

MULTIPLE SCLEROSIS AUSTRALIA

Submission to the Senate Community Affairs References Committee inquiry into the provision of general practitioner and related primary health services to outer metropolitan, rural, and regional Australians

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Introduction

MS Australia (MSA) is pleased to provide a submission to the Senate Community Affairs References Committee inquiry into the provision of general practitioner and related primary health services to outer metropolitan, rural, and regional Australians.

The focus of the comments provided in this submission are on key areas that will impact on people affected by multiple sclerosis (MS) and other neurological conditions for which our state organisations provide services and support. Include are comments provided by representatives of our state organisations and, in some instances, directly from people living with MS. MS Australia's role is to work on behalf of our state and territory-based member organisations to provide a voice for people living with MS across the country.

MS Australia's member organisations are:

- MSWA (providing services and support in Western Australia)
- MS SA/NT (providing services and support in South Australia and the Northern Territory)
- MS QLD (providing services and support in Queensland)
- MSL (Multiple Sclerosis Limited providing services and support in Victoria, NSW, ACT and Tasmania)

Each of these state-based organisations operates independently to provide a range of services and advice to people living with MS regardless of age, and, in some cases, to a broader group of people with other progressive neurological diseases. These services vary from state to state and include: phone information support and advice, on-line resources, MS clinics, specialist MS nursing, physiotherapy, allied health services, education and information workshops, seminars and webinars, psychology, financial support, supported accommodation, residential and in home respite, peer support co-ordination and employment services.

Summary of recommendations

Recommendation 1:

MS Australia recommends providing incentives and requirements for GPs and other primary health care practitioners practicing in rural and remote locations in Australia to participate in education programs that assist in the higher index of suspicion and identification of MS.

Recommendation 2:

MS Australia recommends greater access to, reduced waiting times and improved rebates for, MRIs for people living in rural and remote locations in Australia.

Recommendation 3:

MS Australia recommends that prompt referral pathways by GPs to specialist MS neurologists and their multi-disciplinary teams for those suspected of having MS or a similar condition should be encouraged as best practice.

Recommendation 4:

MS Australia recommends the development of disease specific integrated care pathways and models of care through co-design principles.

Recommendation 5:

MS Australia recommends strengthening the role of the specialist MS nursing workforce in rural and remote Australia.

Recommendation 6:

MS Australia recommends that patients and patient advocacy groups be included in the development of training and professional development material for GPs and primary health care providers as part of a continuous improvement approach.

Recommendation 7:

MS Australia recommends that the Government reconsider the impact of the Medicare rebate freeze and the number and value of the indexation of items on the Medicare Benefits Schedule on the ability of GPs to provide free or very-low-cost healthcare to people with chronic conditions.

Terms of Reference

The provision of general practitioner (GP) and related primary health services to outer metropolitan, rural, and regional Australians, with particular reference to:

- a. the current state of outer metropolitan, rural, and regional GPs and related services;
- b. current state and former Government reforms to outer metropolitan, rural and regional GP services and their impact on GPs, including policies such as:
 - i. the stronger Rural Health Strategy,
 - ii. Distribution Priority Area and the Modified Monash Model (MMM) geographical classification system,
 - iii. GP training reforms, and
 - iv. Medicare rebate freeze;
- c. the impact of the COVID-19 pandemic on doctor shortages in outer metropolitan, rural, and regional Australia; and
- d. any other related matters impacting outer metropolitan, rural, and regional access to quality health services.

In this submission, each of the terms of reference have been addressed in the context of the impact on people affected by multiple sclerosis (MS) and other neurological conditions

a. The current state of outer metropolitan, rural, and regional GPs and related services

About MS

Multiple Sclerosis (MS) is an immune-mediated, chronic inflammatory disease that attacks the central nervous system (the brain, spinal cord and optic nerves). The 'multiple sclerosis' or 'many scars' ¹are the result of an auto-immune response where the immune system, almost at random, attacks the fatty layer around nerves in the brain, optic nerve and spinal cord, resulting in a variety of disabling neurological symptoms². MS damage the whole brain from disease onset. Every system in the Central Nervous System or CNS (myelin, white matter, neurones, axons and blood vessels) can experience damage and loss as a result of MS³. MS is further characterised by focal or diffuse inflammation, demyelination, axonal loss and neurodegeneration⁴ and progressive brain atrophy.

