



*Seeking the Cure.
Providing the Care.*

**Standing Committee on Employment and Workplace
Relations**

**Inquiry into employment: increasing participation in
paid work**

Submission by MS Australia

September 2003

What is multiple sclerosis?

Multiple sclerosis (MS) is a chronic, often disabling disease that randomly attacks the central nervous system (brain and spinal cord). The progress, severity and specific symptoms of the disease cannot be predicted; symptoms may range from tingling and numbness to paralysis and blindness. MS is a devastating disease because people live with its unpredictable physical and emotional effects for the rest of their lives.

Twice as many women as men have MS, with the onset of symptoms occurring most often between the ages of 20 and 40. Studies indicate that genetic factors may make certain individuals more susceptible to the disease, but there is no evidence that MS is directly inherited.

Multiple Sclerosis Australia

MS Australia is the peak body of the MS Societies in the States and Territories.

Its vision is:

MS Australia strives for a world without multiple sclerosis through quality research, and for service excellence to people with multiple sclerosis and their carers.

Multiple Sclerosis Australia's mission is to make a commitment to:

- Enhance the quality of life of people with MS and reduce the impact of MS on the families and carers of those with multiple sclerosis
- Maintain and increase its role as a leading not-for-profit organisation and a preferred charity in Australia for community and corporate support.

People with MS and Employment

Continuity of employment and long term participation in the workforce is of vital interest to people with progressive neurological conditions such as Multiple Sclerosis.

MS Societies around Australia do support people in employment situations. There are few success stories and the course of MS and employer attitudes make these situations generally difficult. Through this experience, we have identified a range of changes, both cultural and specific that would greatly assist the improvement of participation rates in work by people with MS and similar chronic illnesses.

These resources however are not well enough integrated in the employment arena to be accessible to all people who need the support.

People with such progressive conditions are often marginalised in Australian society. They have to contend with difficulties associated with consequent disabilities including physical and psychological pain, health management and day-to-day living problems with self-care, travel and communication.

Many suffer from discrimination because of their disabilities and others have social and domestic problems. People with MS, like people with other disabilities often experience discrimination in the workplace, ranging from being marginalised in relationships with fellow employees and managers, not being offered modified work conditions or hours of employment to accommodate their disabilities, or being forced to resign or sacked outright.

Once out of one job, it is then problematic to find alternative employment that would accommodate their restrictive disabilities. Many prospective employers require details of pre-existing disabilities and are then reluctant to take on those whose capacity to perform a full range of employment duties may be compromised.

Accordingly, many people with disabilities have fractured working lives or at least are unable to maximise their earning capabilities by not being able to advance their employment status and earnings or by being limited in overtime or extra duties.

There is a range of employment programs in Australia, but few concentrate on saving and protecting existing jobs. People who are not currently linked in with disability or rehabilitation services (common for people in the early stages of MS) are unlikely to hear about these services until too late. They may never discover about these services.

The result is that many people with disabilities who are working age experience severe financial problems by having limited disposable income from employment earnings. People may face substantial additional outlays for medical, pharmaceutical and travelling expenses associated with managing their disabilities. For those suffering from a chronic illness or acquired disability it is often a recipe for being mired in a poverty trap.

The course of MS can play havoc with continuity of employment for many people. There are many questions and dilemmas that people face in regard to employment and workplace change.

Regardless of individual circumstances it is important to be informed about work-related issues and options, even in the very earliest days of the illness, as generally employers and others can base decisions on poor information. As

in many areas of living with MS, it falls to those who live with the condition to be the educator. Good information and planning can assist in maintaining employment.

Many people with MS leave work during difficult times and then realise that the decision was premature. Issues such as future job prospects, superannuation planning and financial security are all matters that must be taken into account when making decisions. History shows that it is more difficult to find a new job than it is to maintain one through a period of illness.

The MS Society of SA & NT, who operate Australia's only MS specific employment services have just completed a 2003 Client Census and presented the following figures about the employment status of people with MS in their catchment:

Census respondents		General population
Currently employed	33.7%	54.2%
Employed part time	17.8%	18.5%
Employed full time	12.8%	34.2%

Those respondents who are employed are generally younger, and diagnosed with MS in the last 5 years. For them employment is their main source of income.

In a similar but less formal survey done in Victoria on personal experience of MS and employment, all respondents who were no longer employed reported that once the diagnosis has been disclosed there had been substantial and immediate effects both on employment and superannuation. A high proportion of these felt that disclosure had accelerated the employer's wish to part company.

