



MS Australia

Submission to the National Health and Hospitals Reform Commission

INTRODUCTION

The Multiple Sclerosis Australia (MS Australia) strongly supports the establishment of the Reform Commission, and is encouraged by the emphasis of the Rudd Government on 'ending the blame game'.

Our interest is primarily focused on the management of chronic disease. While the current priority in the chronic disease area is about prevention, not all conditions are preventable through public health measures, nor are they lifestyle related. Multiple Sclerosis is one such condition that although not preventable, is disabling, incurable and result in reduced quality of life and productivity.

Many chronic diseases like MS cannot be managed by the health system alone, as they have their main effects in the community on employment, income levels and relationships. This is where the imperative is to develop a comprehensive chronic disease strategy that goes across portfolios and jurisdictions, and aims to maximise social inclusion, well being and coordinated (lifetime) care.

Health Policy is increasingly being targeted at chronic illness, through prevention and other targeted measures in health, however the comprehensive management of illness is critical to quality of life and community participation for those living with it, particularly where their conditions are not preventable. Good health is important people with chronic illness as well.

Investing in medical and social research into chronic diseases is also an important part of the overall response to disease management.

While there are numerous structural and funding issues related to health and hospital reform in this chronic disease context, this submission focuses on five issues of particular relevance to people with MS:

- Continuity of care – rural access + links beyond healthcare - integration
- Improved drug approval processes
- Healthcare workforce and flexible employment practices
- Catastrophic Insurance
- Research into MS

Following the Background section of this submission, key aspects of these issues are briefly outlined below.



MS IN AUSTRALIA

The fight against multiple sclerosis (MS) has long been a part of the Australian psyche. For nearly 30 years, our children have been collecting sponsorship dollars from their families, friends and neighbours via the MS Readathon™. And yet in 2008, despite this effort and substantial Government support, a cure for this unpredictable and mysterious disease of the central nervous system continues to elude us.

MS currently affects 18,000 Australians directly, and indirectly hundreds of thousands of family members, friends and colleagues of those living with the disease.

While science continues to strive towards a cure for the medical effects, improved social and economic policy can also provide a 'cure' for many of the social effects of living with the disease. Keeping people in good health, maintained in the workforce, living with their families and making positive and productive contributions to the community will help reduce the burden of the disease and improve the quality of life of those affected.

There are substantial costs associated with having MS. Hendrie and colleagues (2005) found that the average annual cost to people with MS and their families in Australia was an extra \$10,500 - a significant outcome of the disease for people on low incomes, many of whom are on partial and full government pensions. The total estimated cost of MS to Australia is \$2 billion per annum, and will grow quickly unless we address the disease with increased research and more effective policy.

What is MS?

MS is a chronic and incurable disease that randomly attacks the central nervous system (brain and spinal cord). Symptoms of MS are unpredictable and vary greatly from person to person and over time in the same person.

They may include: extreme fatigue, tingling, numbness, impaired vision, loss of balance and muscle co-ordination, slurred speech, tremors, stiffness, bladder and bowel problems, difficulty waking, problems with memory and concentration, mood swings and in severe cases, partial or complete paralysis.¹

We all know someone with multiple sclerosis (MS).

In supporting Australians with MS and their families, MS Australia is endeavouring to provide an integrated approach to managing the disease through service programs, a focused research effort and education.

To achieve this we are:

- facilitating Australian research that will accelerate the potential for prevention and better treatments
- providing direct services to individuals and families and working with the health sector to expand health services for all Australians with MS
- promoting early access to new and better treatments that will slow disease progress and reduce symptoms
- educating and informing the community and Governments to improve real life outcomes for those affected by the disease and to reduce discrimination against Australians with MS.

See the MS Fact Sheet at the end of this submission for more information.

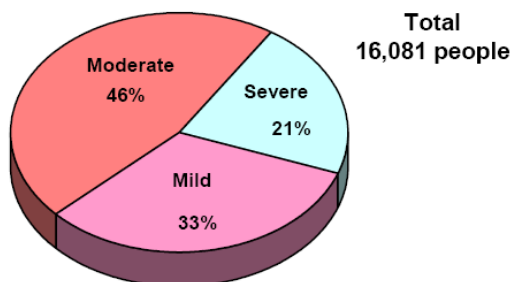
¹ Acting Positively: Strategic implications of the economic costs of multiple sclerosis in Australia. Report by Access Economics Pty Ltd for Multiple Sclerosis Australia. Winter 2005



ACCESS TO HEALTH CARE, CONTINUITY OF CARE AND INTEGRATION OF CARE

The sooner someone is diagnosed with MS and treatment is started, the more effective the intervention strategy.² Consequently, any delays in diagnosis and subsequent treatment are problematic, not only for the person with MS and their family in relation to quality of life, health status and social participation (family life and work life), but also in relation increased (avoidable) healthcare needs and the concomitant extra costs of this care.