Where these attacks occur within the CNS corresponds with the potential impacts or symptoms experienced i.e. if an attack occurs in the optic nerve a person can wake up with double vision or diplopia; attacks in the spinal cord might result in weakness and numbness in their limbs; the cerebellum - loss of balance⁵. MS is therefore a very individual diseases as the effects of the attacks are unique. Similarly, the progress, severity and specific symptoms of MS cannot be predicted. Many of the symptoms of MS are invisible but can have profound impacts on a person's day to day ability to function and tackle everyday roles and responsibilities.

Demographics and disease course

MS, like other autoimmune type diseases, is more common in females. Roughly three quarters of all people with MS are women. The disease usually manifests clinical symptoms during young adulthood, mostly between the ages 20-40 years. In fact, in young adults, MS is the most common acquired disease of the central nervous system and the leading cause of disability in young adults.

There are over 25,600 people living with multiple sclerosis (MS) in Australia. Most people are diagnosed with MS between the ages of 20-40, but it can affect younger and older people too. Often a diagnosis of MS occurs when people are fully employed, planning a family and making significant career choices.

There are three courses MS can take. Around 15% of the MS population is diagnosed with a progressive form of MS with no periods of remission, termed Primary Progressive MS (PPMS). How fast the disease progress may vary, but the declining neurological progression is constant. Relapsing-remitting MS (RRMS), the most common form of MS, is characterised by partial or total recovery after attacks (also called exacerbations,

1 Institute of Medicine (US) Committee on Multiple Sclerosis: Current Status and Strategies for the Future; Joy JE, Johnston RB Jr., editors. Multiple Sclerosis: Current Status and Strategies for the Future. Washington (DC): National Academies Press (US); 2001. 2, Clinical and Biological Features. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK222386/>

² Høglund, R. A., & Maghazachi, A. A. (2014). Multiple sclerosis and the role of immune cells. *World journal of experimental medicine*, 4(3), 27–37. <https://doi.org/10.5493/wjem.v4.i3.27>

³ Cerqueira JJ, Compston DAS, Gherdes R, et al Time matters in multiple sclerosis: can early treatment and long-term follow-up ensure everyone benefits from the latest advances in multiple sclerosis? *Journal of Neurology, Neurosurgery & Psychiatry* 2018;89:844-850.

⁴ Andravizou, A., Dardiotis, E., Artemiadis, A. et al. Brain atrophy in multiple sclerosis: mechanisms, clinical relevance and treatment options. *Autoimmun Highlights* 10, 7 (2019). <https://doi.org/10.1186/s13317-019-0117-5>

⁵ Institute of Medicine (US) Committee on Multiple Sclerosis: Current Status and Strategies for the Future; Joy JE, Johnston RB Jr., editors. Multiple Sclerosis: Current Status and Strategies for the Future. Washington (DC): National Academies Press (US); 2001. 2, Clinical and Biological Features. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK222386/>

relapses, or flares). 70 to 75% of people affected by MS initially begin with a relapsing-remitting course. Secondary progressive MS (SPMS) is a relapsing-remitting course which later becomes steadily progressive. Attacks and partial recoveries may continue to occur. Of the 70-75% who start with relapsing-remitting disease, more than 50% will develop SPMS within 10 years; 90% within 25 years. A further differentiation is made by categorising disease activity as active (with or without worsening) or stable.

Early diagnosis is crucial

Significant damage can be done to the CNS before symptoms appear or a patient notices changes or that their condition is getting worse. Early diagnosis of MS is crucial to avoid more longer-term brain and nerve damage⁶. There is a significant correlation between brain atrophy and Expanded Disability Status Scale (EDSS) and therefore disability acquisition⁷.

The role of the GP

Doctors working in rural/remote locations are required to be generalists in lieu of access to other health care providers and specialists. The journey of each person with their own experience of MS invariably starts within the health sector. After initially experiencing symptoms, GPs are often the first port of call.

