Election Commitments

2016

MS Australia seeks commitments for the 2016 Federal Election.

Find out the 10 important ways our politicians can help people affected by multiple sclerosis.

MULTIPLE SCLEROSIS (MS) is a complex neurological condition affecting all aspects of life for individuals and their families.

There are more than 23,000 people diagnosed with MS in Australia[1]. MS is the most common acquired neurological condition diagnosed in young adults[2]; the average age of diagnosis is 30 years of age and 75% of people diagnosed in Australia are women[3]. MS devastates the lives of young Australians when they are planning families and careers of their own.

Taking into account families, carers and friends, the extended networks of people affected by MS is enormous. People with MS experience the condition in different ways; no two cases are the same.

Most people with MS in Australia are dealing with its relapsing/remitting nature or its rapid progression, so the needs of people with MS are many and varied.

The total cost of MS in Australia is estimated to be $1.04 billion per year, and of that, $500 million is due to loss of productivity. The replacement cost of informal care provided to Australians with MS is $125 million and Australians with MS pay $78 million per year out of their own pockets[4].

People affected by MS have two fundamental needs:

1. A cure for the disease
2. Access to support from the first experience of symptoms, through diagnosis, treatment and ongoing disease management.

A cure is within the grasp of this generation of political leaders and researchers.

However, current access to support occurs through complicated Commonwealth and State arrangements, and some needs remain unmet.

That is why people with MS require both a greater investment in research and a comprehensive approach across all tiers of the Australian, state, territory and local governments.

We want to create **articulated pathways** of diagnosis, treatment, care and support, with an emphasis on consumer-directed care, recognising that families and carers can only do so much.

The introduction of policies to bring about **mandated integration** between the aged care, health care, disability care, education, housing and employment systems will ensure people affected by MS have their needs met, regardless of which system they access. This approach will also **bring about efficiencies** in these systems, through the streamlining of services and support, ensuring people with MS are diagnosed and treated as early as possible, **minimising the need for crisis interventions** and avoiding people being placed in residential care.

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1. Palmer A. et al, A novel method for calculating prevalence of multiple sclerosis in Australia, Multiple Sclerosis Journal 2013; 19(13) 1701-1711.
2. Multiple Sclerosis International Federation. What is MS? http://www.msif.org/about-ms/what-is-ms/ Updated 28 October 2015.
3. Australian Bureau of Statistics (ABS). Profiles of Disability 2009. Cat No. 4429.0. Canberra: Australian Bureau of Statistics.
4. Covance & Menzies Research Institute. Economic Impact of multiple sclerosis in 2010: Australian MS Longitudinal Study, prepared for MS Research Australia.

Election Commitments

MSA seeks an election commitment from all sides of politics for:

1. Full funding and timely roll out of the Medical Research Future Fund and assistance with prioritising an allocation from the Fund of $25 million to Multiple Sclerosis Research Australia for the purpose of funding a number of promising, signature areas of research that will boost the chances of finding a cure for MS.
2. A specific contribution of $15 million for the Brain Health Project; a therapeutic strategy with the potential to minimise disease activity and maximise lifelong brain health for those with MS.
3. Immediately establishing a MS Stem Cell Research Working Group for discussing with key decision-makers how to alleviate the need for people with MS to risk travelling overseas for AHSCT ('stem cell') treatment.
4. A commitment to the full and timely roll out of the National Disability Insurance Scheme (NDIS).
5. Specific improvements to the Aged Care/Disability care interface.
6. Specific improvements to employment options and workplace flexibility.
7. Specific improvements to early intervention processes.
8. A blanket prevention of young people entering residential care.
9. The introduction of a single and national medical energy concession.
10. The full implementation of Australia's Liveable Housing Design Guidelines by 2020.

1.

MSA seeks: Full funding and timely roll out of the Medical Research Future Fund and assistance with prioritising an allocation from the Fund of $25 million to Multiple Sclerosis Research Australia for the purpose of funding a number of promising, signature areas of research that will boost the chances of finding a cure for MS.

Why is this necessary?

A cure for MS is possible within our lifetime. It is a distinct possibility that it will be this generation of scientists and political leaders who make MS an historical footnote.

This is dependent upon adequate funding being invested in this effort.

That is why the establishment of the $20 billion Medical Research Future Fund (MRFF) in April 2014, was so publicly welcomed by MS Australia. There has undoubtedly been great progress in the fight against MS over the last decade. We anticipate a contribution from this fund would catalyse this momentum and significantly advance ground-breaking research in conditions such as MS.

That said, it is important that any allocation of funding is invested wisely. To this end MSA on behalf of MS Research Australia seeks assistance with prioritising funding for a number of peer-reviewed, promising, signature areas of research that have the best chance of finding a cure for MS in the near future.

What will this do?

As proposed, the MRFF will build to a $20 billion perpetual fund, providing annual disbursements of $1 billion by 2022-23. The MRFF is intended to have a transformational impact on long-term future health and medical research in Australia and, through this, the efficiency and effectiveness of the Australian health system.