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



Source: AMSLS

Once diagnosed, new efficacious treatments such as the newly approved drug Tysabri can slow the disease progress, reduce disabling symptoms and improve quality of life and productivity. Pharmacological treatment of fatigue and refractory neuropathic pain has also proven effective for people living with MS. Access to the full range of treatment options is critical.

Currently, 79 percent of people living with MS in Australia rate their level of disability as being mild to moderate.

A total disease management model is required to provide timely and flexible interventions across the public and private health systems to assist people to manage their conditions over a lifetime. It is also vital that this model bridges the traditional divides between health care, disability programs, housing and other vital services. Additionally, people living in rural areas are often especially disadvantaged in relation to access to neurologists, which hinders both early diagnoses and effective ongoing treatment, as well as access to other vital services.

MS Australia supports the development of a comprehensive disease management approach that can draw on private health funds, public health and disability services. 70 percent of people with MS involved in the MS Life Study have private health insurance – compared to 43 percent of the general Australian population. This higher level of uptake is a clear indication of their lack of faith in their ability to get necessary and timely treatment through the public health system, and is undertaken in spite of the overall high levels of poverty amongst people with MS – within 10 years of diagnoses 80% of people with MS are unemployed, and approximately 50% of all people with MS (under 65 years of age) are reliant on income support payments.

The burden of MS is currently estimated at \$1.3 billion per annum, with direct costs (MS health expenditure) at a further \$659m per year. Improving treatment options will reduce this

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, 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.³

² Acting Positively: Strategic implications of the economic costs of multiple sclerosis in Australia. Report by Access Economics Pty Ltd for Multiple Sclerosis Australia. Winter 2005

³ op cit



Co-ordinated care is essential and will need to be achieved via multiple structural, process and funding changes to ensure coordination and integration across private, public and community health domains, across the healthcare continuum from primary to tertiary health care, and across other essential sectors such as disability services and housing. Disease management approaches, while not sufficient on their own, are one of the key strategies for delivering the necessary integration.

The Coordinated Care Pilot Programs for people with progressive neurological diseases being trialled in Victoria and NSW are examples of one possible model of coordination which brings together the some of services and funding programs necessary to meet the complex and widely variable needs of this group. Evaluation results will be available in mid-2009.

IMPROVED DRUG APPROVAL PROCESSES

As noted above, timely access to treatment is vital for people with MS. A new generation of pharmacological interventions that have the potential to reduce the advancement of MS, improve the quality of life for people with MS, and reduce growth in direct and indirect costs of MS, are coming online over the next few years. The MS community was fortunate to have the first of these (Tysabri) approved for listing on the PBS from July 2008.

The PBAC process is complex and depending on the outcome of negotiations with drug companies, can run for lengthy periods. During the approval process, consumers and disease groups often are frustrated by the lack of transparency of the process, and the fact that there is no formal avenue to inform the negotiations. People who are pinning their hopes on new treatments that they know are being considered have gone to extraordinary lengths to try to influence a process that for the most part is not open to this type of pressure.

This highlights a significant gap in the approval process - regarding a more direct avenue for involvement of people living with chronic disease who could potentially benefit from drugs under consideration, as well as their families and organisations. These are the groups who bear the brunt of burden when the approval process is excessively slow, and not including them more directly in the process disenfranchises those most affected.

Affordable access to a range of pharmaceuticals is a key aspect of disease management throughout the disease course. Earlier access to immunomodulatory treatments upon diagnosis has been proven to improve outcomes, however current Pharmaceutical Benefits Scheme (PBS) rules stipulate that these treatments are only available after two MS 'attacks'. This can sometimes mean a long wait for some newly diagnosed people getting active treatment, and can result in permanent loss of function. This situation can be remedied by changing the PBS requirement that a confirmed diagnosis and a single MS attack is all that required to access the available drugs.

There needs to be a mechanism in the PBAC process to initiate the examination of drugs for listing where the data exists about efficacy. Currently the process relies on pharmaceutical companies initiating applications – and where there is not a commercial advantage to seeking a listing, the application is not made, and consumers do not get the affordable access they need.

