

***MS Australia  
Federal Budget Submission 2008  
Executive Summary***

***Leading the way - care and cure***

***Improving support for 18,000 Australians***



## Executive summary

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 hundreds of thousands of family members, friends and colleagues of those living with the disease. The rate of diagnosis of MS is predicted to increase by 7 percent to 2010.

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.

The Social Inclusion agenda of the new Rudd Government contains a number of policy themes that are vital to achieving change in areas identified in this submission.

***MS Australia has identified four areas presenting challenges and requiring action. Where costings have been able to be done they have been included. Some of these required actions have not able to have been fully costed at this point, but are no less important to the outcomes identified.***

### **1. Research**

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.

**That's why MS Australia, through its research arm, MS Research Australia (MSRA) is seeking a matched grant program of \$5m from the Federal Government over a 3 year period from 2008.**

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

## **2. Health**

MS is a disease that needs a lifetime care approach. In the course of the disease, people need to seek assistance from a range of programs in the health, employment, community care and carer support areas, in many cases concurrently. Improved care coordination and the ability to combine and articulate programs across jurisdictions are much needed. Co-operation of Federal and State Governments in the delivery of these programs is essential to ensure continuity of care and prevent unnecessary hospitalisation and family breakdown.

### **MS Australia seeks:**

- **Changing the PBS requirement so that a confirmed diagnosis and a single MS attack is enough requirement to access the available drugs.**

Affordable access to a range of pharmaceuticals is a key aspect of disease management. 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.

- **Subsidised access to anti-fatigue and neurogenic pain drugs through the Workplace Modification Scheme**

Pain and fatigue are symptoms of MS that can severely compromise employment participation and quality of life. A number of anti-fatigue and neurogenic pain drugs that are proven to be useful in the long term treatment of MS symptoms are not listed on the PBS for MS.

## **3. Employment and financial security**

Currently, 87% of people living with MS in Australia are of working age, however the reality is that 80% of people with MS will lose their employment within 10 years of diagnosis. With the average age of diagnosis being 30 in Australia, lost productivity is a major problem. Only part of this loss of employment is due to disease symptoms, much of it is a result of workplace discrimination and poor workplace adjustment.

Critical to reducing the impact of the disease is the introduction of targeted employment retention programs for people with chronic illnesses and their carers. Currently there is no specific employment retention program that prevents premature exit from the workforce for this risk group, although we know that gains can be made in this area to promote extended workforce participation.

### **MS Australia seeks:**

- **Expansion of the Job in Jeopardy program** within the Department of Employment and Industrial Relations to keep people at work and accommodate their changing support needs – **Estimated cost - \$11 million per year**
- **Expansion of the Work Based Personal Assistance Program** for people with needs for support in mobility and environment control in the workplace currently leaving work due to lack of support– **Estimated cost - \$14 million per year**
- **Establishment of a Flexible Workplace Advisory service** to inform employers and employees of their options in maintaining carers and people with chronic illness in their workforce. This service would link industrial and health resources with Government labour market initiatives.
- **Introducing greater flexibility to the Centrelink Sickness Allowance** to cater for the episodic and chronic nature of MS and similar conditions. Rather than requiring people with chronic illness to use up 100% of their leave entitlements before accessing this benefit, a category that can allow financial support for people during periods of illness who have a job to return to (as well as holidays and other leave just as other workers have) would be a useful long term strategy in maintaining people at work over the long term.

- **Reform of the Welfare to Work Program** and access to partial Pension top up to remove the Newstart pathway for people with neurological conditions with partial capacity. This program was designed for people to move into the workforce and ignored the specific needs of those with partial capacity who need to work part time

The 15 hour threshold is inappropriate for this group, as is the marginal tax trap that accompanies placement on Newstart if a part time worker does not meet the narrow criteria for partial DSP. The current arrangements with the blunt Job Capacity Assessments are punitive and poorly targeted for this group who require additional supports to stay at work.

#### **4. *Lifetime Care***

Australians living with MS and their families need viable alternative care models to those currently available. Many support programs are designed for static disability or ageing, and do not cope with increasing and changing needs. The expression of this is the high number of young people with MS and similar conditions living in aged care.

The critical support areas for people with MS and their families are in the ambit of the Commonwealth/State and Territory Disability Agreement (CSTDA), the HACC program and carer support programs.

MS Australia endorses the recommendations of the 2007 Senate Inquiry into the operation of the CSTDA and fully supports their implementation in the renegotiation of the new agreement. Unmet need for disability services and community care are unfunded liabilities for the Australian community, and the next CSTDA needs to have a future plan to cover these liabilities in the form of services and support to unpaid family carers. A priority in dealing with this unmet demand is overhauling the interfaces of the various care and support programs within and across Government jurisdictions to make transitions more fluid and consumer focused, and increase the efficiency of the system overall.

**In particular, MS Australia proposes the following priority actions for 2008/09:**

##### ***National Continuous Care program***

Respite care and Community care is a major unmet need area for people with MS with increasing needs. As well as being a major growth area for the CSTDA agencies, the Aged Care and health systems can also play a more integrated role with disability services.

People with MS pose a significant challenge to these systems due to the changing nature of their condition, which does not respect waiting lists. The need timely access to aids and equipment and personal support services is central to the best management of the disease related disability. It is also the best way of preventing untimely placement in a nursing home.

A dedicated continuous care program that allows people with degenerative conditions to articulate or combine different support programs as their needs increase (to prevent nursing home admission) is being trialled as part of the COAG Young People in Nursing Homes initiative. FACSIA needs to oversee the implementation of this program in each jurisdiction in 2008/09 to inform the development of a dedicated aged care diversion program for this group in the future.

**Estimated Cost \$1.7million**

##### ***Respite Care***

Respite care is a well documented unmet need area for people with disabilities and carers, and is certainly a significant issue for people with MS. Growth in respite funding through the CSTDA and Carer support programs is essential.

In many cases people with MS are forced to utilise respite care in aged care facilities because of lack of options, particularly in rural areas. While being able to access up to 63 days per year of respite in aged care, people would rather have in home respite or stay in specialist facilities that cater for younger people with complex needs.

The capacity for people who are young but ACAT eligible for Aged Care services to 'cash out' this entitlement and purchase more flexible and appropriate respite would add significant capacity to the system, and help to deal with the with demand for respite in the CSTDA and HACC sectors

### ***Aids and Equipment***

Disability equipment is a persistent area of unmet need and inconsistent policy in Australia, and impacts significantly on people with MS. While primarily administered by States and Territories, these programs need to be made part of the next CSTDA, and moves initiated to develop a national framework and standards for equipment programs.

With over 40 separate schemes for purchasing aids and equipment across the country, there is currently no capacity for bulk purchasing or administrative efficiencies that would free up much needed money, and no service level standards for people with disabilities. This needs to be a priority reform area in 2008/09.

### **References**

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.

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