They also expressed that information flow was critical, and all felt there would have benefited if they have been less rush and pressure in the cessation of employment. None have recommenced any type of work.

For some years now government policy has supported people with disabilities to stay at home, in preference to moving into facility based care.

Many people with MS would like to see a policy in parallel with a move to 'stay at work', since maintenance of meaningful employment is so important to the maintenance of life in the community.

The integration of work and family takes on a new meaning in the case of people adjusting to and living with MS.

Compulsory Superannuation and retirement incomes for people with disabilities

The centrepiece of the retirement incomes policy of successive Federal Governments has been compulsory employment-based superannuation.

Supplemented by voluntary superannuation contributions and other retirement savings, compulsory superannuation was seen as the main vehicle to ensure that the "baby boomer" generation and generations beyond provided for their own retirement and were not an intolerable burden on the welfare system.

However, whilst the debate has raged over whether the level of superannuation support mandated under the SGAA is sufficient for adequate retirement incomes, attention needs to be given to the level of retirement incomes for those who leave the workforce prematurely because of disability.

The linkage of compulsory superannuation to employment inevitably means that only those with 30 to 40 years in the paid workforce have reasonable prospects of accruing sufficient superannuation for retirement.

Those with limited working lives, such as people with MS, are severely disadvantaged under the existing retirement incomes regime.

However, perhaps more dramatic is the impact of the premature exit from the workforce of many people with disabilities. Those with chronic illnesses, degenerative conditions and acquired injuries often have to leave the workforce before normal retirement age or struggle on in a reduced capacity.

The result is that many people with disabilities are not able to accrue anything like adequate superannuation for their retirement and are inevitably dependent upon the welfare system not only during their working lives, but even more so in retirement. Their retirement ends up being much longer than their working lives.

As the number of people with severe disabilities increases, so will the proportion of the Australian population dependent upon the welfare system in retirement, unable to self-fund for their retirement in the compulsory superannuation regime.

Impact of Diagnosis of MS on people

The onset of disability from a chronic illness has an impact that goes well beyond a person's health status and has a significant impact on their life choices and their future.

Being diagnosed and adjusting to a condition such as MS with no cure can be a devastating experience. A condition where there is gradual but inevitable loss can have dramatic consequences on the quality of life enjoyed by an individual and their family.

A number of elements are critical to the adjustment of the individual and those around them, including family, friends and employers.

Key issues here are:

- Most people want to be treated as 'whole' people with attributes other than their illness. For a person who is employed, this is most often seen in the workplace, where they still want to be a contributing member, despite needing changed working arrangements
- People with chronic illness experience limitations in being able to do what they used to. Social isolation can often be a consequence of leaving the regular social milieu of a workplace

In order to effectively support people with MS in the community, an individualised approach is necessary that takes into account the necessity to remain employed and relatively financially independent.

The retention of employment for a person with chronic illness is critical on a number of fronts. Being employed allows people to maintain

- Social activity and reciprocal relationships
- Economic independence
- Maintenance of housing and family arrangements
- Maintenance of private health insurance

Experience of people with MS in the workforce

Discrimination, both covert and overt is still a problem experienced by people with MS in workplaces across Australia. While there is information and some assistance available, in many cases employers display little to no interest or inclination to access support in their enhancing the employment relationship with their employee with MS.

The increased casualisation and mobility of the Australian workforce also makes the value of employer investment in any employees with chronic illnesses less reliable.

People with MS in the workforce are often faced with the decision to leave work, or are pushed out of work prematurely with inadequate time to plan. When they run out of sick leave they are often encouraged to leave work by

the employer as they are unaware of their entitlements, opportunities or even the value that could be retained by keeping a worker on.

If someone is 'off work' experiencing early symptoms, they can suffer great stress and want to get away from work to 'concentrate on their health'. It is not until they are at home with greatly reduced social contact and life purpose that they realise just how important work is to health.

Much is made of employer responsibilities in regard to occupational health and safety, however it appears to be framed by the limits of their legal liability rather than any other sense of good practice or other obligation to the worker.

While there are detailed procedures governing what happens to workers when they are injured, there is virtually no guidance given to employers or employees when the worker is diagnosed with a chronic illness.

Diagnosis and disclosure issues

Commonly raised issues within workplaces is that employers and coworkers frequently have a poor understanding of the nature of MS, and how the impact upon work (as in all disabilities) has to be treated individually. Descriptors of MS can often be worst case scenario and will not necessarily apply.