Pain and fatigue are symptoms that can severely compromise employment participation and quality of life. A significant number of people with MS currently buy anti-fatigue and neurogenic pain drugs that are proven to be useful in the long term treatment of MS symptoms from Internet pharmacies at retail prices because they listed on the PBS for MS (despite low income status).

We recommend that such non-PBS treatments be made available through the Workplace Modification Scheme to employed people as a start to increasing the availability of these drugs more widely.



HEALTHCARE WORKFORCE AND FLEXIBLE EMPLOYMENT PRACTICES

As indicated by its inclusion in the Commission's terms of reference – workforce issues are a critical factor in relation to improving the healthcare system in Australia. There is a need for the development and establishment of flexible workplaces that will support the retention and recruitment of people who have chronic illnesses and/or disabilities, and people who have family caregiving responsibilities. It is vital that these people are able to continue to work, or to be able to enter the workforce – and one of the most common barriers is a lack of flexibility and responsiveness to their needs.

A focus on flexibility for both employees and employers has the potential to provide many benefits to the healthcare system, including a much needed framework to ensure that people with chronic illnesses and disabilities, and the families caring for them, are able to participate in the workforce as much as possible while balancing complex interplay of: disability/illness – family – community – family caregiving – work.

Real flexibility is required to meet the rapidly changing needs of the health workforce in relation to the nexus of: (a) the ageing of the population; (b) increasing levels of disability and chronic illness; (c) increasing dependency ratio; (d) increased workforce participation of women; (e) low levels of unemployment; (e) reduction in the availability of family caregivers into the future; and (f) deeply entrenched employment practices and cultures that continue to disadvantage and to discourage people with disabilities and chronic illnesses (and the family members who care for them) from maximising their participation in paid work.

The need for flexibility covers the inevitably broad spectrum of human experience. Some employees will need a small amount of flexibility over a long period of time, others will need episodic flexibility where they need a few days or a few weeks several times a year, and a small number will need large chunks of time such as 3-4 months or 12-24 months of unpaid leave to deal with particularly demanding caring situations that have a clear endpoint such as death or residential care.

It is also important to note that given the very high level of employment of women in the health workforce, and the high proportion of women with MS (3 out of 4 people with MS are women, and the vast majority are of working age), as well as the very high proportion of women who have caregiving responsibilities within their families, that flexibility is of higher importance in health care than in many other sectors.

While many people with disabilities and chronic illnesses are able to exercise considerable independence with minimal assistance from family or paid carers, some are not. Approximately 20% of the Australian population report having a disability, with approximately 6.4% of the population reporting a severe core activity limitation (ABS 2004).

In some situations caring for someone with a chronic illness or disability requires the same intensity and time commitment as looking after a child under school age. Approximately 13% of people living in households are carers, and approximately 20% of these are primary carers: 55% of primary carers report providing 20 or more hours of care each week. In relation to those of working age, there is a gradual increase over time with 9% of 18-24 year olds reported as carers gradually increasing to 22% of 55-64 year olds. (ABS 2004)

People with disabilities and carers have significantly lower incomes and less workforce participation than the Australian average (ABS 2004). More flexibility in workplaces would increase these participation rates, and provide employers with access to additional skills and labour.



In particular there needs to be increased capacity for employers and employees to enter into dialogue and negotiations in relation to:

- (a) requests for flexible working arrangements
- (b) flexible leave arrangements
- (c) personal/carer's leave.

All of these arrangements need to be negotiated, and need to be workable for both employers and employees. The Draft National Employment Standards which were circulated earlier this year by the Government for comment are a good starting point for many of these issues, but need to be extended to more adequately cover the needs of people with chronic illnesses and/or disabilities and family caregivers.

Requests for flexible working arrangements should enable employees and employers to find workable week-to-week arrangements in relation to working hours, shiftwork and so forth.

Flexible leave arrangements must enable the negotiation of paid and unpaid leave to cover both expected and unexpected contingencies that arise. Some people may need 6-12 months of unpaid leave to care for a family member who is going through a particularly difficult time, or even dying. Someone with a disability or chronic illness may need a period of 6-12 weeks of paid or unpaid leave to recover from an episode of illness, a disruption in housing arrangements or in other contextual issues that impact on their health and/or capacity to work.