MS Research Australia implements an informed and robust scientific agenda to accelerate advances that will prevent, better treat and ultimately cure MS. MS Research Australia focuses on funding research that will increase understanding of the biology driving MS and discovering how to stop the triggering of the disease. It also has a primary aim to investigate how to repair existing damage caused by MS. This is a medium to long-term strategy and it requires extensive funding, collaboration and coordination.

In the short term, MS Research Australia funds clinical research that measures the benefits of alternative symptom management approaches. Social research through the Australian MS Longitudinal Study measures the physical, social and economic impact of MS on Australians for advocacy and service development purposes.

The following promising areas of research will significantly boost the chances of finding a cure for MS:

1. Investigating compounds or those research directions, including stem cells, that show promise in the repair of what was once thought to be irreparable damage to the myelin sheath and nerves caused by MS.
2. Strengthening the role Australia now plays in leading the global fight to find a cure for progressive MS – a form of MS normally associated with a higher level of disability, lower quality of life and a comparatively higher health burden on the Australian health system.
3. Boosting the world's largest Vitamin D clinical trial investigating whether Vitamin D may be given to prevent MS. Over 240 patients will be recruited to look at not only the effectiveness of Vitamin D in preventing MS for people who have had a first clinical attack, but also the effective dose needed.
4. Investigating the genetic links between MS and other autoimmune diseases such as Juvenile Diabetes (type 1) to help unlock the mysteries of immunological diseases in general. Breakthroughs will potentially benefit over 145,000 people in Australia and millions worldwide.

CONNIE Alfonso, from Melbourne, was diagnosed with MS in 2014. Connie is married with two children, aged 6 and 4.

CASE STUDY 1.

What would a cure for MS mean for me?

"My fear of the unknown would no longer be. When I wake in the mornings, I pray that all will be well, not knowing what MS will take away from me next, this scares me - it has already taken the sight from my left eye, my future is unknown. Thoughts go through my mind at times; will I be walking and still independent in the future? Will I be in a wheel chair and require a carer to assist me with getting my children ready, to shower me? Help me with cooking? Cleaning? And taking me on outings? To lose my independence scares me. Will I need to be placed in residential care and if so where? My background is working with the elderly and people with disabilities. I would rather be dead than placed in a nursing home surrounded by old and dying people. There is no place for the young in residential care; how ironic that now I have MS and that I may need care when I'm older?

2.3 million people are affected by MS world-wide; 23,000 in Australia; more women than men are affected, between the ages of 20-40 years of age. No one is protected. Please help us find a cure. A life free of MS is a dream come true, please help it become a reality!"

2. **MSA seeks:** A specific contribution of $15 million for the Brain Health Project; a therapeutic strategy with the potential to minimise disease activity and maximise lifelong brain health for those with MS.

This will:

1. Enable targeted health policies to minimise delays in the diagnosis of MS and in the time to treatment initiation as these can result in irreversible disability progression (e.g. prompt referral by GPs to neurologists).
2. Encourage healthcare professionals to set goals for treatment and ongoing management that aim for the best possible outcome for every person with MS (e.g. ensure that MS healthcare professionals can take the time to monitor disease activity, agree and implement standard data collection techniques, protocols and data sets).
3. Encourage healthcare professionals and healthcare providers to consult the most robust evidence base possible, and generate further evidence, to make good decisions about therapeutic and management strategies for MS (e.g. carry out economic evaluations of therapies and other healthcare interventions from a societal perspective).

The *Brain health: Time Matters in Multiple Sclerosis* report presents consensus recommendations on diagnosis, therapeutic strategies and improving access to treatment in MS. Its core recommendation is that the goal of treating MS should be to preserve tissue in the central nervous system and maximize lifelong brain health by reducing disease activity.

The report was developed by an international multidisciplinary group of experts. It summarizes the evidence and consensus findings from structured discussions with clinicians, researchers, specialist nurses, health economists and patient groups, all with expertise and experience in the area of MS. It presents an expert, evidence-based position for policy recommendations aimed at improving outcomes for people with MS.

A full copy of the *Brain health: Time Matters in Multiple Sclerosis* report is available at www.msbrainhealth.org/report.

Why is this necessary?

Multiple sclerosis has a profound personal, social and economic impact. Recent years have seen rapid developments in diagnostic criteria, treatment options and monitoring procedures in MS, as well as an improved overall understanding of the disease by medical researchers. Major policy changes are needed, however, to translate these advances into better outcomes for people with MS and those who care for them.

What will this do?

A specific allocation of $15 million to MS Australia and MS Research Australia would enable the implementation of each of the recommendations in the *Brain health: time matters in multiple sclerosis* report. Enabling and promoting the widespread adoption of the therapeutic strategy in this report will minimise disease activity and maximise long-term brain health for each of the 23,000 people with MS in Australia.

This will:

- Minimise disease activity and maximise brain health thereby reducing the burden on individuals, carers, families and the healthcare system
- Minimise crisis situations and reduce the burden on hospital emergency departments
- Minimise the number of people admitted to hospitals and aged care facilities
- Improve the quality of life, health and wellbeing of all people diagnosed with MS
- Minimise overall cost to health, aged care and disability sector, especially to reduce numbers of people with MS accessing the NDIS.

CASE STUDY 2.

