment and management of the disease;
- take a thorough and strategic approach to research by focussing on promising areas, eliminating duplication with overseas researchers and improving accountability;
- apply the results of worldwide research towards programs of treatment, prevention and cure;

- encourage individuals and organisations to support a coordinated and nationwide research program; and
- develop common systems to reduce costs, compare data and share resources.

MS Research Australia will focus its research activity within five major scientific disciplines:

1. immunology;
2. genetics and epidemiology;
3. neurobiology;
4. clinical research; and
5. applied therapeutics.

Australia is fortunate to be home to some of the best immunology experts in the world. Within these disciplines a prioritised research strategy is being developed that provides a focus for funding large scale research on three central areas relating to:

- genetics and MS;
- the blood-brain barrier; and
- myelin repair and regeneration.

MS Research Australia can coordinate cross-state research programs addressing important issues in MS through Federal research programs schemes such as the National Collaborative Research Infrastructure Strategy.

A national MS register

Another initiative to catalyse research would be the establishment of a national register that could collect accurate and ongoing data about the incidence and prevalence of MS and bring together the work of existing state-based registers into a national framework for data collection. Such a register could enable government and services to be informed of the present and future needs of people with MS and provide a framework for research. A similar register has recently been investigated in relation to Cerebral Palsy[20] which provides valuable insights for establishing an MS register, and other similar registers exist around the world in relation to other disorders (particularly similarly low-prevalence debilitating disorders such as Motor Neuron Disease). Issues that would need to be addressed would include:

- notification processes to the register;
- location and software platform;
- funding, staffing and coordination for establishment and maintenance;
- security, privacy and ethical integrity, particularly in relation to consent and verification processes;

[20] See **www.acpa-inc.org.au/cpregister.htm**

- relationship with existing MS databases such as state MS Societies' memberships and the AMSLS;
- collaborative partnerships, eg with the AIHW, universities or corporate partners; and
- identification of the growth in numbers of children being diagnosed with MS to track this suspected new phenomenon.

3.2.7 COLLABORATIVE PARTNERSHIPS

MS Australia is not alone in its advocacy for the community of people with neurological disorders. Indeed, there is a significant degree of collaboration already between the representative bodies within this community with the aim of working together in public policy engagement at the national level. MS Australia undertook a scoping study in 2003 investigating the support for a formal collaboration with other neurological organisations. The organisations consulted in this project are those that MS Australia works with variously across service and policy networks and on discrete projects. They were:

- Alzheimer's Australia
- Australian Leukodystrophy Support Group
- Charcot Marie Tooth Disease Association
- Epilepsy Foundation of Victoria
- Motor Neurone Disease Association of Australia
- Muscular Dystrophy Association of Victoria
- National Brain Foundation
- National Huntington's Disease Association
- Parkinson's Australia
- Tourette's Syndrome Association of Victoria
- Chronic Illness Alliance
- Genetic Support Network of Victoria
- Neurosciences Victoria
- Physical Disability Council

This collaboration is aimed at pragmatically achieving critical mass and economies of scale as a coordinated neurological sector for a more effective voice in relation to national policy, as a forum for discussion and with equitable representation for participants. Marot et al (2003) sets out the rationale for closer collaboration.

PMSEIC (2003) highlights the unprecedented pace at which neuroscience is expected to progress over the next decade in its report to the June 2003 meeting of the Prime Minister's Science, Engineering and Innovation Council. It made recommendations in relation to:

1. enhanced basic research networking;
2. forming an alliance – the "**Brain and Mind Research Alliance**" and forming a short-term Neuroscience Consultative Task Force to develop the alliance; and

3. implementing a national approach to brain and mind disorders through the alliance's action agenda to:
    a. foster basic research and its translation to consumers, carers and industry;
    b. take advantage of neuroscience strength that already exists in Australia, as well as build new networks and research collaborations;
    c. provide national network funding as the 'glue' to encourage innovative collaborative ventures;
    d. enhance international research and industry links; and
    e. contribute to policy setting in terms of research setting, health outcome evaluation and ethical issues.

To further develop the recommendations PMSEIC (2003) report, in August 2004 the Minister for Health and Ageing, the Hon Tony Abbott, established the **National Neuroscience Consultative Taskforce.** The purpose of the Taskforce is to provide advice on how Australia can best harness scientific advances in understanding and managing social and health problems associated with disorders of the mind and brain and to develop strategies to prevent, reduce or contain the chronic and debilitating consequences of these disorders.