Screening for chronic health conditions sits at the crossroad between prevention and early intervention⁸. Knowledge of, and therefore the identification of, early symptoms of MS is crucial to achieve optimal patient outcomes. After early detection and screening, early diagnosis through a referral to a specialist neurologist is key to achieve optimal health outcomes in MS⁹. Generally, the earlier a chronic condition such as MS can be identified, the earlier the patient can receive personalised treatment and the earlier the disease can be managed. Ultimately such a preventative and early identification approach will improve the health outcomes for the person living with MS. Anecdotal evidence however suggests that MS symptoms are still not being detected early by GPs and other related primary health care services.

'We must empower and enable general practitioners to improve early diagnosis of conditions and better manage chronic conditions'¹⁰

Getting diagnosed - the experiences of people with MS

⁶ See <https://www.msbrainhealth.org/>

⁷ Ge Y, Grossman RI, Udupa JK, Wei L, Mannon LJ, Polansky M, Kolson DL. Brain atrophy in relapsing-remitting multiple sclerosis and secondary progressive multiple sclerosis: longitudinal quantitative analysis. *Radiology*. 2000;214:665–670. <http://dx.doi.org/10.1148/radiology.214.3.r00mr30665>

⁸ Canberra Health Summit, National Preventive health Strategy, 2019

⁹ Brain health: time matters in multiple sclerosis (2016), Crossref DOI link: <https://doi.org/10.1016/J.MSARD.2016.07.003> Published: 2016-09

¹⁰ Canberra Health Summit, National Preventative Health Strategy, 2019

The following comments regarding diagnosis were received by MS Australia via social media channels:

'Yes, kept going to GP for different symptoms, she told me off for putting them together & making something out of nothing. Then I had a double vision, dropped face, vertigo and a multitude of other issues at the same time, but nope still not diagnosed was told it was an ear infection, wasn't until 6 weeks later saw another GP who stated I was getting worse so sent me off for an MRI. Hmf and my usual GP was wondering why I was happy I had been diagnosed, wasn't happy I have MS but happy to find out I wasn't losing my mind!'

'3 pregnancies and 12 years after symptoms, I was treated for stress, postnatal, hysteria was mentioned probably true, depression too. I was told repeatedly I was really overworked and just too tired also probably true with 3 little ones..... However it took me having a total breakdown for anyone to take me seriously I eventually almost yelled at the DR saying if he or anyone else wanted to tell me how hard it is to be a mum and I'm JUST stressed and depressed, I might explode. Eventually Diagnosed with a spinal disease (AS) 14 months later MS and since then a connective tissue disease regular osteo arthritis. It was so crazy how hard. Soldiering on was a mistake I fully regret.'

"Everyday I wake up and think oh maybe this is just a dream, I am going to be better and feel better. No. Why was I ignored and learn to ignore myself, my symptoms?

Told "its ok it will go away"

"Do this, take this it will go away".

*"But I can't feel down here" *another laugh and a head shake* "just do exercises You will get better".*

*I Wake up *I can't feel my legs. There must be something wrong with me maybe I am mentally ill? *I question my every thought, *I can't trust myself, * my body is saying there is something wrong, the Doctors say there is not. It must be all in my head there must be something wrong with my head. It will be fine I will wake up tomorrow and it will be all ok, it's all in my head.*

**I need to wash my hair ... but the effort to dry it .. I am so stupid its all in your head don't be lazy and wash your bloody hair. Ok, boots on uniform on belt on off to work*

**be careful today*

**be guarded we need the money "it's all in your head".*

Being thrown around the truck oh the pain, focus keep your head up look out for risks.

Load the trolley deliver the money climb the stairs up the stairs down the stairs, open the safe lock the safe, whats her name?

30 jobs today oh well we will get through it.

The pain the no pain its all in my head. I can move but I can't feel the pain its all in my head.

Mabey I will feel pain again today.Woke up cant feel.

It's not a dream. Its real. It's not in my head."

