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STANDING COMMITTEE

30 MAY 2006

ON HEALTH AND AGEING



AUSTRALIA

**MS Australia**

**Submission to the House of Representatives Committee  
on Health and Ageing**

**Inquiry into Health funding**

May 2006

## **1. Introduction**

MS Australia is pleased to have the opportunity to submit to this inquiry. This written submission will be brief, however we are keen to present to the Committee in a public hearing to provide more detailed and directed information about these important questions. Our interests in the wider health system are varied, however they centre largely on the management of chronic disease.

The impact of a lifelong chronic disease has many facets, and in the case of Multiple Sclerosis, they are many and varied. The disease follows those that live with it everywhere in life, and takes its toll in many different portfolio areas. It demands a truly whole of Government response.

The Australian Government already provides a significant part of the support for people with MS and their families, with the PBS subsidies for the Interferon and Betaferon MS drugs, through the funding of care in aged and also through the Social Security system. Disability and other health services are provided by State and Territory Governments.

A large number of people with MS self fund a range of health services - mainly allied health and non PBS medication. In addition, around 70% people with MS hold private health insurance, which is a remarkable figure.

Nevertheless, there are still large gaps between the opportunities and experiences of Australians with MS and those of other Australians. The disease itself can account for some of these disparities, although attitudes, policy settings and discrimination contribute unnecessarily.

People with MS are represented in the part time workforce one third more than other Australian workers, and have been found to have generally lower incomes.

Multiple Sclerosis is a disease of working people, with 87% of those living with disease of working age. Yet continuity of employment participation is at great peril for people working with MS, and re entry to the workforce is difficult for doubly disadvantaged people who have previously lost their jobs. With the right policy focus much can be done with the Government's workforce participation initiative.

We have yet to discover the cure for the health effects of MS, but we know enough to cure many of the social effects of the disease, which are as debilitating. The physical symptoms of fatigue, loss vision, strength and balance all contribute to the destabilisation and loss of employment, family relationships and financial security.

The challenge for the health system is to be prepared, capable and efficient in dealing with the course of the disease. We are experienced enough and have enough data to manage the disease course extremely well - by taking an actuarial view of chronic illness, and creating timely responses across the many parts of the system, an effective chronic illness management approach could greatly improve health outcomes.

## 1.1 Cost of Chronic Illness

In a recent study on the costs of Chronic Illness in Victoria, the costs of medications and other health expenses were shown to be significant and persistent over a lifetime. It showed that households of people with chronic illness took care of their health needs first, regardless of their income.

In many households, health costs contributed to increased poverty, and in the lower income groups studied, the cost of health was so great that it sometimes led to dire poverty.

**Table 1- cost of medications – Chronic Illness Alliance**

Annual income	<\$13,000	\$13-25,999	\$26-36,399	\$36,400-51,999	\$52-78,000
No of households	N=39	N=113	N=64	N=73	N=80
Av annual overall costs	\$3585	\$3539	\$4289	\$3585	\$5767
Av annual costs medications	\$747	\$934	\$1345	\$954	\$1162
Costs of medications as % of annual overall costs	21%	26%	31%	27%	20%

The importance of concessional medicines for households with chronic illnesses was amply demonstrated by the study. 92% of households in the lowest income group had concession cards, so they were eligible for medications at the concessional PBS rate. Medications accounted for 21% of their total health costs. In contrast, only 47% of households in the \$26–36,399 income group had concession cards. Medications accounted for 31% of their total health costs.

This highlights the poverty trap for people moving into income levels that are not high and losing their health card benefits. The CIA study showed a 10% increase across all chronic illness groups – people with MS who are heavily reliant on medications indicate a much greater burden.

Since this research was completed the oil price rise has exacerbated this situation further.

## 1.2 People with MS and the health system

People with MS and similar chronic progressive conditions use many parts of the health and community care system (including local Government and disability Services), and the fragmentation of services, policies and funding schemes is omnipresent and unhelpful.

MS is a disease that is largely treated in the community. People with MS have cause in the course of their disease to require services from all levels of government. This includes public and private hospitals

The chart below shows that less than 20% of the total cost to the health system relates to direct involvement with health professionals and hospitals.