ASTRID Edwards was diagnosed with relapsing remitting MS at the age of 32. Faced with the uncertainties of life with MS, she started blogging about life with chronic disease. Already engaged in her own healthcare, the *Brain Health: Time Matters report* means a new approach to treatment of her MS.

What the *Brain Health: Time Matters report* recommendations mean to me

“I was diagnosed with MS in late 2013. My diagnosis was swift by MS standards – less than a month between the onset of symptoms and the MRI results. I experienced ascending bilateral paresthesia (in other words, numbness and tingling on both sides of my body) that began in my feet and crept up to my abdomen. I thought I was going mad. I couldn’t feel my own body properly. After weeks of this, as well as a day in ER and a night in hospital, an MRI indicated MS.

The generalist neurologist put my MRIs up on the wall and pointed to the lesions in my brain. She said I would feel sad about my diagnosis. And then she said she would book me in with another neurologist, and if I was lucky I could see him in a few months. That was it. No treatment for the relapse I had just experienced, not even an information booklet. I was sent home.

I am now a National Advocate for MS Australia, and based on the conversations I have with other people with MS, such an experience is relatively common. There is an assumption, even by practicing neurologists, that there is no short term intervention that can help someone experiencing an MS relapse.

But there is. And the Brain Health: Time Matters report *makes this clear. The report recommends that major public policy changes are needed to translate recent advances in the diagnosis and treatment of MS into improved outcomes. The first of these recommendations arrests me each time I read it – it recommends minimising delays in the time to treatment initiation as this can result in irreversible disability progression.*

In my case, the system had no intention of minimising my time to treatment, and it thus left me with an increased chance of irreversible disability progression. I remain unsure if the generalist neurologist who diagnosed me even knew there was such an option.

But I was lucky. A medical professional friend took matters into her own hands. Within two weeks she found an MS neurologist in a different hospital and begged him to see me. To his everlasting credit, he took me on and remains my neurologist to this day.

His approach differed from the first hospital, and is an example of the Brain Health: Time Matters report *in action. He immediately began treatment for the relapse I was recovering from, and scheduled tests to determine the best management and treatment plan for me.*

The first hospital did not treat me, or even mention the possibility of treatment. The second hospital did. It is my hope that all hospitals and neurologists get on board with the Brain Health: Time Matters report. *If they do, we can improve long term outcomes for people with MS.”*

Astrid became a National Advocate for MS Australia in March 2015. She blogs about life with MS at www.LadywithMS.com.

3.

MSA seeks: An MS stem cell working group to be immediately established with key decision-makers in the health arena to alleviate the need for people with MS to risk travelling overseas for AHSCT ('stem cell') treatment and to ensure that the AHSCT debate in Australia is well-informed.

We propose an agenda for these talks to include:

- The formation of a Working Group, including State and Australian Government representatives, to determine and implement solutions that will alleviate the need for people with MS taking the risk of travelling overseas for AHSCT treatment
- Consideration of the establishment of Centres of Excellence in each state to undertake gold-standard research that links seamlessly to Australian and international clinical trials, and to promulgate their findings regarding AHSCT
- A briefing from expert haematological representatives of St Vincent's Hospital Sydney, including the achievements of the AHSCT observational trial being conducted there
- Assistance from the Department of Health in gathering accurate data regarding the number of people travelling overseas for AHSCT treatment.

Why is this necessary?

A recent BBC program Panorama on Autologous Haematopoietic Stem Cell Treatment (AHSCT) in MS has ignited an increase in interest in the MS community.

AHSCT is a bone marrow transplantation involving an immunosuppressive dose of chemotherapy; similar to a protocol traditionally used to treat cancer. The BBC program revolved around two or three people being followed and reported on by the media in their treatment journey in the UK. The cases (out of 20 on the UK arm of the trial) that were highlighted showed the treatment in their case did have a profound impact, however, the trial has at least two years to run before the full results will be known.

Subsequent media stories on this issue generated by both SBS and Channel 7 ran in January 2016 to which MS Research Australia and MS Australia contributed. The global consensus position among MS organisations, remains that whilst AHSCT may be able to stabilise or improve disability in some people with MS, it may not be effective or suitable for all types of the condition. It is also noted that it is an aggressive treatment with considerable risks. More research is needed into this important area which would include the completion and publishing of the results of the trial on which the BBC program was based.

What will this do?

One of the main sources of frustration that is often raised and sometimes sensationalised in the media and through special interest groups, is the perceived lack of access of treatment of this kind in Australia and the need for Australian people with MS to travel overseas to have the treatment to places such as Moscow, Chicago and Singapore. It is not difficult to understand the desperation some people may feel to access this treatment and further, their feelings of being let down by the Australian health system.

CASE STUDY 3.

JESSE Frick from Adelaide was diagnosed with Relapsing Remitting MS in 2005 when he was just 18 years old. His condition was aggressive and by the time he was 22 he used a wheelchair to get around. After exhausting all the treatment options available to him, his neurologist suggested that AHSCT could be of benefit for him.

How would the expansion of AHSCT treatment in Australia help me?