Anecdotally, MS Australia has heard many accounts of people living with MS stating that they felt as if they were initially being 'fobbed off' and not heard.

'My gp was saying stress, after 2wks I said there is no way this is stress, the pain is erratic yet predictable plus I could barely function, I said there is no way this is stress and I went and paid for my own mri at \$400 then 2 months of mucking around I finally got diagnosed at a ms clinic'

" My Doctor told me the numbing sensation that I felt in my toes was due to me wearing shoes too small as a child! I knew this to be totally untrue and my grandmother always bought new shoes for the grand children.. Until I went to her 6-7 years later telling her I was walking on what felt like someone had poured dry uncooked rice in my shoes and I was walking on it.. Suddenly she took notice"

"I was first told by my GP that he thought I was having a stroke because the left side of my body and face was numb. Wanted to call an ambulance but I told him I'd make my own way there. When I got there, I was told by the doctor that I had a migraine (I didn't even have a headache!). The next day I couldn't walk. Was sent to a different hospital where I was admitted and they did further testing. Was diagnosed on Mother's Day in 2010 after a week and a half in hospital"

"At 40 I was told just to get used to it. It's part of getting old."

"Got told my numb feet was from poor circulation because i was a smoker"

'A GP told me to go home and do exercises when I told him I was numb and couldn't fell from my waist down and couldn't feel myself going to the toilet.'

"I saw my GP 3 times over a week. He said it could be stress, The 3rd time I saw him, he said I should take myself to emergency (living in Darwin at the time) if symptoms continued. And so I did...I was fortunately diagnosed within a month or two.'

'4 years+ until I finally got diagnosed. It pretty much came across as though they thought I was a hypochondriac...'

'Yes! When I was 20 I had bladder retention and had to be put in hospital. I was told I had an episode of "Female Hysteria". I had several symptoms including numbness, eye problems, depression and severe fatigue. I had an attack of Optic Neuritis in my 40's then finally dx at 52 after another attack of Optic Neuritis. All along this nightmare I was treated like a hypochondriac 🙄 63 now and secondary progressive stage.'

'One GP said I had 'Migraine Aura' when I had double vision! 😬'

'My doctor told me "sometimes when we are anxious we can imagine these things". I had pins and needles that started in both feet and spread all the way up to the perineum. That made me anxious!!'

'Depression and a never ending parade of viruses. I ended up in a psych ward after starting to cut my arms because I was so frustrated with coming across as a half witted, hypochondriacal attention seeker. I was actually relieved to finally gain a diagnosis. It gave me back my dignity.'

'I went to the GP with what felt like trouble trying to swallow. Was told it was all in my head (partially correct). Wasn't till later on that I went to new GP with ear pain and left side of face went numb that I was sent for MRI.'

'My gp told me it was a weight problem that was causing my double vision go figure. So I took it on my self to go too optom who diagnosed my MS'

Comments from social media channels

"Oh yes always...not to mention "it's all in your head"

well that actually turned out to be right 😞'

'Patients expect and deserve more from their health teams than a six-minute appointment block; there should be mechanisms to incentivise, empower and enable healthcare providers to screen at-risk patients, where appropriate, for chronic conditions to assist in the early identification of chronic diseases. This may require greater education and support to GPs, specialists, pharmacists and other healthcare providers. There is a clear need to address and improve standards of care through increased and improved education of all healthcare professionals, from GPs, to specialists and pharmacists.'¹¹

Recommendation 1:

MS Australia recommends providing incentives and requirements for GPs and other primary health care practitioners practicing in rural and remote locations in Australia to participate in education programs that assist in the higher index of suspicion and identification of MS.

The importance of MRIs in diagnosing MS

As with most CNS inflammatory demyelinating disease, magnetic resonance imaging (MRI) is included in its diagnostic criteria. The McDonald diagnostic criteria (2017) for MS are based on the number, size and location of brain and spinal cord lesions. Neuroimaging goes beyond providing an accurate diagnosis. It also assists with disease management, including the identification of active or non-active disease, the disease type (i.e. relapsing or progressive), assist in disease monitoring activities and aid research efforts that are being undertaken in this disease¹². Studies in MRI, which have improved the diagnosis of MS significantly, have demonstrated that for every single lesion that causes symptoms, it is preceded by 80-90% clinically silent scars or lesions with no corresponding symptoms¹³. Significant damage can thus occur without initial detection.