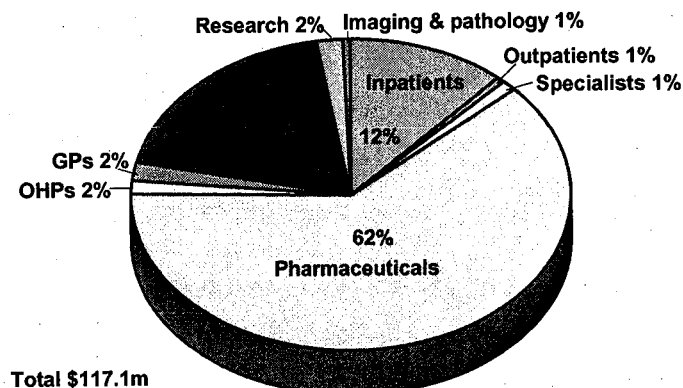
Nearly 80% is in drugs and aged care, meaning that most people are managing most of the time in the community or generic settings. Services provided through the Commonwealth State Disability Agreement are additional to this data.

Although MS is a long term chronic condition, there is clear benefit to early intervention and health self management programs to ease the disease burden, which stands at the value of \$1.3b per year.

The largest direct cost is that of the provision of informal care. The loss of productivity associated with MS of individuals and their carers is a significant issue in the design and function of the health system.

We must work to change attitudes that a diagnosis of MS condemns individuals to a wheelchair, bed or a nursing home. 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. This is particularly pertinent for employers. Kidd (2001) is strongly supportive of early intervention concluding that it *has the potential to make MS a truly manageable disease*".

This points to the benefit of increasing the investment in overall disease management, including self management and education programs, so the management of the disease by individuals and families, and health workers is more effective.



*MS total cost to the health System in Australia (Access Economics 2005)*

## 2. Health Issues for people with MS

The following is a sample of the types of issues faced by people with the lifelong chronic degenerative condition of multiple sclerosis. They cover a number of jurisdictions and programs, and raise some general and specific issues that highlight the need for coordination across programs and planned disease management responses. It is not an exhaustive list but represents some of the more obvious examples where an investment strategy in chronic illness would improve quality of life and potentially improve efficiency

### 2.1 Pharmacology

People with MS are fortunate to have the MS immunomodulatory drugs on the PBS, which has been a life changing treatment for those who are eligible with Relapsing remitting MS. It has allowed people to manage their symptoms and lengthen their workforce participation, and generally improve their well being and their involvement with family and community.

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 Sclerosis) and ETOMS (Early Treatment of MS). A review of the available evidence points to an argument for early intervention in the treatment of MS.

### **2.1.1 Non PBS medications**

Due to the variability and severity of MS symptoms, other drugs than the basic MS drugs are sometimes required. Neurogenic pain and fatigue are amongst the most common and debilitating symptoms, and the drugs that are available and effective in combating these symptoms are not indicated for MS on the PBS

*Amantadine* and *Modifinil* are two PBS listed anti fatigue drugs (for Parkinson's Disease and Narcolepsy respectively but not for MS) that show positive effects for people with MS in combating fatigue

*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. Zifko (2004)*

*Neurontin* is currently included in the PBS for the treatment of refractory neuropathic pain not controlled by other 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. They are indicated for Epilepsy but again, not for MS.

We are aware of people purchasing Neurontin over the Internet, which is cheaper than over the counter prices in Australian pharmacies, but still comes at great cost to people who are on lower general incomes than the general Australian population.

It is a proven drug that needs to get PBS listing for Multiple Sclerosis.

*Baclofen pumps* are inserted into the body to administer baclofen, an anti spasticity drug. Intrathecal administration is the most efficient means in those patients with severe spasticity.

Not a high percentage of people with MS need this, however when it is indicated it is a major contributor to quality of life for the individual and the carer. The Intrathecal Baclofen is also a non PBS medication and so even if money can be obtained for the pump, the ongoing cost of the drug is prohibitive outside of a funded program.