He says, *"I remember him telling me that the most he hoped for was that the treatment halted the progression of disability and anything else was a bonus. Of course I was apprehensive as although the mortality rate was low at 2-5% it was there and something I had to consider."*

Jesse was the first person to undergo this treatment at a clinic in Adelaide. He says, *"The treatment itself was very invasive and the whole experience was very isolating. I was under no illusion that it would work miracles for me but at the time the benefits outweighed the risks. However I was given the appropriate care before and after the treatment to increase the chances of it working for me."*

Four years on and Jesse hasn't experienced any major setbacks and his latest MRI showed no real disability progression. He says, *"There's no doubt it was a worthwhile treatment for me to have as I was out of all other options but it hasn't been the miraculous experience that the media seem insistent to report on. My disability hasn't been reversed; I still use a wheelchair every day."*

He adds, *"I don't like to read much into media stories anyway and I'm pleased I don't because I would only have been disappointed with the outcome. I'm proof this treatment is not the miracle cure they're reporting it is. They are always going to sensationalise and I think it's irresponsible playing on the vulnerability of people living with this unpredictable condition. All I can really say is talk to your neurologist about it to see if it's an appropriate option for you. I'm proof that it isn't miracle cure treatment."*

An important aspect of Jesse's treatment journey in Australia was his pre-treatment assessment and the provision of appropriate care before and after treatment. This level of assessment and care is not always available at clinics overseas.

4.

MSA seeks: A commitment to the full and timely roll out of the National Disability Insurance Scheme (NDIS).

Why is this necessary?

The NDIS is a single, national scheme designed to provide a package of services and support for people living with a disability. Once fully rolled out, beginning July 2016, it is expected to benefit 460,000 people across Australia, providing a direct benefit to an estimated 30% of the MS community who are eligible to receive NDIS packages, which amounts to approximately 6,900 people affected by MS.

The scheme is estimated to cost just over $22 billion a year when fully operational in 2019, partially funded by an increase in the Medicare Levy (which is expected to raise $20.4 billion by 2018-19) with commonwealth, state and territory governments contributing the remainder.

Many in the MS community, indeed in the wider disability community are concerned that perceived increases in the cost of the NDIS, will lead to cut backs and compromises to full scheme roll out.

What will this do?

This commitment will reassure the MS community and provide a seamless transition without loss of services.

There are a number of trials underway in various states and territories to ensure there is a smooth transition to full scheme rollout for everyone involved, both in terms of service providers and recipients of the scheme.

Now that bilateral agreements have been signed in most states and roll out timetables announced, we are keen to ensure a seamless transition process occurs without any loss of services in the disability, health, community care and aged care sectors.

We are also keen to see reforms to establish key linkages for cross sector collaboration, across government portfolios, linking policy and service areas to produce optimum outcomes for individual, their families and communities to provide sustained support for people with MS living with a disability.

MS Australia is working with its state member organisations gaining experience as to how the NDIS is supporting people living with MS.

We want to make sure that the unpredictable nature and invisible symptoms of MS are properly understood so that people can be fully supported to live independent lives.

Tasmanian resident ANDREW Potter was diagnosed with MS aged just 23. A year into his marriage, the MS diagnosis came as a shock to both Andrew and his new wife, Jane. Within six months he had lost sensation in the lower half of his body and was confined to a wheelchair.

CASE STUDY 4.

Why does the NDIS matter to me?

Through hard work and determination, Andrew gradually was able to walk again and regain some control of his body. They had two daughters, Grace and Nicola, and he was starting to manage life with the neurological condition. But eight years later, Andrew's MS worsened at a rapid rate and, at the advice of his neurologist, Andrew then commenced two years of chemotherapy to try and put his MS into remission. The treatment had severe side effects making Andrew unable to work and putting strain on the family's finances. Jane found a job to cover home loan repayments while Andrew became a stay-at-home dad while continuing to deal with the side effects of chemotherapy.

The chemo had limited success and Andrew's MS progressed with ongoing, sporadic double vision, extreme levels of fatigue and an uncontrollable tremor. He also experienced bowel and bladder management challenges, non-specific neurological pain and sensory loss in his hands and parts of his body. New medical treatments available in Australia have assisted Andrew to manage his MS; he regained much improved health and he is able to work part-time.

Andrew said of the NDIS – *"For me the NDIS will be an integral part of my future – be it supports I require at home, at work, physically, psychologically or medically. Whilst right now I'm very well, my MS brings with it the challenge of looking well when you're not; MS may well strike you at any time and have everlasting repercussions. I am excited that with the full rollout of the NDIS my future needs will be met, no matter what they may well evolve into becoming both now and as I age, there will be a worthy support system in place to ensure my future is secure – as best it possibly can be…"*

5.

MSA seeks: Specific improvements to the Aged Care/Disability care interface.

This includes:

1. Policy action by the Australian Government to bring about far more integration between the aged care, health care and disability care systems such as mandating the consideration of a person's disability needs, any functional impairment, the progress of any chronic illness and the likelihood of a crisis situation developing at all decision points along their health care/disability care journey.
2. A commitment to adequate levels of funding and provision of specialist services for people with MS aged over 65, such as:

- Aids and equipment and assistive technology
- Flexible respite options (for person with MS and carers)
- Individual case management
- Appropriate therapy/health service supports with an adequate level of hours of support to ensure a person can remain at home
- For those in residential care, a system for ensuring changing and complex needs are assessed adequately and met within the residential care setting
- Employment support
- Ensuring the number and level of care of at home packages are adequate to address people's disability needs.

