

Job in Jeopardy

A closer look – MS and chronic illness



MS Australia



Peak body for MS organisations in Australia

Representing over 18,000 Australians living with MS

Public Policy and coordination focus

MS Societies in Vic and SA are specialist DES providers

MS in Australia - numbers



75% people with MS are female

Average age of diagnosis in Australia is 30

87% of people with MS in Australia are of working age

80% lose their employment within 10 years of diagnosis
(globally 50% leave work within 3 years)

High family cost of disease - \$10,500 per year

Broad areas of disease impacts



- *Physical limitations /disability*, mobility, fatigue, bowel and bladder disturbance, vision loss, unpredictability
- *Impairment of cognition*, or mood requiring support with memory, planning, decision making/ judgment
- Need for *Regular & Clinical monitoring of symptoms* pain, medications, incontinence, memory, communication, range of movement,
- *Social and emotional*; constant adjustment, family and relationship difficulties, employment continuity financial insecurity, mental health co-morbidity

Experience of the labour market 2003-07



- Between 2003-2007, longitudinal employment reduction of people with MS of 5.4% with over 64% not in the paid labour force
- Impact of MS symptoms cited as predominant reason for leaving employment, although workplace factors still an issue
- Early intervention essential – advocacy, information, clinical support and self management
- Environmental factors also a barrier to employment – physical access, transport and equipment
- 58% of carers of people with MS report having to change their work hours due to the impact of the disease

Simmons, et al: Living with multiple sclerosis: longitudinal changes in employment and the importance of symptom management. *Journal of Neurology*, Jan 2010