Employers frequently fail to ASK employees, and employees are frequently afraid to disclose their condition, for fear of loss of job security.

Many employers appear to expect that their worker with MS will imminently be seriously disabled (ie in a wheelchair), and therefore neither understand, nor are adequately able to address the more insidious issues concerning 'hidden disability'. These include fatigue, shorter work routine tolerance, proximity to toileting facilities (for some), possible cognitive issues, etc. These are all of quite manageable within normal work routines with appropriate workplace accommodation and support.

Disclosure can have a significant impact upon long-term employability and future advancement.

ex: One person with MS reported recently in Queensland that their employer actively and openly discourages her from taking on higher roles with comments such as "well, we don't know how long you'll be around and able to work". The employer is at, best, insensitive to the person's need to be seen as an active part of that work group; and at worst, is being quite discriminatory. The person does not have a visible disability.

Another who works in a professional role, and who is reluctant to disclose, because of changes within the structure of the workplace: If his condition were known, he feels it is highly likely he would be replaced, or "moved sideways".

He has no visible disability and has had no adverse impact on work since his diagnosis 5 years ago.

MS Australia is aware of exceptional examples of employer accommodation of employees with MS that have resulted in sustainable and productive outcomes for all parties. A number of these are situations where the person with MS is a professional or managerial employee and has the skills to negotiate with their employers.

ex: In one case, a HR professional in a large company was able to continue work for 11 years after he was initially advised to leave work. This man received no outside assistance in his negotiations with his employer.

In other cases where people with MS are younger and not working in professional jobs, the outcomes are generally much poorer.

Based on experience, certain factors work towards job retention for people with MS.

Some of these include:

- 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
- Workers knowledge of employment rights (Disability Discrimination Act, Equal opportunity legislation)
- Good workplace modification and around job requirements and flexibility
- Thoughtful career planning
- Effective management of symptoms by the individual. This includes the use of the betaferon/interferon MS drugs that allows suppression of symptoms to facilitate longevity in work

Conversely, the absence of these factors will contribute to poor workplace outcomes for people with MS.

In many cases poor information is just as significant as negative employer attitude may be in contributing to early exit from the workforce for a person with MS.

A number of personal factors influence decisions about how a person with MS manages their situation at work, including whether they disclose their diagnosis (many people do not disclose for fear of discrimination)

Other people with MS arrange their lives around their reduced capacity by working part time and supplementing this income with the Disability Support Pension. This arrangement works extremely well for people who can maintain their workforce participation and their independence for many years.

Their participation in work assists them to maintain their health, their dignity and their role in the community. These people demonstrate the reality of the rhetoric about mutual obligation and community participation for people with disabilities. The current government policy framework which promotes this welfare/work mix is vitally important and should not be compromised.

Changing the culture of work

We would agree with the comments of the Prime minister on the 18th September 2003 when he says that people should stay in the workforce longer:

The point I'm making is that we have to in a wide range of areas, encourage people to remain in the workforce longer,"

"We have to alter the culture, we've got to alter the culture of private business, we've got to alter the culture of governments, we're beginning to do that." AAP

Although he was referring primarily to older workers, the same change in culture will benefit people with MS and their families.

Typically employees with MS report feeling "obligated" to do whatever it takes to maintain work, rather than risk job loss. Where a particular company had an in-house culture of after-hours work participation and missing of breaks/lunch, an employee with MS felt obliged to comply, and left work on "stress leave", caused largely by fatigue in the circumstances.

Since disclosing her condition she works less hours but reports that her supervisor reminds her of deadlines and tasks "up to 10 times per day". She reports there is now a heightened emphasis on her "not carrying an 'appropriate workload'".

She is considering leaving work due to the over-eagerness of inappropriate monitoring, reminders and implicit lower performance. Her workload is actually more productive with better pacing and through the taking of regular breaks including lunch.

Work routine demands

Workplace expectations are increasingly, based on multi-skilling and multi-tasking. This potentially disadvantages people with MS where fatigue, long work hours and other symptomatology may further diminish work sustainability.

"Time is money" remains an ethic across administrative, sales, hospitality and a range of other occupations, so employers sometimes consider it "outside of their capacity" to consider workplace accommodations. Typically they DO NOT have a culture of inclusion for people with any limitations or restrictions based on their disability.

Ex: It is a delicate balance to ensure continued workplace support where the nature of the work is demanding in any case (ex: Fatigue impacting on a nurses ability to perform her duties).