Currently this treatment is limited to people who are receiving compensation funding or through specific brain injury rehabilitation programs such as the Victorian Slow to Recover program. Pumps about \$15,700 replacement after about 7 years. Catheter implantation costs around \$1000. A box of refills under authorised script costs \$160 for 2 months supply.

*Erectile Dysfunction* drugs, including *Viagra* *Cialis*, *Levetra*, are indicated for people with erectile dysfunction resulting from MS and many other chronic illnesses. These drugs have been recognised and recommended by the Pharmaceutical Benefits Advisory Committee but were not listed.

Due to the fact that MS is a disease of working age people, treatments that allow people to work, function in their families, or relieve symptoms that result in relief for family carers must be given higher priority for listing.

### **2.1.2 Cost of medications**

The higher PBS co payment and the increased number of scripts per year to reach the safety net are creating financial issues for some people, particularly using a range of medications.

Certainly those living in the Disability Support Pension have raised the additional cost in these areas as being difficult to manage. A number of people have related the situation where they feel that the need to get the additional 2 scripts per year is a disincentive to good self management, and a concern for people whose condition is unpredictable.

There is a large group of people with MS who are employed, and do not have income support or a health care card. The costs of medications for these people are high because they have to pay the full \$29.50 co-payment on all their medication.

These higher costs, along with increases in the cost of living due to oil prices have meant that people are forgoing some medications (mainly non PBS) and buying over the Internet

## **2.2 Aids and Equipment**

Access to aids and equipment is an important for people with MS. Home and workplace modifications, wheelchairs, pressure mattresses and like equipment are things required by many people in the course of their MS. With the progression of the condition, upgrades and refitting is often required.

The Aids and Equipment schemes are run by State Governments, and across the country the waiting times and funding limits are problematic. These schemes supply people with disabilities and older people, so demand is growing and specialised equipment can be expensive. It is the case that this equipment is essential, and that attempts to limit or deny access to some equipment is a false economy. If a person cannot get the equipment they need, other problems occur as a result.

We are aware that there are people with MS who have experienced long periods of hospitalisation for skin breakdown (pressure sores) because the prescribed pressure mattress or wheelchair could not be fully funded through the Government schemes.

Funding limits for equipment like mattresses or wheelchairs can be as little as 50% of the purchase price, leaving the individual and the family to find the difference. In most cases the \$4,000-6,000 required is simply not there. This is also a common reason for young people to end up being admitted to nursing homes, because either disability is worsened by the lack of correct equipment, or the effort required by families to care for a person with a severe disability without the right equipment is overwhelming.

It is an appalling and recurring experience that people are forced into long term, expensive institutional care as a consequence of one government program being underfunded and inflexible. MS Society staff and community case managers can spend a lot of their time chasing small pots of money from a range of programs to get the equipment people need – sometimes wasting more resources in the pursuit of this funding than the dollar amount actually required.

What is occurring here is wasteful cost shifting. As the example used in the attached Opinion piece by Robert Pask, in order to avoid spending the additional \$3,000 on a pressure mattress required by an individual with MS the aids and Equipment program creates the situation where the person's skin breaks down and results in a \$50,000 hospital stay, and even upon discharge, the mattress is still required!

This cost shifting and splintered responsibilities of health and community care programs is wasteful and creates poor management practices based on bureaucratic structures rather than clinical imperatives.

### **2.2.1 Contenance Equipment**

The Contenance Aids Assistance Scheme provides a subsidy for continence aids for people with MS and other disabilities. This subsidy is \$470 per year. Depending on the nature of the person's needs, this is nowhere near enough, and the cost has to be met privately, or through supplementation from the State Aids and Equipment schemes where possible (this is mostly where spare capacity).

Also once a person turns 65 they are no longer eligible for this program and must find an alternative source of support.

It is imperative that this barrier be removed from the program and that a way found to continue funding people who require continence aids from the one program. There is an opportunity to fix this in the process of remaking the HACC agreement, and also in the upcoming renegotiation of the Commonwealth/State Disability Agreement. This is one area of split responsibilities that is difficult to defend from any standpoint.

### **2.2.2 Workplace Modifications**

MS Australia is pleased with the expansion and streamlining of this scheme in the DEWR portfolio, and believes that this program should incorporate a wide view of the measures required to support a person at work.