Why is this necessary?

People with a disability should be able to access whichever support system, the NDIS or aged care, which best meets their needs.

Currently there is inequity in Government support of people living with MS. For people diagnosed with MS when under age 65, the NDIS will, when fully rolled out, provide access to supports to meet individual needs, but people aged 65 and over must rely on the aged care system which is designed to address ageing, not disability.

What will this do?

To ensure people with MS who become disabled after age 65 are able to maintain their well-being and live a fulfilled life, it will be necessary to ensure that adequate support is provided for them to:

- Stay at home for as long as possible
- Engage in the community
- Stay at work for as long as possible with appropriate support in the workplace
- Ensure their financial security is maintained to cater for such things as housing, aids and equipment and a quality social life.

CASE STUDIES 5.

Case study A

MARGARET a 68 year old woman with primary progressive MS was living alone and finding it increasingly difficult to manage living independently in her own home. In 2014, after a significant deterioration in function, Margaret received a Home Care Package, however she was initially only able to access eight hours of service (Level 3). This meant that if she was unable to get a friend or family member to help her get ready and into bed in the evenings, she was being put to bed in the afternoon by her service provider, as there was little ability to access flexible hours of care.

After some months Margaret's package was increased to Level 4 – equating to 12 hours of care per week, unfortunately the provider she was using did not have capacity to provide her with the total number of hours in her package. Consequently Margaret moved providers to one she thought would be able to give her the increased hours more quickly. At this time she developed a pressure area which necessitated her package having to pay for community nursing to manage her wound dressings. To access this service she had to forgo one of her personal care services.

This was not sustainable so Margaret resorted to using her private health insurance to access respite in the form of a private hospital admission so she could 'bank' some hours, it also enabled her to get her pressure areas attended to properly.

This gave Margaret a reprieve for a while but regrettably, early in 2015 she had to move to an aged care facility because her package just was not sufficient to allow her to remain living independently at home.

Case study B

ALEX is 66; she lives with her 75 year old husband (who is her main carer) and their daughter. Alex mobilises with a stick, she finds shopping and domestic tasks challenging due to a lack of mobility and the level of fatigue she experiences. Alex's husband has chronic heart failure, is not in good health and has limited capacity to undertake these tasks. Alex's daughter also has serious health issues and has limited capacity to assist.

Alex reports that they are socially isolated. There are home modifications that are required – ramps at front and back doors and rails in the bathroom. Alex has had several falls recently and she experiences lower limb and upper arm weakness, she is a 'falls risk'.

Alex is on a Disability Support Pension, her husband receives the Aged Pension and they live in rental accommodation.

Alex was in receipt of an Attendant Care Package but this has now ceased as she is over 65 and she is receiving a lower level of domestic assistance through the aged care system; this is not meeting her needs.

6. **MSA seeks:** Specific improvements to employment options and workplace flexibility.

This means:

1. The Australian Government's National Disability Employment Framework is retained and enhanced to help people living with MS to stay employed; specifically components such as Employment Assistance, Job in Jeopardy Assistance, Ongoing Support, and the Employment Assistance Fund.
2. The removal of arbitrary, geographical Employment Service Area (ESA) boundaries so that everyone with MS has access to the right support at the right time and people are not precluded from accessing their choice of service simply because of where they live.
3. Expansion of specialist disability employment services to offer greater choice to people living with MS to realise their career ambitions, foster innovation, provide a better match between job seekers and opportunities, and offer services based on needs.
4. Development of more appropriate, holistic, assessment processes for entry into Disability Employment Services programs to ensure people living with the invisible symptoms of MS are supported to overcome any barriers they might have.

Why is this necessary?

50% of people with MS are not in paid employment compared with 37% of the total Australian population[5], almost half of people leaving work prematurely due to MS do so within three years of diagnosis and 34% of carers say their employment is affected[6].

56% of people with MS had lost a job due to MS. Over 4 years, the longitudinal loss of employment was 5.4%. Compared to the Australian population, people with MS were less likely to be employed (49.8% vs 59.6%).

The most frequently listed symptoms relating to employment loss were:

- Fatigue (70%)
- Mobility-related symptoms (44%)
- Arm and hand difficulties (39%)
- Cognitive deficits (37%).

What will this do?

All people with MS should be supported in maintaining the financial security and independence that arises from employment. Furthermore, we encourage employers to look at opportunities to offer enhanced workplace flexibility to people with MS to support their ongoing employment whilst effectively managing their symptoms.

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[5] Simmons et al, 2010, Living with multiple sclerosis; longitudinal changes in employment and the importance of symptom management, J Neurol. 2010 June;257(6):926-36.

[6] Multiple Sclerosis International Federation Survey on employment and MS, April 2010.

MIKE WELSH is a digital banking guru at ANZ Bank. He lives with his wife Kate and their two young children, Lila and Ciarán. Mike was diagnosed with relapsing remitting MS nine years ago at the age of 31.

CASE STUDY 6.

What does MS mean to my employment?

"MS means I work flexible hours.