I was told I was fat and lazy or I was just depressed and making it up in my own head since I was 16 I got diagnosed on the 1st of March this year I'm 28 on Saturday they say i have scarring from when I was 16!

Unfortunately yes. 2 GP's told me stress. My first symptom was Lhermitte's sign, which the GP shrugged off as stress. When my sight eventually went double I was sent for a CT scan, but it showed nothing so their original stress diagnosis must be correct. When my side went numb I went for a second opinion but that GP tried discouraging me from getting an MRI by telling me how expensive it was. I pushed for it and results of that said either mini strokes or MS. After all that run-around, the neuro I was subsequently sent to wasn't convinced of the MRI results because he didn't like the place that did the scans. "I'm having a mini stroke just

¹¹ Canberra Health Summit, National Preventative Health Strategy, 2019

¹² MAGNIMS consensus guidelines on the use of MRI in multiple sclerosis—establishing disease prognosis and monitoring patients. *Nat Rev Neurol* 11, 597–606 (2015). <https://doi.org/10.1038/nrneurol.2015.157> and Tillema JM, Pirko I. Neuroradiological evaluation of demyelinating disease. *Ther Adv Neurol Disord*. 2013 Jul;6(4):249-68. doi: 10.1177/1756285613478870. PMID: 23858328; PMCID: PMC3707351.

¹³ Institute of Medicine (US) Committee on Multiple Sclerosis: Current Status and Strategies for the Future; Joy JE, Johnston RB Jr., editors. *Multiple Sclerosis: Current Status and Strategies for the Future*. Washington (DC): National Academies Press (US); 2001. 2, Clinical and Biological Features. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK222386/>

reading this!" he joked sarcastically. Went for a 2nd MRI which confirmed MS. Nobody's laughing now 😏"

Comments from social media channels

MRIs have also assisted in what we now call personalised medicine or the determination of the efficacy of treatments for each individual, allowing neurologists specialising in MS to measure the effectiveness of treatments, seeking no evidence of disease activity (NEDA), rather than relying on symptoms. MS, in its most common form, relapsing remitting MS, waxes and wanes. A patient will therefore have intermittent periods of activity and then recovery, not necessarily linked to treatment. Specialist interpretation of such MRIs can objectively measure these clinical episodes¹⁴.

It is therefore important that people suspected of having MS can access MRI scans in a timely fashion, regardless of where they live, without having to be concerned about the cost of the scan, or how the cost will be covered.

Recommendation 2:

MS Australia recommends greater access to, reduced waiting times and improved rebates for, MRIs for people living in rural and remote locations in Australia.

Disease modifying treatments for MS

Disease modifying treatments for MS¹⁵ have been available for around 25 years. There are no medications to cure MS, rather they are used to modify the course of the disease. 64%-79% of people with MS in Australia are using a disease modifying therapy (drug treatments designed to reduce the number and severity of relapses and slow or halt the progression of their MS).

Initial treatments were modestly effective but advances in immunology have since provided specialist MS neurologists with powerful tools to better understand the underlying causes of MS and has led to new therapeutic advances that increased in efficacy. Treatments are now strong enough to induce genuine and protracted remission; not for everyone, but for a large proportion of people living with MS.

Therapeutic targets can modify the immune system prospectively. Induction therapy can also attempt to destroy immune cells causing the autoimmune response. These more potent medications do however come with adverse reactions and side effects that must be actively managed within a specialist MS health care team. There is a potential for infections, other autoimmune sequelae, therefore making the prescribing and management of MS medications a specialist function.

The longer that access to diagnosis and effective treatment is delayed, the more damage and potential chronicity of lesions may occur. Rather than a singular acute lesion, it is noted that lesions can become smouldering and ingrained. Treatment goals are therefore not only to attempt to stop inflammation and prevent disability acquisition, but to stop the progression of this pathological problem. MS treatments are really very specific.