Whatever the details of arrangements are, they need to cover the continuum of needs for employees, and be viable for employers. And as much of this is beyond current employment entitlements arrangements, the key is that employees are supported and encouraged to enter into discussions, and that employers are able to turn requests down on 'reasonable business grounds.'

Importantly, if progress is not made on flexible employment arrangements in healthcare, employers will continue to miss out on engaging many skilled and willing potential employees.

DISABILITY (Long Term Care) INSURANCE

People with MS have lifetime care requirements, and yet there is no pathway to provide that care to an agreed standard in Australia. People with neurological conditions are said to be around a third of all young people living in aged care facilities across the country, and most are there through the failure of the community care system to deliver an adequate and timely response.

A national disability insurance scheme was recommended at the 2020 Summit, and is something that would greatly assist the efficiency of the health and community care systems for people with complex disability.

Disability in Australia is an unfunded liability, and as need increases with the ageing of family carers, funding from the budget will become more difficult to meet these needs into the future. People with acquired disabilities like MS are competing for scarce budget resources for their services, and long waiting lists are the norm. Progressive diseases do not respect waiting lists, and the lack of service can exacerbate symptoms and/or result in aged care placement.

The existence of young people in aged care exacerbates the problem of older people being stuck in acute hospital beds, as these young people are in situ for long periods. A fully funded insurance scheme that can fund needs as they fall due means that more people can remain at home and avoid unnecessary hospitalisation and adverse outcomes caused by neglect.



The model for such a scheme needs to be designed carefully, requiring the Commonwealth and States to work together to achieve a workable scheme. A disability insurance scheme with a capacity to fund rehabilitation and lifetime care is a necessity for Australia's health system from both a financing and service delivery perspective.

We support the recommendation from the 2020 Summit and urge it to be considered at the COAG level as matter of Commonwealth/State reform.

COORDINATED CARE AND YOUNG PEOPLE IN AGED CARE

Another response to the co-ordination of care across the health and disability sectors for this group is to create portable packages of care that can draw down from a range of programs concurrently. This effectively utilises the lifetime care approach of the insurance model within the existing system. This is a response that ideally would be made available to those people who do not fall into a disability insurance scheme because of timing. A trial of this model is proceeding in Victoria.

As indicated above, the timely meeting needs cannot be achieved in the disability system, and too often people are forced into acute settings or aged care facilities in order to get the care they need.

The well documented fragmentation of the community care system is partly to blame for this, as is the difficulty in accessing services to new entrants into the disability system.

A solution to the problem of having to shift jurisdictions and programs as a persons needs increase lies in the development of a package of care that can grow and adapt to meet the various needs.

This type of adaptable package is one that can grow to meet a person's changing needs over time. In simple terms it can start small as disease symptoms start to appear, and may be a HACC home care service, and then can grow to include personal care and support with activities of daily living.

This continuous care approach was first described by McCallum et al in the aged care context, there aiming to build a bridge between community and residential aged care. It was called the *Continuous Care Restructuring Program (CCRP)*". It could be easily adapted for people with progressive conditions within the disability context

'The Continuous Care service structure would require us to revisit the way public funding is provided to subsidize long term care for older people who have high levels of dependency and require specialized assistance with activities of daily living. The concept realises the potential to remove the boundaries between residential care and community care, and to focus on assessed care needs, care planning, and choice of care setting as an outcome of those'.⁴

The attached diagram shows how this could easily sit across existing jurisdictions.

The existence of such a package that is available to people who are assessed as having genuine need related to a progressive neurological condition would greatly reduce the incidence of premature placement into aged care.

⁴ McCallum, et .al Australian Aged Care & the New International Paradigm. AUSTRALASIAN JOURNAL ON AGEING, VOL 20.3 SUPPLEMENT 2, SEPTEMBER 2001 PP 5 - 14



The central theme of a continuous care package is the client and the care needs. The full suite of services is currently operating in the HACC/disability/aged care spectrum, but the journey through the sectors is not linear or even accessible at present.

A portable package of care will require back of house protocol arrangements between various jurisdictions and funding programs, however that is entirely possible. The course of these conditions and the range of required services is predictable in the sense that the conditions are degenerative (although individual changes are less predictable) so we can create a response to them accordingly.

The ability of the various jurisdictions to develop an articulated response to the challenges of progressive conditions could well demonstrate how to fix many other jurisdictional interface problems that plague the community care system.