A decade ago, I worked long hard hours. But then MS happened. MS is one of those things… Anything can – and does – happen. But day to day, it is the fatigue that gets me. I have learned how to manage it, but it requires effort.

Managing the fatigue means long hours are no longer feasible. That was a difficult to accept, because I equated my career success with the hours I worked. But as I learned to manage my fatigue, I also learned that is my experience and ability, not simply the number of hours I am in the office, that is valuable to my employer.

But it does not make me a less valuable employee.

I 'came out of the MS closet' at ANZ Bank in 2015. It was confronting, as I didn't know the response I would get. But MS is a part of who I am. I am pleased to say ANZ – both management and colleagues – have been enormously supportive.

ANZ Bank demands quality performance. But the organisation understands that high performance doesn't just mean being in the office for the most hours. The bank allows me flexible working hours, giving me the freedom to fulfil my role when I am best able. This means ANZ gets the best out of me.

The confidence and self-worth that comes with employment – particularly employment in line with carer aspirations – is valuable. Keeping people with MS employed is a goal we as a society – including the government and the NDIS – can and should facilitate."

Mike became a National Advocate for MS Australia in March 2015. Read his full story at http://wedonttalkabout.com/latest/juggling-ms-family-and-work-priorities-and-possibilities.

7.

MSA seeks: Specific improvements to early intervention (following a diagnosis of MS) processes.

This includes:

1. A consistent (evidence-based and repeatable) approach by the NDIS to the identification of those people with MS best placed to receive early intervention support funding by the NDIS.
2. The identification of mechanisms that will assist individuals and NDIA planners to recognise the common, often silent and invisible, symptoms that can manifest in significant functional impairment: providing the right services at the right time to minimise the impact of MS.

Why is this necessary?

Early intervention is the process of providing specialist intervention and support services for a person who needs them, as soon as possible after diagnosis, and/or early in the development of an issue or problem as the disease progresses.

Relevant interventions that consider the individual's personal and social context in relation to their functional impairment are required at each disease transition point across the lifelong journey with MS. The level of functionality of the individual can change depending on the impact and interplay of symptoms. Some of these are set out in the table below. People can often experience significant fluctuation and exacerbation of their symptoms within short time periods, so they can experience more challenges on one day compared to another, or even fluctuations within a day.

Understanding these issues and the benefit of timely implementation of the right intervention is likely to allow for enhanced quality of life outcomes, including maintaining economic and social independence for as long as possible.

Examples of interventions:

- Assessment by an experienced neurological-physiotherapist to identify impairments of strength, balance and reduced sensation, as well as making recommendations for individualised exercise programs, prescription of walking aids and management of pain.
- Assessment by an experienced Occupational Therapist to identify goals and develop individualised strategies to maximise independence and achieve desired outcomes.
- Assessment by a Specialist Employment Support Service to address work needs/aides to maximise the opportunity to remain in work. These can include the planning and management of work, home and community tasks and activities, initiating and attending appointments, engaging socially to remain connected to family and friends, and being able to contribute positively and meaningfully in social valued roles.

What will this do?

The inclusion of timely coordination of care and advocacy (early-on in diagnosis) is imperative for people with MS to ensure the provision of information, linkages and referrals, community awareness and individual capacity building.

There is significant cost to the individual over a lifetime and evidence to support the need to establish a stronger evidence base for timely and targeted funded support, as early as possible after an MS diagnosis.

CASE STUDIES 7.

Why does early intervention matter?

The person	The situation	The intervention	The outcome
34 year old female, married with 3 children, has relapsing remitting MS but also recently diagnosed with anxiety and depression. Her primary role is caring for the family and maintaining the home.	Husband works 60 hours a week in order to meet the family's financial commitments. Since her MS has progressed, the client no longer has the energy to keep up with the chores beyond daily meal preparation and dishwashing. This has significantly impacted on her health and is a large contributor to her recent mental illness diagnosis. Client was feeling 'useless' and 'a burden' to her husband who had no time to help with the extra chores.	Client not deemed 'disabled enough' to be eligible for HACC or state Disability Services. MS Society provided client with counselling and ongoing assistance with cleaning. Client also referred to MS Society physio for advice on managing fatigue.	This has provided client and her husband valuable time to spend together with their family. In client's words, *"The support is fantastic! The change it has made to my family is enormous. I now even have the energy to get to my physio appointments so I can learn new ways of managing my fatigue. With my extra energy, the kids think they have a new mum!"*
J is a male in his 40's with MS and is passionate about his work in customer service in a busy call centre.	J's employment is important to his social, emotional and financial wellbeing. J is valued member of the team however muscle fatigue was impacting his productivity, mobility and safety in moving around the office (falls risk).	Implementation of a software program that limited the number of clicks when J was using his computer. Assessed for a scooter.	J maintained his employment. Work place affirmed J as an important member of the team. Moved around the office safely, reduced falls risk and managed fatigue.

8. **MSA seeks:** A blanket prevention of young people entering residential care.

1. No new admissions of young people into residential care.
2. A commitment to the provision of funding to support a program to implement integrated care pathways.
3. Leadership from the Australian Government to seek a commitment by all State Government disability systems to deliver their full suite of general and specialist disability services to young people who remain in aged care settings while they wait for the NDIS to reach them.