¹⁴ <https://www.msaustralia.org.au/living-with-ms/expert-blog/story-behind-mri-process-multiple-sclerosis>

¹⁵ See <https://www.msaustralia.org.au/about-ms/medications-and-treatments>

Importance of referral to a specialist MS neurologist

At times, GPs do not immediately and proactively refer patients to specialist neurologists for a neurological assessment and early diagnosis. Generalist neurologists do not always have the current knowledge of advances in MS treatments or system support to assess, prescribe, monitor and complete the necessary and important safety and screening protocols for the various MS treatments available. It is important to refer people suspected of having MS to a neurologist specialising in MS, or to a MS or Neuroimmunology Clinic for appropriate personalised and early diagnosis and treatment.

Brain Health: Time Matters in MS

A global initiative based on the internationally endorsed report, *Brain health: time matters in multiple sclerosis*¹⁶, recommend expert consensus standards¹⁷ on brain health and MS and has produced a benchmark for clinical standards that could facilitate local change¹⁸ (as set out in Attachment 1).

These standards for timely MS care were developed by a panel of global MS specialist neurologists and define 'core', 'achievable' and 'aspirational' time frames reflecting minimum, good and high care standards, respectively. A multidisciplinary Reviewing Group (MS nurses, people with MS, allied healthcare professionals) also provided insights to ensure the recommendations reflected perspectives from multiple stakeholders. These quality standards for care provide MS teams with a three-level framework for service evaluation, benchmarking and improvement. If implemented, they could revolutionise the care of people with MS. GPs play a vital role in achieving these standards in the initial referral and diagnosis phase.

A concise guide for GPs¹⁹ has also been produced to assist GPs and primary care providers to put these standards into practice (see Attachment 2).

Recommendation 3:

MS Australia recommends that prompt referral pathways by GPs to specialist MS neurologists and their multi-disciplinary teams for those suspected of having MS or a similar condition should be encouraged as best practice.

These international consensus guidelines note that once MS is diagnosed and a treatment option or care plan has been established with their prescribing specialist MS Neurologist, it would be ideal if GPs collaborated with the patient's MS team in providing treatments and ongoing support for symptom management. As previously stated, symptoms can range from depression and anxiety, cognitive impairment or cognitive fatigue, pain, bladder and bowel problems to sleep disorders and other motor impairments. Often, symptomatic treatments (medicines) and the management of MS requires a specialist multiple disciplinary response.

¹⁶ See <https://www.msbrainhealth.org/recommendations/brain-health-report/>

¹⁷ See <https://www.msbrainhealth.org/healthcare-professionals/ms-brain-health-consensus-standards/>

¹⁸ See <https://www.msbrainhealth.org/healthcare-professionals/a-tool-to-benchmark-clinical-standards-and-facilitate-local-change/> and <https://www.msbrainhealth.org/healthcare-professionals/brain-health-time-matters-in-multiple-sclerosis-slide-deck-for-hcps/>

¹⁹ <https://www.msbrainhealth.org/healthcare-professionals/brain-health-in-multiple-sclerosis-a-gp-and-pcp-guide/>

GPs and primary care practitioners should also be able to recognise that not every symptom or health condition is MS related. People with MS may be at an increased risk of infections (such as urinary tract infections) and comorbidities such as obesity, hypertension, diabetes and mental health issues such as depression and anxiety. Patients should be encouraged to continue their regular check-ups (in line with other universal health advice) as health promotion, screening and early treatment of these infections and comorbidities ultimately impact on patient outcomes.

The specialist MS team will screen the patient for a number of known risk factors prior to the commencement of disease modifying therapies (DMTs)²⁰. Immunisation should often be updated before DMT commencement. Whilst on DMTs, the GP and other primary care providers should be aware of any signs of rare events or safety events that might be related to DMT usage. This can often present through fevers, altered cognition, personality changes, various herpes responses, meningitis, liver toxicity and other neurological symptoms. Similarly, patients diagnosed with MS have a higher prevalence for secondary autoimmune conditions. DMT side effects should be urgently assessed by the patient's MS team who will be in the position to assess the need for possible acute treatment responses.