Stigma of MS in the Labour Market

People with MS have expressed feeling "forced out" of work because their work capacity has sometimes varied and they have sometimes taken days off work (although not excessive). In these circumstances, it is the MS, not the workplace's willingness to participate in reasonable support, which is targeted as adequate reason for early work cessation.

People with MS are disadvantaged in their confidence in accessing alternative employment especially when they have previously left work due to poor employer support. The stigma of MS usually ensues - applicants are reluctant to either disclose their condition, (due to assumptions they feel will be, or have been, made) or to nominate referees previous supervisors. (despite the quality of their work still being good)

Employment Incentives

In order to achieve improved participation in the workforce by people with MS, and the resultant financial and personal gains this can bring, a range of new support programs and employer/employee incentives are needed.

Greater incentives need to be offered for employers to 'save and extend' jobs and not just to create new positions or to provide placements for new job seekers. These incentives can be similar to those offered for new jobs and to older workers working beyond 70.

In addition, a greater focus is needed by employers and employment programs in supporting people with MS and other chronic illnesses to remain in the workforce.

It is important that these arrangements are part of the mainstream employment support framework in Australia, and not seen as a last resort service.

Organisations operating in the world of employment could take a greater role in the move to keep this group at work longer. Unions, employer associations and workers compensation schemes all have significant roles to play in providing the means to improve the culture of work as it relates to younger workers with chronic illnesses.

They need to work closely with specialist agencies that can assist in designing best practice interventions and information for workplaces in Australia.

Similar incentive arrangements for longevity of employment currently offered through the Job Network and disability employment programs could be better utilised.

We applaud the 2003 Federal Budget decision to expand the much needed work based personal assistance program to enable more people with disabilities to receive support in the workplace once they have been identified and have a supportive employer.

What is still missing in the current policy framework, however is the widespread availability of practical guidance available to workers and employers to ensure maximum flexibility in providing job accommodations.

Making workplace accommodations

Feedback from people with MS is that few employers embrace the notion of workplace support. MS Australia state by state receive very few unprompted calls from employers for assistance and advice.

Website Information regarding workplace support for people with disabilities in employment are disproportionately represented by Universities in Australia, and by some community agencies. With the exception of a NSW govt site, state Governments do not provide web site information consistently across Australian Employer groups. There is considerable information from the US and UK available on the Web, but is specific to those jurisdictions.

Employers generally are quite uncomfortable with discussion of workplace accommodation and generally accede from a fear of allegations of discrimination, rather than from an overt desire to provide appropriate assistance in the workplace.

Flexibility in work conditions appears to be generally poor across the Australian workforce as experienced by people with MS. Across administrative, policy, clerical and sales areas, very few people with MS report having the opportunity

to even consider job-share or work-from-home arrangements, where, for example, it would be quite feasible for them to productively fulfil work requirements at optimal times.

Employers also remain concerned with "visibility" of disability.

Ex: A number of people with MS working in bank and large department store environments have battled to negotiate occasional use of a stool to permit sitting, to alleviate lower limb fatigue from continuous standing.

Reasons cited by both employers were that they did not wish customers to see someone "sitting on the job", and that this would create an adverse impression upon the public.

Multi-tasking requirements in both small and large organisations are cited as reason for not taking on someone with MS.

Workplace support information emanates from agencies such as the MS Society and other community-based organizations. Government incentives on anti-discrimination fail to address the detail of particular conditions and the likely impact, and are a poor source of material on reasonable adjustment and workplace accommodation.

Most employers appear to perceive their responsibilities as being limited to legislated workplace-related injury management through WorkCover or other related schemes. They do not make the connection between general workplace organisation and employee health. This is dealt with in the following section.

A workplace, which offers adequate support to all staff (as/when required), would appear to manage MS far better than those workplaces that ignore fundamental issues. The focus needs to be about enhancing employer knowledge across all levels, not just at middle and lower management.

Role of employers and workers compensation agencies

The community bears the cost of illness and disability regardless of cause. In Australia we have many disconnected personal injury insurance schemes, including CTP and workers compensation that have the effect of insuring for cause, not effect. As stated earlier, people whose MS symptoms have an effect on their work patterns (and their employers) have few options for practical assistance when they need it.

Employee Assistance and like-training programs in medium /large employers need to be taken more seriously at all levels of management. Organisations frequently send middle and lower management (or simply HR) staff to training

on discriminatory work practice, but fail to educate at higher levels and thus inadequately embrace appropriate work principles that promote long-term participation.