Why is this necessary?

Young people affected by MS in, or at risk of placement in, residential aged care should be supported to live in the community in their own homes with the supports they require.

There are well over 6,500 young Australians in residential aged care in Australia and according to a Monash University/Summer Foundation white paper from 2011, 13% of young people in nursing homes have MS[7]. These 6500 young Australians with disability presently occupy around 5% of residential aged care beds because our existing disability service system cannot provide the supports and services they need.

As the Young People in Nursing Homes Alliance stated, ‘these young people with MS require service responses not just from the disability services sector, but from multiple sectors including health, housing and sometimes aged care amongst others. Arriving at the door of the disability system in crisis, these young Australians require immediate and often intense responses that the service system, in its current form, cannot deliver in a timely or effective manner. Aged care providers indicate that the majority of younger residents in aged care are categorised as high dependency and enter residential aged care on discharge from hospital. Having an able bodied life before the acquisition of a [chronic] illness means our members have different expectations concerning service responses to those living with a congenital disability. They expect to access the rehabilitation needed to restore health and independence; and to live in the community as other able bodied young people do’[8].

What will this do?

In particular, young people with MS need an integrated housing and support model that is tailored to their needs and offers access to support and health services while keeping them connected in the community.

Residential care should only be an option of absolutely last resort and if accessed, must be a temporary measure only until a return to the community can occur.

The NDIS promises to offer individual support packages to people who live in residential care and support to live in the community, but there is a critical shortage of places.

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[7] Winkler et al, 2011, Young people in nursing homes: White paper, Melbourne, VIC: Summers Foundation Ltd & Monash University.

[8] Young People in Nursing Homes Alliance website http://www.ypinh.org.au/about/our-members.

SAMMY is 26 and was diagnosed with primary progressive MS three years ago.

CASE STUDY 8.

Why is residential care wrong for me?

"When I was diagnosed with primary progressive MS at aged 23, I was overcome by a lot of fear and anxiety. My biggest fear was that I would become reliant on other people to help me live my life. One of the biggest challenges for all young people, whether they have a chronic illness or not, is establishing an individual sense of identity. This challenge increases when coupled with the struggle of adapting to a new way of life, as well as battling the emotions that surround the illness.

It took some time to realise that I can have an illness and still be independent. I have tried various treatment programs and created a blog where I release my anxieties. Several aspects of my life are more difficult now but through the love and support of my family, I have been able to work out new strategies to adjust life activities accordingly.

I understand that not everybody with MS has access to a support network but it is our responsibility to ensure that MS doesn't mean resignation. Residential care is quite dangerous in this regard. When you are constantly in situations where others need to take care of you, it drives home this message that you lose your independence upon diagnosis. Of course the assistance of others is a real need for many with the condition but programs that encourage independence are more effective. Practically, this makes more sense as there are many with MS that can contribute to society in a variety of meaningful ways. By placing young people in residential care, we are giving up on them and wasting a valuable resource. We are also losing funds that could be applied to more long-term projects that encourage an independent lifestyle.

I spent a lot of time being depressed by my diagnosis but I never gave up on myself. I am a person of value that has a lot to offer this world. This is true of so many of us. Yes we have challenges but these are opportunities to reshape our lifestyle and should never be seen as defeats. MS is not a death sentence but rather a life sentence - a reminder that we are alive and should not waste that opportunity. As I continue my journey through life, I have every confidence that I can overcome any challenges. This is growing every day and I hope that all members of the community share that confidence."

9.

MSA seeks: The introduction of a single and national medical energy concession for people with MS.

1. A single national medical energy concession utilising a percentage of the energy bill rather than a daily rate.
2. The introduction of schemes to ensure people with MS have access to a range of options to make their homes more energy efficient.

Why is this necessary?

Living with MS means high energy use, primarily because 90% of people with MS are heat intolerant and run their air conditioners 15 times more than average households.

This high energy use results in significant economic and environmental costs.

Each state provides vital assistance through energy concessions for people with a medical need to keep cool, though these concessions vary considerably.

Most are capped and based on a set daily rate; only in Victoria are concessions calculated as a percentage of the bill.

What will this do?

A single national medical energy concession for people with MS will:

- Alleviate financial hardship
- Dramatically improve symptom management, quality of life, health and wellbeing
- Reduce the stress associated with simultaneously coping with financial and health stresses.

Additionally, more needs to be done to make the homes of people with MS more thermally efficient and to help households develop more energy efficient habits.

Currently in Australia with the introduction of full retail contestability and price deregulation, energy retailers now compete for customers more than ever by offering a range of contracts to meet the different needs of consumers.

The range of available concessions and contract options is confusing and in most cases, demand management strategies are irrelevant for people with MS; they are constant high energy users.

CASE STUDY 9.

EMILY, married, 55, lives with husband in Home Hill, Queensland (100 km south of Townsville). Emily has no solar power, but has an air conditioning system consisting of three units covering her bedroom, lounge, and kitchen/dining area, which was purchased some time ago.

Why do I need access to a national energy concession?

Emily recently called MS Queensland looking for some advice around getting financial relief for the air conditioning in her house as she wasn't eligible for any of the concessions.