Access to the non PBS medications detailed above to combat fatigue and neurogenic pain where indicated would be a boon to many people with MS for whom those symptoms affect their ability to work, and who have no other means of access.

Such a measure for Neurotin would cost in the order of \$1,500 per year, but have many health and productivity benefits. Already DEWR fund workplace attendant care services to people with disabilities that cost up to \$15,000 per year, so it is not expensive.

This DEWR program has potential to be extremely effective if it takes a flexible and pragmatic approach to workplace support.

### **2.3 Young People in Nursing Homes**

COAG has recently canvassed this issue, and in February announced a joint funding package with the States worth up to \$244m over 5 years. MS Australia has

The fact that there is the need for COAG to solve this problem has been generated by disconnection and cost shifting across the jurisdictions.

While the funding package is welcome to enable young people to rejoin the community and move out of aged care, the critical success of the initiative is not in moving a small number of people, but fixing the structural problems that allows this practice to continue.

To do this goes to the core of the fragmentation of the wider system, and the allocative inefficiencies that exist. A young person being placed in an aged care facility is the expression of complete failure of the system to provide an adequate health and disability service response.

MS Australia welcomes the recent decision of the Senate to inquire into the Commonwealth State Disability Agreement. The fact that the CSTDA has little interaction or input from jurisdictions such as health and aged care at both levels of government, means that these areas of government have ended up wearing the slippage and overflow from disability services, but without the required policy and practice arrangements in place.

#### **2.4 Private Health Insurance**

The Australian MS Longitudinal Study reports that 70% of participants continue to hold private health insurance. This is much higher than the Australian average of 43%. People with MS hold on hard to their insurance, because the need for choice of provider and access to better hospital (hotel) services when frequent hospitalisation is required means that it is a rational choice.

Given that most disease management occurs in the community, the rising cost of premiums has not delivered any additional value for this group of members, despite being in a high cost class.

MS Australia welcomes the recent announcement by the Minister for Health for the inclusion of out of hospital services in the suite of benefits available through the private health funds.

At this point it remains unclear as to the types of services that will be included in this change. We believe strongly that funding services outside the hospital needs to be consumer focussed. Powerful professional groups such as doctors and private hospitals have a huge sway in the way resources are allocated.

If health funds are to move outside the hospital, it is very important that they have a strong focus on consumer needs, and that there is good evidence for the way money is spent. The funds need to give priority to the needs of the consumer and it needs to be based on good evidence. Consumer consultation and involvement is the key.

Individualised funding and reimbursement for a range of services including non PBS medications and aids and equipment will provide value to consumers and reflect a good preventative measure by the funds. The out of hospital model has some potential to improve certain elements of the system if there can be good integration of their role with the public system.

#### **2.5 Self management programs**

In a range of chronic conditions, including MS, self management programs and health promotion activity have been proven to be effective in improving health outcomes. People with MS and their carers would benefit from tailored programs that inform and educate people about the range of lifestyle options and treatments that could assist in the long



term management of the disease. These are currently available in small measure in the capital cities through MS Societies, an expanded program that could be offered in regional and outer suburban areas is needed for better coverage.

## **2.6 Research**

Access Economics found funding of medical research into Multiple Sclerosis is 30% lower than other the national average for disease research. It is still the case that MS researchers in Australia receive more support from the National MS Society of the USA and other US funders than from the Australian Government.

The funding of chronic disease research needs to be coordinated and articulated with policy and practice efforts by governments in Australia. Utilising the same model as is in place for national health priorities, a strategic effort to line up direct health programs, community care, health promotion initiatives and for all chronic disease areas needs to be implemented.

## **3. Summary**

### **3.1 An investment strategy for Chronic Illness**

The health system has pockets of good chronic illness management – with some of the national health priorities being able to manage complex responses to disease groups. Some of these have features of an investment strategy, with a mix of prevention, health promotion, processes, research and workforce capacity.

This type of planning and service delivery cannot be just limited to some conditions because they happen to be on the health priority list, but must inform a chronic illness strategy within the health system. This strategy needs to be led by the Australian Government and joined by the States, and encompass those conditions that do not fit well into the episodic nature of health funding.