Employers are mostly familiar with principles of work adjustment in relation to injury management, but fail to apply the principles of workload pacing, task restructure and job re-design to accommodate staff with long-term illness.

Workers compensation schemes have the potential to offer a valuable resource for employers and employees in the case of job protection through proper management of disability. These jurisdictions have a large body of experience in employer education, job and workplace modification, and the use of 'early intervention' strategies to keep injured workers in the workforce. Variations of these models can be applied to keep people with chronic illness at work.

They also have excellent communication channels with employers that could be used to inform employers of strategies which will enhance employer/employee relations.

If employers could be given the kind of assistance that is available for work injuries to help them manage a worker and a chronic illness, then significant community dollars would be saved in welfare and rehabilitation services and create additional retirement income for the employees concerned.

Unfair dismissal laws are also of limited value in these cases. Certainly people with MS and similar conditions have used these in the past, but in many situations these laws and particularly the associated processes are adversarial in nature. This reduces the chances of reintegration into the workplace and the likelihood of continuity of employment in the future.

The additional resources required to extend this service could be directed through existing employment schemes with targets to maintain numbers of jobs.

The UK example

The Employer Forum on Disability is an employer group initiative in the UK that provides information, legal frameworks, advice, ideas and practical suggestions to ensure people with disabilities and employers get the information they need to make the most of work.

In 2002 the UK Forum produced a guide for employers on how to manage disability at work within the framework of the National disability discrimination Act and other legislation/policy.

(Solutions at Work-practical guides to managing disability, Employers Forum on Disability, 2002 ISBN 1-903894-03-4)

This guide details legal responsibilities and practical adjustments that employers can make to keep workers productive. It provides practice examples across a range of disability types as well as legal precedents for employers to consider.

It is instructive that the UK employers groups have taken the initiative to provide leadership to their members in promoting positive management solutions to issues of disability and chronic illness in the workplace.

A similar initiative by employer organisations in Australia would be most welcome and would be supported by MSA.

The Commonwealth Rehabilitation Service

The Job in Jeopardy program at the Commonwealth Rehabilitation Service (CRS) is one of the very few programs that has the capacity to intervene in situations where people with MS are at risk of premature or unfair exit from work. With the increased corporatisation of CRS over recent years, its program delivery is now of shorter duration than in past years.

An important issue with CRS service delivery is that of eligibility - where a person is already working, there are limits to assistance, as the main cost-recovery process comes from Centrelink-related programs or from insurers.

People with MS who struggle with significant part-time or fulltime work are both ineligible for Centrelink support and for CRS programs unless they are prepared to define their circumstance as "job-in-jeopardy".

Many people with MS report that involving a new agency in the workplace, is problematic where the culture is unlikely to be supportive.

MS support is by definition a longer-term issue and requires that support programs are able to assist and intervene over months and perhaps years, and this is contrary to current CRS policy and practice.

Similarly, disability employment programs are targeted on finding jobs, and use a diminishing support model that is largely unsuitable for people with progressive illnesses like MS. The Work Based Personal Assistance program does continue long term, but not all people with MS need this kind of personal care support at work.

The MS Society of Victoria is currently working with the Department of Family and Community Services to design and implement a targeted employment service aimed at preventing premature cessation of work through the provision of articulated information and long term support.

Conclusion

MSA supports moves to challenge the culture of work in Australia and urges the Committee to consider younger workers with MS and Chronic Illness in the changes that are under consideration.

These people represent a small but costly group who may rely on government income support for many years longer than necessary. This is due to premature exit from employment and consequent lack of savings for adequate retirement income.

For relatively small investments in targeted support programs to people with conditions such as MS, significant benefits in quality of life and savings to income support benefits for individuals can be realised.

A focus on educating and informing employers about the benefits of retaining workers should form part of the change program, and must include references to managing chronic illnesses with subsequent adjustments in the workplace. There is a role for workers compensation agencies in promoting "healthy work" environments.

MSA is keen to make a formal presentation to any hearing that the Committee convenes for this inquiry. We will present more detailed statistics and let the committee hear first-hand the experiences of people with MS in the workplace and their ideas about how to improve long term participation in employment.

For further information and correspondence in relation to this submission, please contact:

Alan Blackwood
Manager Policy and Community Partnerships
The Nerve Centre
MS Society of Victoria
03 9845 2713
ablackwood@mssociety.com.au