Need for a specialist service



Complex interactions of symptoms and workplace factors

Demonstrated employment risks

**Progressive nature of condition
Need for multifaceted interventions**

Ongoing assistance and education in symptom management

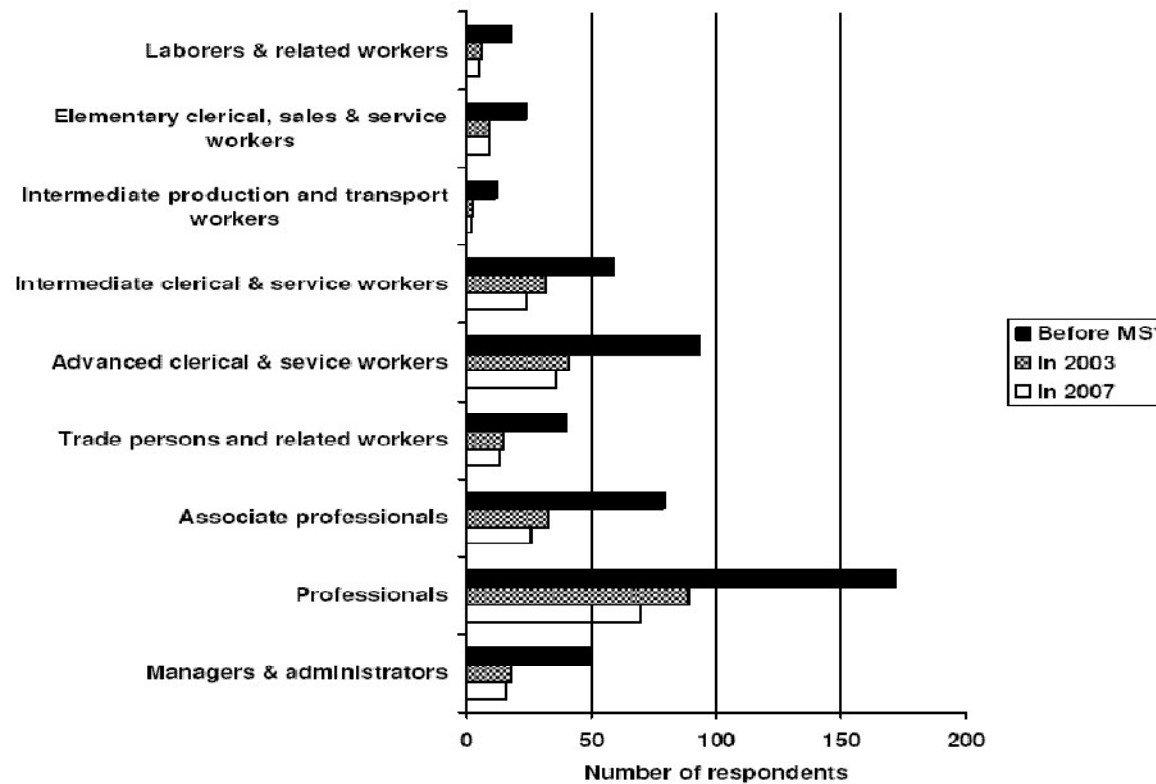
Disclosure issues

Access to peer support

High degree of individual control



Occupation type not predictive of employment outcome



Simmons, et al: Living with multiple sclerosis: longitudinal changes in employment and the importance of symptom management. Journal of Neurology, Jan 2010

Supporting people in careers not just saving a job



People with MS (and their carers) have skills and experience that pre-date their diagnosis

Provision of support through disease and career transitions – combining work and lifestyle advice

Planning ahead for future career paths, work styles and management strategies

Maintenance and applicability of skills and productivity

MS teacher needs aide

PORT Fairy multiple sclerosis sufferer Sonia Sandars is continuing her fight for her teaching career but is still without assistance in the classroom.

The Heywood and District Secondary College VCE maths and chemistry teacher's classroom has been transformed into a state-of-the-art hub to ease her role at work but funding can't be found for a teacher's aide.

Her balance and endurance are deteriorating as the result of the debilitating disease which attacks the central nervous system.

But a new trike provided by a Federal Government grant has eased mobility concerns in and around the school.

The classroom has also been fitted with a special whiteboard which allows Mrs Sandars to write while sitting at her desk.

Previously she was forced to pack her own trike in and out of her car each day with the help of students at college and husband Stephen at home.

She said the equipment helped, but her main priority was getting funding for a teacher's aide.

"We are still working on the teacher's aide. The kids do everything they are asked to do and so do the teachers around you. I have an excellent support network but that is where my priority is set," she said.

Funding for the trike was sourced by Western District Employment Access disability employment consultant Peter Mitchell through a Federal Government work-



Sonia Sandars has MS and uses a computer to help her teach secondary school classes.

000905014

place modification scheme.

Mr Mitchell said he had been down nearly every avenue to find funding for a new employee but had hit many obstacles.

"There are still a few avenues but I think I'll be bashing my head against a brick wall. Everyone wants her to stay at school. You can talk to anyone at the school and they

will tell you the same thing. She just needs this assistance to ease her job."

A teacher's aide would help write on the board, assist students and carry books.

Risks to employment



A number of common risks for targeting employment support

Immediate Impact Risks	Gradual Impact Risks
<ul style="list-style-type: none">• Onset of acute disease symptoms requiring hospitalisation or inability to work• Leave account at zero• Crisis at work – restructure, pressure situation, performance review• Discrimination and stigma• Competing life demands	<ul style="list-style-type: none">• Disease adjustment and job re-design• Individual symptom management• Individual interpretation of risks to employment• Complex decision making about disclosure - assessment of consequences• Managing leave and multiple medical appointments over time• Communication and relationships at work, performance management• Co-worker and management understanding• Discrimination and stigma• Competing demands• Workplace systems• Competing life demands

Disclosure – a difficult and individual decision



Major issue for people with a chronic illness and for carers

Need to weigh up a lot of factors

- Timing
- Advantages and disadvantages
- Legal and financial issues
- Personal identity

Who do I tell and what do I say?

Will I be sidelined for promotion or other opportunities?

Do I legally have to disclose?

What is going to happen to my work relationships?