RESEARCH INTO MS

Australian research is very well placed to contribute significantly in the battle against MS. We are leading the world in the epidemiology of MS and have world-class projects in the genetics and neuro-immunology of MS. These areas will lead to better treatments, possible prevention strategies and progress towards a cure.

However, the amount spent on MS research currently in Australia falls at least 20% below the National Average for medical research by category. Dedicated funding is required to meet this shortfall, and to support existing world-leading efforts currently underway in Australia.

Since its inception in 2004, MSRA has addressed the under-resourcing of MS research and has affected a 4-fold increase in private sector support. It has identified where Australian research can contribute most to the world-wide effort and developed collaborative research partnerships with all of Australia's major research institutes dealing with MS.

MSRA has formulated the **Australian MS Research Platform** – a portfolio of fully-costed projects, established by MSRA's Research Boards, that uses Australia's research strengths and with extra Government and private sector support will progress our knowledge towards a cure (the healing of MS), over the next 3 years, 2008/09 to 2010/11. These projects come under 6 Research Streams:

- Social and Applied Research
- Genetic & Epidemiological Research
- Neurobiology & Immunology Research
- MS Clinical Trials Centre
- Capacity Building
- Ongoing Investigator-Driven Projects

We support the greater investment into research as a function of the overall approach to chronic disease management in Australia

CONCLUSION

This submission has briefly identified some of the key issues for people with MS in relation to the health and hospital system in Australia. Importantly, many of these issues are similar for people with other chronic illnesses and/or disabilities, and also for their family caregivers.

We are looking forward to the Commission's hearings, and the opportunity to add some additional details and to hear from people with MS directly.



References

ABS 2004, *Disability, Ageing and Carers, Australia: Summary of Findings 2003*, ABS Catalogue Number 4430.0.

Access Economics 2005, *Acting Positively: Strategic Implications of the Economic Costs of Multiple Sclerosis in Australia*, Access Economics, Canberra.

Hendrie, D., McDonald, E., Simmons, R. & Tribe, K. 2005, *The Economic Impact of MS in Australia*, Fact Sheet 1, from research undertaken as part of the Australian MS Longitudinal Survey, Multiple Sclerosis Australia, Lidcombe, NSW.

Mccallum, et .al Australian Aged Care & the New International Paradigm. AUSTRALASIAN JOURNAL ON AGEING, VOL 20.3 SUPPLEMENT 2, SEPTEMBER 2001 PP 5 - 14



Prevalence

- Over 18,000 people have MS in Australia
- 75% are women
- 87% are of working age
- Average age of diagnosis is 30 years
- Prevalence in Tasmania 8-10 times that of North Queensland along the latitude gradient
- Prevalence of MS increasing by nearly 7% to 2010

Symptoms & Impacts

- Extreme fatigue and chronic pain
- Impaired mobility and vision
- High co-morbidity with depression
- Relationship and employment problems
- High costs of chronic illness – can be as high as 20% of income spent on health

Burden of disease

- MS costs Australia \$2 billion per year
- Loss of productivity costs \$150 million per year
- The replacement cost of informal care provided to Australians with MS is \$250 million
- Australians with MS pay \$160 million per year out of their own pockets in health costs

Employment

- Lower rate of full time employment than the Australian population (19% v 38%)
- 80% of people with MS lose their job within 10 years of diagnosis
- 30% higher representation in part time employment
- Higher occupational skill level than the Australian population

48% of people with MS earn less than \$300 per week compared with 39% of the Australian population

Annual lost productivity estimated at \$160m

Care services

- 20% of all dollars spent in health services in Australia on MS are spent in the aged care system
- There is difficulty accessing basic Health and Community Care (HACC) disability services

Welfare

- 40% of working age people with MS are recipients of disability support pension - equating to 5% Australian Population

Carers

- Informal carers provide an average 12.3 hours a week to people with MS
- The cost of replacement care is \$260 million (43% of direct cost of MS)

Private Health Insurance

- 70% of people with MS hold private health insurance despite the rising costs and lower incomes – compared to 43% of other Australians
- Current products are not suitable in all cases for people with chronic illness

Research

- Current research investment in Australia is 30% below average disease spending
- Main Australian research into MS concentrates on Genetics, epidemiology, Genetics and neurobiology including adult stem cell research and proteomics (study of cell chemistry)
- New treatments are coming through for clinical trials – despite being recognised for 160 years, only 2 treatments have been released since 1998. A third is now available overseas (Tysabri) and a raft of potential treatments are in phase 2 and 3 clinical trials