She says: *"I hadn't ever contacted MS Queensland before as I have just been getting on with life but with the soaring summer temperatures I was really concerned about my energy bills. My husband works full time so I am not eligible for any (Queensland government) concession. I need to have the air conditioning on all night in the summer because otherwise my MS symptoms increase ten-fold. I feel too fatigued to get out of bed and often feel like I'm going to faint in the heat. It would be so helpful to get some assistance in this area as it would enable me to keep living in my own home.*

We can't afford to buy solar, yet my friends with solar have said, 'we use our solar 24/7 because it's costing us nothing, so we may as well use it' and it just doesn't seem fair.

I wish I had the ability to pay a weekly deposit so it wasn't always such a huge bill. I always have to be mindful of other expenses that come up at the same time such as chemist and doctor bills.

I try to keep fit and so I go to the local pool and just lie in the water, although in these summer temperatures I don't go to the pool as it is like an oven outside and even getting to the car it is like an oven and negates any of the positive activity that I have undertaken."

10.

MSA seeks: The full implementation of Australia's Liveable Housing Design Guidelines by 2020.

1. The Australian Government supporting and appropriately resourcing the ongoing implementation of Australia's Liveable Housing Design Guidelines.
2. The Australian Government and all state governments supporting the inclusion in the (National Construction Code Series) Building Code of Australia (BCA) of minimum access requirements for all new and modified housing.

Why is this necessary?

Current housing designs do not work for many families; families with young children, older people, people with temporary or permanent injury or chronic illness such as MS.

The implementation of these access requirements would ensure viable accommodation options for everyone, regardless of age, family needs, disability and disease and resulting disability progression.

Existing building regulations do not require minimum access or universal design features, despite the low cost of including these features during construction as against the much larger cost of retrofitting.

Liveable Housing Australia (LVH) is a partnership between community and consumer groups, government and industry. This partnership champions the mainstream adoption of liveable design principles in all new homes built in Australia.

What will this do?

Minimum access requirements and adaptability standards are defined by the Australian Network for Universal Housing Design, equal to the 'silver level' of the Liveable Housing Design Guidelines, that sets standards for parking spaces, doorway widths, adequate space in toilets, bathrooms and kitchens, and reinforced walls to allow for the installation of grab-rails.

The application of these standards would benefit all people with access needs, including older Australians, people with temporary impairments and people with disability.

Regulation is required to ensure an equitable system and to allow incentives to be applied for early adopters. Bonus incentives could apply as higher standards (gold and platinum levels) are implemented.

MS Australia supports the collaborative proposal of *The Australian Network for Universal Housing Design* and *Rights and Inclusion Australia* proposal to review the Australian Standard AS 4299 Adaptable housing (1995) to align with the 2010-2020 National Disability Strategy regarding liveable housing design.

This review will hopefully align the Standard with current government policy, advance the commitment in the Strategy to an agreed 'universal design standard' in all new housing by 2020, eliminate any confusion over current guidelines and reduce overall cost to the community.

About MS

Multiple Sclerosis is a chronic disease that attacks the central nervous system. There is overwhelming evidence that MS is primarily caused by an autoimmune process where the body attacks its own myelin, a fatty sheath that covers our spinal tissues and nerves, although the exact mechanism remains unclear. There is no known cause or cure.

The physical impact of MS varies as no two cases of MS are identical. The visible and hidden symptoms of MS are unpredictable and vary from person to person and from time to time in the same person. Common symptoms include:

- Extreme tiredness
- Visual disturbance, such as blurred or double vision
- Difficulties with walking, balance and coordination
- Altered muscle tone, such as muscle weakness, tremor, stiffness or spasms
- Dizziness and vertigo
- Altered sensation, such as tingling, numbness, and pins and needles
- Extreme sensitivity to temperature, usually heat
- Pain
- Bladder and bowel changes
- Emotional and mood changes
- Sexual changes
- Changes in memory, concentration and reasoning
- Slurring or slowing of speech.

The economic and personal cost of MS cannot be overestimated:

- MS is estimated to cost Australia over $1 billion per year
- Loss of productivity $494 million per year
- Australians with MS spend $78 million per year in out of pocket health care expenses
- The informal care provided by family and others to Australians with MS would cost $145M per year to replace.

Impact on employment

- 50-80% of people with MS cease to work full-time within 10 years of diagnosis
- Of the 20,400 people with MS aged 15-64, an estimated 9,800 were employed, with 5,900 being part-time
- People with MS have a 30% higher representation in part-time employment compared to the average Australian and a lower annual income
- People with MS are less likely to be in paid employment compared to those with other chronic diseases.

About MS Australia

MS Australia (MSA) is the national peak body for people living with MS in Australia. Our role is to work on behalf of all state and territory based member organisations to provide a voice for people living with multiple sclerosis across the country to support the development of:

- Research
- Advocacy and awareness
- Communication and information
- Services provided by our member organisations
- International collaboration.

MSA advocates across all stakeholders, governments and communities, on behalf of our members, to represent people who are diagnosed with the disease, their carers and the broader MS community.

MSA works closely with partner organisation, MS Research Australia – the largest not-for-profit funder and coordinator of MS research in Australia.

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