A principle of funding services for this group is that if the effects of the condition last a lifetime, then so should the funding. Having to hop jurisdictions to components of care is poor design. The rise of the case manager in health shows that we have created a new class of professionals in the system not top treat the patient, but to manage the system.

An example of an investment approach to long term disability exists in the no-fault insurance schemes that manage the health and disability needs of people with acquired brain injury and spinal cord injury. Their brief is to manage the seemingly competing demands of scheme viability with meeting the lifetime care needs of their claimants. Some schemes, like the Victorian Transport Accident Commission do this well, and have developed a lifetime support model of service. Legislated schemes like the TAC do not have the luxury of cost shifting, as they are responsible for all injury related costs. They can plan over a lifetime, and invest in critical phases of recovery and rehabilitation to generate long term outcomes that save money and deliver positive benefits to individuals.

The removal of the ability and incentive for cost shifting has meant that lifetime planning is critical to their system. In very much the same way, the systemic response to many chronic lifelong diseases such as MS can be improved by matching long term financial imperatives with good practice and disease management.

A strong consumer focused chronic disease approach would have the features of the no-fault model, but with the addition of the private funds to pay for services and equipment where it is most expedient and advantageous. We would propose a disease management model trial that incorporates the private and public funders to examine how an integrated funding model would best work.

Like many other submissions will do in this inquiry, we stress the need to seriously address the fragmentation and competing funding programs within and across jurisdictions, and focus on needs and outcomes. The conflict of aims and practices of supposed companion programs must be addressed as a priority. Examples abound where hospital funding leads to practices that are anathema to community care providers – quick discharges from acute care only to push a person into a service gap, and services not being available to prevent an expensive admission (i.e. home care or equipment) are solvable, but need a dedicated policy focus and a model where programs have a vested financial and quality assurance stake in health outcomes. COAG is the best place for this discussion to begin, given the interdependent nature of Governments in relation to the health system.

MS Australia can provide specific recommendations and examples to the inquiry at a public hearing.

### **3.2 Contact**

For further information about this submission, please contact

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### **3.3 References**

*The Cost of Chronic Illnesses for Rural and Regional Victorians*, Christine Walker and Jo-Anne Tamlyn, Chronic Illness Alliance 2004

*The Economic Impact of Multiple Sclerosis in Australia First Working Paper: Australian MS Longitudinal Study*: Dr Rex Simmons et.al. MS Australia, 2004

*Acting positively: Strategic Implications of the Economic Costs of Multiple Sclerosis in Australia*- Access Economics, Canberra, Winter 2005

*Management of fatigue in patients with multiple sclerosis* Zifko UA (2004) "Drugs 64(12):1295-304".

### **3.4 Attachments**

*How to Heal our Health Services* – Robert Pask, Herald Sun April 20 2006

# MS in Australia – facts and figures

Acting positively: Strategic Implications of the Economic Costs of Multiple Sclerosis in Australia- Access Economics, Winter 2005

## Basic facts about MS in Australia

- Over 16,000 people have MS in Australia
- Three quarters of people with MS are women
- 87 per cent of Australians living with MS are of working age
- Average age of diagnosis is 29
- The age of onset is from 20 to 40, when career and family building are at their peak
- Prevalence is going to increase by nearly seven per cent in the next five years
- The further from the equator the higher the incidence of MS. Victoria and Tasmania have nearly double the incidence of MS measured in Queensland

## Comparisons

- In any single year MS is more prevalent than breast and bowel cancer and sporting injury.
- MS causes more disability and loss of life than rheumatic heart disease, chronic back pain or mental retardation.

## Total economic costs of MS

- The total financial cost in Australia of MS is over \$600 million a year.
- The value for the loss of healthy life is \$1.3 billion a year.
- Altogether the financial and disease burden cost approaches **\$2 billion a year.**

## Areas of greatest cost

### Loss of productive capacity

- This year 3,200 people with MS will not be able to participate in the workforce.
- The annual lost production cost from reduced hours, early exit from the workforce and temporary absence is \$160 million.
- The number of people with MS who work part-time is disproportionately high.