The Taskforce has so far received public submissions and is undertaking a national program of consultations with the neuroscience research community, practitioners and carers to incorporate in its report to the Minister. It brings together recognised leaders in the fields of neuroscience, neurosurgery, psychiatry and psychology as well as members with broad experience in the community and consumer sector and in the biotechnology industry. Professor Judith Whitworth, Director of the John Curtin School of Medical Research at the Australian National University, is the chair.

There remains the need to agree and implement a prioritised action agenda.

3.2.8 SERVICE CAPACITY OF MS AUSTRALIA

MS Australia aims to enhance the quality of life of people with MS and reduce the impact of MS on their families and carers.

To this end, a range of services are provided to people with MS, their families, friends and carers around Australia. Training and information is also offered to health professionals and other relevant agencies. Direct client services are managed and delivered at state level by the state MS Societies. To access many specialist services, people with MS need to register with their state MS Society (free of charge). Specialist services[21] vary state by state and include:

[21] There are also national basic services that include:

- toll-free information line (1 800 CURE MS) available during business hours and staffed by qualified health professionals;
- on-line information services and support (see www.msaustralia.org.au) with links to (reviewed) online communities and web sites tailored for people with MS living in Australia;
- library - for more detailed searches and specialist information, the MS library is staffed by specialist librarians and holds an extensive range of information on MS, printed information packs are available on request as well as booklets, pamphlets and videos for loan and sale;

- home and workplace visits;
- support groups for people with MS and their families and carers;
- immunotherapy education, assistance and counselling;
- medical and neurological assessment and attendant care;
- allied health – nursing, physio and occupational therapy, hydrotherapy; massage;
- social work, advocacy, counselling and programs to support independent living through individual needs assessment such as
  - fatigue management (cooling devices, energy conservation techniques, work simplification strategies);
  - psychological/cognitive symptoms (assessment, counselling);
  - bladder/bowel problems (advice, referral, samples of aids);
  - sexuality/relationships (counselling, management strategies for physical symptoms);
  - maintaining physical abilities (assessment, therapies, home programs);
  - maintaining independence (home assessments, specialised equipment such as mobility aids, taxi vouchers, parking permits);
- case management and community access coordination, information and transport;
- limited permanent accommodation, temporary respite accommodation and in-home care;
- outreach to members in rural and isolated areas;
- research into the cause and a cure for MS;
- education and awareness for health professionals and the community about MS and its effects; and
- employment services (liaison with employers, information).

MS Societies around the country are thus well positioned to assist Australians with MS across a broad spectrum of areas. MS Australia's *National Service Model* adopts a strategic long term collaborative approach to service provision.

However, there is currently no Federal funding for MS Australia's education and support programs. Pharmaceutical companies and the States fund allied health services such as treatment education for injections and community nurses addressing health complications. This is unusual among peak bodies representing people with disabilities, who are often well placed and have comparative advantage in providing services, in particular employment services.

The overwhelming majority of people with MS requiring assistance services will self refer to their medical practitioners or their MS Societies. People with MS who are encountering difficulties in their employment tend to seek assistance directly from their local MS Society because they interpret it as a MS-related problem, not as a 'labour

- Peer Support – People with MS Australia: PwMSA is a network of peer support and advocacy groups in all states (city and country) where members meet regularly, produce newsletters, and participate in community education forums to increase public awareness of the effects of MS.

market' problem. The MS Society will be known to these individuals, whereas other programs such as the Job Network may be a less familiar option.

In the context of employment, a job in jeopardy situation involving emerging MS symptoms requires a highly specialised response. MS Societies are specialised services that can more easily recognise the subtle changes associated with disease progression. The literature indicates that there are complex and disabling interactions between MS symptoms and workplace environments that need to be managed by experienced allied health practitioners to ensure that MS symptoms are not misinterpreted and passed over (Johnson et al, 2004).

Although policy in a number of health and disability support areas is moving to generic sectors (such as the Job Network and Community Health) to provide support to people with specific needs, there is a demonstrated argument for specialist agencies like MS Australia to play a key role (including partnerships with such sectors) in employment and other services. Because of their expertise, capacity and community profile, they are well placed to contribute to provide positive strategies to individuals, employers and providers – and also ensure that individuals do not get lost in unfamiliar bureaucracies.