Acting quickly to treat relapses

Another potential for healthcare team collaboration is when patients experience a potential relapse or pseudo relapse. Relapses are characterised by a sudden episode of either new symptoms or a worsening of existing symptoms that continues for longer than 24 hours (i.e. not temporary) in the absence of fever or other causes and is separated from a previous attack by at least 30 days²¹. Clinicians can assist in providing the specialist MS team with a medical history and also by eliminating other possible causes. Additionally, patient information such as a symptom diary could be invaluable. A relapse might indicate that a patient is on a treatment that is not suitable or efficacious. It is not advisable to therefore delay seeking expert support or to advise the patient to wait until their next neurological review.

Impact of MS on pregnancy

MS in general does not impact on fertility. Decisions about contraception should be made reflecting on any potential contraindications with symptomatic treatments as they may interfere with each other's effectiveness²². Family planning conversations for patients who are on DMTs should be made in consultation with their prescribing neurologist as most DMTs should be stopped and some may require an accelerated elimination protocol. Pregnancy should be discussed with all women with MS who are of childbearing age or those who would like to consider having a baby. Several peer reviewed publications, including an international study led by Monash University

²⁰ See <https://www.msaustralia.org.au/about-ms/medications-and-treatments>

²¹ Avasarala J. (2017). Redefining Acute Relapses in Multiple Sclerosis: Implications for Phase 3 Clinical Trials and Treatment Algorithms *Innovations in clinical neuroscience*, 14(3-4), 38–40.

²² Houtchens, M. K., Zapata, L. B., Curtis, K. M., & Whiteman, M. K. (2017). Contraception for women with multiple sclerosis: Guidance for healthcare providers. *Multiple sclerosis (Houndmills, Basingstoke, England)*, 23(6), 757–764. <https://doi.org/10.1177/1352458517701314>

researchers²³, have investigated fertility and pregnancy during MS. It is now clear that the neuroprotective hormones produced during pregnancy can protect women during pregnancy. There is however an increased risk of a relapse after pregnancy. Expert consensus guidelines exist in this regard in other countries such as the UK²⁴, but not yet in Australia. The best approach is therefore to work closely with the patient's MS specialist neurologist.

MS can take a lot of control away from patients. GPs and primary health practitioners can give some of that control back to patients by reminding them of the importance of adopting important lifestyle changes²⁵ that directly relate to their experience of wellness and brain health. Some of these modifiable lifestyle behaviours can be tackled little by little whilst others such as smoking cessation might require a more urgent conversation around suitable referral pathways.

- b. Current state and former Government reforms to outer metropolitan, rural and regional GP services and their impact on GPs, including policies such as:**
- i. the stronger Rural Health Strategy,**

MS Australia supports the central notion of the Department of Health's *Stronger Rural Health Strategy*²⁶ and *The National Strategic Framework for Rural and Remote Health*²⁷ shared commitment, across state and federal boundaries, to provide health care planning, programs and service delivery models that is adapted and reflective of community need.

Burden of disease increases with remoteness

Notwithstanding, 28% of all Australians (those living in rural and remote areas) still have differing levels of life expectancy, disease burden and outcomes, risk of injury and access to health services. Even with adjustments for age, the total burden of disease and injury still appears to increase with remoteness. Poorer access to health services persists. Non-hospital non-referred attendances per person (such as a visit to a GP) remain lower per person than those living in inner regional and major cities. And whilst such barriers and inequalities exist - the post code lottery for health outcomes of people living in rural Australia continues. Australians living in rural and remote locations continue to achieve poorer health outcomes due to lower rates of prevention and screening, higher rates of preventable hospitalisations, poorer access to early intervention and lack of coordination and access to treatment and management of especially chronic health conditions²⁸.