### Growing informal care costs

- Informal carers provide an average 12.3 hours a week to people with MS
- The cost of replacing family carers with paid staff is \$260 million
- The disease's increasing severity over time requires increased informal care

## Areas of greatest challenge

### Work and family

- Using health management, employment policy and responsive welfare to keep people well, working and with their families for as long as possible
- Providing policy and income support to people who have reduced earning capacity and higher costs because of their MS.

### Support for informal carers is a priority

The replacement cost of informal carers is a quarter of a billion dollars. The cost of replacement residential care would be 60 per cent higher.

### Medical research

- Government spends less than the national health average on MS research.
- More MS research funds come from the USA than from governments in Australia.
- Last year the PM launched MS Research Australia, which requires \$30 million over four years to deliver better treatments and products.

### Health and long term care

- There are too many young people with MS in nursing homes.
- People with MS use many parts of a health system that requires improved coordination of services.
- People need effective access to some pharmaceuticals currently not PBS-listed for MS.

# How to heal our health services

**M**ANY Australians are wondering whether it is worth keeping their health insurance.

So is the Government, now that it has decided to sell Medibank Private.

But for many people, getting out of health insurance is something they cannot do, much as they might like to.

I'm one of these people. I sat down with my wife and worked out what we should go without this winter to meet our higher health insurance bill.

If only it meant having to ditch either yoga lessons or a trip to the ski slopes.

We are going to go without heating in the mornings so we can halve our gas bill.

I've got multiple sclerosis, and like many other Australians with a chronic illness I survive on a combination of the disability support pension and my wife's part-time income.

If the truth be told, we simply can't afford health insurance these days. But then again, we can't afford not to have it either.

In spite of financial hardship, nearly 70 per cent of people with MS maintain their health

## Robert Pask

insurance. This compares with 43 per cent of other people.

But even though we're crazily loyal to our health insurance companies, they must hope that every price rise will encourage members like me to leave, because we cost them serious money.

Everyone knows the health insurance system is not working well.

It's heavily subsidised by about \$3 billion a year. I believe this gives the Commonwealth Government a duty to fix the problem.

And I've thought of a way to do that. When it comes to chronic illness, let's encourage private health companies to fund prevention as well as cures. Here's a good example.

People with MS, confined to bed for long periods, have a high risk of developing pressure sores. These sores can take months to heal.

Four months in hospital with pressure sores costs at least \$50,000.

That's right, \$50,000 — the equivalent of a year's salary for a beginner nurse or teach-

er. This cost could be avoided by the use of a common pressure-relieving mattress for an outlay of only \$7000.

However, while health funds and governments contribute to a stay in hospital, consumers receive little assistance towards cost-saving equipment such as pressure mattresses.

It's an example that applies to any number of chronic illnesses. As any economist will tell you, financially, this is a no-brainer.

**T**HIS isn't entirely the fault of health funds. Government regulations prevent private insurers from funding out-of-hospital care.

The private insurers are largely restricted to funding hospital admissions. They can do little in the way of cost-saving prevention.

Clearly, these regulations are completely irrational and it's time they were changed.

For me and other chronic illness sufferers to get value for money from our health insurance, we need to go to hospital at every opportunity.

But of course we don't want to go to hospital if we can avoid it, and my fund certainly doesn't want me to.

I would prefer to get my value through services and products at home that can assist me to manage my health all the time, not just in times of crisis.

This approach would generate huge savings.

Access Economics reported last year that MS alone cost Australia \$2 billion a year in health costs, loss of productivity, and the cost of informal care.

The total health cost of MS was \$117 million.

While some hospital admissions are unavoidable, a slice of this cost could be saved by better healthcare co-ordination and community services.

Clearly, the private sector would have a lot to gain by investing more in early intervention.

We urgently need changes to the health insurance industry to allow it to fund care that's cheaper for families, more profitable for companies, less onerous for taxpayers, and most importantly, better at keeping people healthy.

It remains to be seen whether the Government can rise to the challenge.

ROBERT PASK has MS, and is an advocate for those with the illness.