Reasons for leaving employment



	Self-reported reason for leaving employment	% of respondents indicating had left employment due to MS, 2003 (n = 554)	% of respondents indicating had left employment due to MS, 2007 (n = 619)
Workplace Related	More suitable work not found in same organisation	23.8	19.2
	Asked to leave/ sacked	16.1	17.6
	Not allowed flexible work hours or conditions	11.6	12.4
	Ran out of paid sick leave	10.5	9.2
	Not considered for promotions	3.8	4.0
Transport	Unable to get to/ from work	17.0	13.6
	Unable to get up & dressed in time for work	9.7	8.6
	Unable to obtain appropriate parking	5.4	5.0
Workplace mobility	Architectural barriers	17.5	17.4
	General area accessibility	6.7	4.5
	Inaccessible bathroom	3.4	3.9
	Inaccessible tearoom	2.9	2.9
Equipment use at work	Unable to stand for long periods to use equipment	33.0	20.7
	Unable to use necessary equipment	15.2	10.2
	Chair or desk inappropriate for comfort and support	5.8	4.2

Reasons for leaving employment - symptoms



	Self-reported reason for leaving employment	% of respondents indicating had left employment due to MS, 2003 (n = 554)	% of respondents indicating had left employment due to MS, 2007 (n = 619)
Impact of MS symptoms	Fatigue	79.1	69.5
	Physical problems with legs or feet	54.9	43.8
	Physical problems with arms or hands	44.8	39.4
	Difficulty with memory, concentration or thinking	34.7	36.7
	Balance or dizziness	41.5	31.2
	Heat sensitivity	34.1	30.0
	Pain	20.8	23.3
	Bladder or bowel problems	28.3	23.1
	Poor vision	23.5	17.1
	Tremor	15.7	14.9
	Non-pain sensation symptoms	16.1	13.1
	Speaking difficulties	9.7	9.7

Self reported reasons for leaving and perceived risks



	% Left Work		% perceived risk	
	2003	2007	2003	2007
Felt too stressed by the effort	40.4	36.8	30.3	27.2
Felt I was not doing a good enough job	33.8	33.3	36.1	42.7
Doctor or health professional advised	28.5	27.8	9.8	3.9
Unable to work fast enough	25.1	23.4	15.6	20.4
Felt I was a burden to my colleagues or employers	20.4	15.2	18.0	23.3
Felt people at work were critical or unhelpful	9.6	10.5	9.8	15.5

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general intervention principles



- Ensure worker has good information
- Identifying fitness to work, realistic goal setting and necessary accommodations
- Assist employer manage chronic illness consistent with the privacy legislation requirements
- Promote good communication
- Early intervention and staying the course
- Assist individual to coordinate external clinical and other supports and the dynamic of how to working with treaters, line management, and support providers

Not just MS – Chronic disease a real issue for skills and productivity



- People with chronic disease are 60% more likely to not be in the labour force than people without chronic disease
- Of approximately 10.5 million Australians aged 25-64 years, 33% reported at least one of the following chronic diseases: [arthritis](#), [asthma](#), [heart disease](#), [chronic obstructive pulmonary disease](#), [depression](#), [diabetes](#) and [osteoporosis](#).
- The Australian economy loses nearly 540,000 full-time workers associated with chronic disease each year.
- Represented nearly 10% of the full-time workforce in 2005.

(AIHW Chronic disease and participation in work, Feb 2009)

Good response from Government but more to do



- Well designed labour market programs for people with illness and disability
- Positive Ageing Package – mentoring, intervention and training for workers over 45 with chronic disease
- Need labour market program for carers
- Extended mandate for workplace flexibility in Fair Work legislation
- Expand Work Based Personal Assistance Program

On the job support



- DES system provides greater scope to provide ongoing support
- Combining ongoing support with specialist clinical services very useful
- Support programs can be a longer term proposition
- Need to develop improved interfaces with support programs

Work Based Personal Assistance



- Operation of WBPA needs overhaul – only limited personal care in the workplace with very restrictive eligibility criteria
 - Nursing services
 - Tube feeding
 - Personal hygiene
- Small amounts of assistance to people with a range of physical assistance needs is extremely useful but difficult to source for long periods
- The lack of WBPA has caused people to leave work

Working with Employers – the other imperative



- Cultural change in the employer sector is occurring
- Promoting general and specific strategies by industry to maintain continuity of employment for the chronic disease group
- Creation of sustainable links between employers, labour market programs and health agencies
 - Sick leave pooling
 - Injury and illness management
 - Flexible work options
 - Information and advice