3.2.9 DISADVANTAGED GROUPS

Section 1.4.2 showed that people with MS are over-represented in **rural and regional** areas, where access to services (particularly respite) and workforce adequacy (notably medical) is poorest. There is no evidence that Aboriginal and Torres Strait Islander people are doubly disadvantaged through ethnicity in relation to elevated MS prevalence or needs, over and above their locational disadvantage. Smarter use of new information technologies can assist in delivering health and support services to people in rural and remote areas, including web-based information resources and messaging, moderated chats and forums, videoconferencing and clinical communications.

An emerging issue is the special needs of people from culturally and linguistically diverse backgrounds, especially people from Italian and Greek communities. People from non-English speaking backgrounds can face added challenges in relation to possibly delayed MS diagnosis, language barriers (eg, translation of information and support materials), employment obstacles, culturally appropriate services, and individual customs, traditions and values. These Australians have equal right to access affordable, quality MS assessment and care services, which can only be available for them if specialist resources are developed to promote access.

3.2.10 FINANCING ISSUES

Many people with disabilities and of working age experience severe financial problems by having limited disposable income from employment earnings together with substantial additional outlays for medical, pharmaceutical and travelling costs to manage their disabilities.

In the first instance, the challenge is to extend the productive working life of people with MS through employment support measures (Section 3.2.1).

Another possibility is earlier access to preserved superannuation lump sums for people with MS, perhaps from age 45 or 50 years, based on individual capacity assessments (appropriately tailored capacity assessments are also discussed in Section 3.2.1).

There is some intuitive justification for this idea given that people with MS are likely not to live as long as other Australians (see Section 1.1.3) and also because of the life-cycle aspects (unlike most Australians they may still be repaying mortgages as well as requiring home/vehicle modifications when they are no longer able to work). It would be important in any early superannuation payout arrangement to preserve the incentive to work, while also enhancing the timeliness of retirement incomes for people with MS.

For consistency, such arrangements would need to apply for similar medical conditions. It is also noted that there are currently hardship provisions enabling people to access super under certain circumstances, such as being unable to meet reasonable and immediate family living expenses, or receiving relevant Commonwealth income support payments for six or more months prior (ATO, 2005). The benefit is limited to a single gross lump sum of no more than $10,000 with only one payment per member permitted in any twelve month period. Applications for release on severe financial hardship grounds must be directed to the trustees of the member's superannuation fund. However, there is a case for reviewing such arrangements to make the access process less onerous and more consistent for younger people with diagnosed chronic illnesses.

Australians with MS tend to have a desire to maintain continuous private health insurance, despite the obstacles they face in terms of affordability.

> *"65.9% of people with MS participating in the longitudinal study maintain private insurance. This is higher than the 43% for the general community. Health insurance comes at a very high price for people with MS given that they have generally lower incomes than other Australians – but the capacity to have choice and easy access to specialist neurologists and hospital care is essential, and for which people have made demonstrable financial sacrifices to maintain." (MS Australia, 2005).*

The private health insurance subsidy substantially assists people with MS to achieve this goal. More broadly, however, intergenerational planning needs to acknowledge the need for spending on health, aged and disability care to grow in real and relative terms, with strategies for successfully managing the change. Various tiers of government are already taking steps in this direction, for example the "Future Fund" proposed in the 2005-06 Federal Budget. The future private-public mix of care provision and insurance provision is also an important issue for national debate.

3.3 CONCLUSIONS AND RECOMMENDATIONS

1. Employment support: It is recommended that:

- a discrete policy focus is created within DEWR (covering Disability Open Employment sector and the Job Network) to develop programs aimed at retention and adaptation of existing jobs for people with MS and other chronic illnesses;
  - such programs should involve innovative strategies such as workplace environment adaptation, job restructuring or tailoring, part-time and flexible work-from-home options, and transport assistance, as appropriate;
  - rehabilitation and workers compensation models should be considered for integration into job retention policy and programs;

  - existing employer incentive schemes could be extended to include employers supporting workers with MS and other disabilities in job retention programs; and

- education and awareness strategies are developed to counter workplace misperceptions and discrimination against people with disabilities (including MS) and encourage employers and employees to identify and implement positive long term solutions.

2. Early intervention and health promotion: It is recommended that the range of specific health, wellness and self management programs for people with MS and their carers is extended to improve health and lifestyle outcomes for both groups, including:

- early access to cost-effective pharmacological and other therapies that will improve health outcomes and workforce participation; and
- a change in community perceptions and attitudes to MS so that the potential for positive strategies and outcomes is realised by employers, policy makers and the community.

3. Pharmaceuticals: It is recommended that the Federal Government fast track the process for expanding the PBS-listed indications for anti-fatigue and anti-convulsant therapies for people with MS that have strong clinical evidence. Access to these medications can improve the management of some of the most debilitating symptoms of the disease that prevent participation in employment and other forms of community life.

4. Community and residential care: It is recommended that:

- to improve efficiency and efficacy of community care programs, alternative and better coordinated models of care are established across the Commonwealth and State jurisdictions to result in more seamless, flexible and multidisciplinary care that is able to follow the course of the disease;
- to this end, formal protocols and transfer agreements need to be struck between Commonwealth/State disability and aged care programs to formalise service access and continuity for people with MS and similar progressive conditions with the aim of supporting people in the community and delaying residential placement for as long as appropriate;
- where residential accommodation is required, it is age-appropriate and incorporates specific care for disease related symptoms as well as disability support;
- the Council of Australian Governments (COAG) Health Working Group delivers a detailed plan for the move of younger people with disabilities out of aged care, incorporating the recommendations of the National Alliance of Young People in Nursing Homes for a national taskforce to undertake the initiative, in particular to:
  - develop services in every State and Territory to provide alternative housing and support options for a targeted number of younger people wishing to move out of nursing homes;
  - reduce further admission of younger people into nursing homes through the timely provision of flexible community service packages to ensure they are able to access choices about where they live;
  - build measures and resource allocation into the Commonwealth State Disability Agreement to specify funding responsibilities and ensure

sustainable service delivery for the existing target group and those others at risk of inappropriate placement in aged care; and

- make CSTDA services available to younger people with MS and other disabilities living in nursing homes.

5. Support and respite for informal carers: It is recommended that:

- additional recurrent funding is provided for design and delivery of support, education and respite services for informal carers of people with MS;
- the recent budget initiative for respite care to assist employed carers is expanded to target the carers of people with MS to ensure that respite services are introduced in a dignified and relevant manner, and will offer greater employment continuity to carers;
- the Commonwealth National Respite for Carers program and State disability programs fund shared care and respite services for carers and people with MS (and other young people with disabilities) that:
  - are lifestyle friendly, flexible and age-appropriate;
  - are available over the long term course of the disease; and that
  - offer improved case management input to ensure good planning and packaging of services.

6. Research: It is recommended that:

- the scope to address the relative under-funding of MS is reviewed with a view to bring research spending on MS up to the national average with investments directed through MS Research Australia; and
- a National MS Register is established from 2005 to bring together accurate ongoing data about MS incidence, prevalence, impacts and services into a national framework for data collection, with appropriate linkages to other existing MS databases and as a framework for research.

7. Collaborative Partnerships: It is recommended that the National Neuroscience Consultative Taskforce establish a Brain and Mind Research Alliance in line with the recommendations of the Prime Minister's Science, Engineering and Innovation Council Report from 2003 to, as a priority, implement strategies through a national action agenda to prevent, reduce or contain the chronic and debilitating consequences of neurological disorders. This could be facilitated by a national network of neurological associations.

8. Service capacity of MS Australia: It is recommended that the scope for Federal and State funding of the MS Societies be reviewed with a view to improving national infrastructure and service delivery capacity for Australians with MS, through the introduction of new services and improvement of existing responses in the following areas:

- carer education and support programs
- rural and remote outreach programs for people with MS and their families;
- employment support, job in jeopardy programs and employer education about particular methodologies around MS in the workplace;
- community education; and
- health promotion and self management programs.

9. Disadvantaged groups: It is recommended that MS services reflect the different needs of different groups of people, with equal and improved access for people with MS and their families and carers, in particular people who live in rural and remote regions of Australia and/or who are from culturally and linguistically diverse backgrounds, through:

- better and more appropriate use of smarter new technologies in diagnosis, treatment and referral; and
- specific attention to workforce development in outer metropolitan and rural locations for allied health workers capable of working with people with MS and similar progressive neurological conditions.

10. Financing issues: It is recommended that:

- Government consider less onerous and more consistent access to preserved superannuation lump sums for younger people with MS and other chronic illnesses, potentially from age 45 or 50 years, based on individual capacity assessments; and
- longer term intergenerational financing makes adequate provision to appropriately fund the growing community needs for health, ageing and disability services, in view of the demographic ageing and the projected expansion in prevalence of people with chronic disease and disability.

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