²³ See <https://www.eurekalert.org/news-releases/606596> and *JAMA Neurology* titled: Association of Pregnancy with the onset of clinically isolated syndrome. DOI: 10.1001/jamaneurol.2020.3324; and Bonavita S et al. Family Planning Decision Making in People with Multiple Sclerosis *Front. Neurol.*, 28 April 2021 | <https://doi.org/10.3389/fneur.2021.620772>

²⁴ Dobson R, Dassan P, Roberts M, et al UK consensus on pregnancy in multiple sclerosis: 'Association of British Neurologists' guidelines *Practical Neurology* 2019;19:106-114.

²⁵ see <https://www.msaustralia.org.au/about-ms/help-keep-your-brain-healthy>

²⁶ See <https://www1.health.gov.au/internet/main/publishing.nsf/Content/stronger-rural-health-strategy-factsheets>

²⁷ See <https://www1.health.gov.au/internet/main/publishing.nsf/Content/national-strategic-framework-rural-remote-health>

²⁸ See <https://www.aihw.gov.au/reports/australias-health/rural-and-remote-health>

MS Australia acknowledges the premise that planning for rural health delivery must adapt to a greater geographical population density and spread, limitations in existing infrastructure and a significant higher cost of delivery and implementation. Added to that, various factors influence workplace location choices for different allied health professionals²⁹ and retention of GPs remain in remote Australia³⁰.

MS Australia, however, believes that the solution will be found in *more than* supply and demand analysis, additional targeted funding, new incentives schemes and bonding arrangements. The ongoing and unsolved healthcare issues that people in rural Australia face have not been resolved by previous health care strategies, frameworks, planning and resource allocation (and incentives) for rural Australia.

Co-design principles might influence policy, program delivery and research

MS Australia supports the National Rural Health Alliance's 8th Rural & Remote Health Scientific Symposium's ³¹ focus on strengthening the connections between research, practice and communities to improve health outcome for people living in rural and remote Australia. These connections are the backbone of the tremendous advances that have taken place in the management of MS over the past three decades. The principle of '*doing with, not for*' apply. We therefore promote the concept of exploring patients and their families and loved ones' lived experiences and explore how co-design principles might influence policy, program delivery and research.

Innovative solutions could be found by looking at the health crisis in rural Australia differently. Only by walking in the shoes of those living and working in rural Australia, understanding their real struggle in system navigation, exploring the barriers and access issues, can real insights and solutions be found.

Developing articulated and integrated care pathways

As a compliment to existing frameworks and strategies, MS Australia suggests that improved health outcomes could be achieved by developing articulated and integrated care pathways for particular disease groups, such as MS.

Health economic impact studies will provide a further incentive and environmental pressure for such a decision. Neurological conditions such as MS are the leading cause of disability in young people. MS alone is estimated to have a \$1.75 billion price tag for the Australian community (2017). In 2017, the average cost of MS per person was \$68,382 – similar to that of someone with Parkinson's disease or the first year's costs after experiencing a stroke. Triple that of a person with type 2 diabetes. Loss of wages account for 32% of the economic burden of MS. The quality of life of people with MS in

29 Couch A, Menz HB, Coker F, White J, Haines T, Williams C. Factors that influence workplace location choices in the different allied health professions: A systematic review. Aust J Rural Health. 2021 Sep 9. doi: 10.1111/ajr.12768. Epub ahead of print. PMID: 34498324.

30 Jessica Ogden, Scott Preston, Riitta L Partanen, Remo Ostini and Peter Coxeter. Recruiting and retaining general practitioners in rural practice: systematic review and meta-analysis of rural pipeline effects. Med J Aust 2020; 213 (5): 228-236. doi: 10.5694/mja2.50697 Published online: 3 August 2020 and

31 See <https://www.ruralhealth.org.au/8rrhss/>

Australia is 31% less than that of the overall Australian population, and 41% lower for those living with severe disability or progressive MS³².

The existing consultation structures created by the Australian Health Ministers' Advisory Council's (AHMAC) Rural Health Standing Committee (RHSC) and the National Rural Health Alliance, could be utilised to initiate consultation with both patients/ patient groups and their relevant specialised health care teams. The outcome of such consultations could identify and inform innovative and improved primary health care pathways and integrated models of care that might ultimately deliver cost savings but also improved patient experience and outcomes measures.

Having a focus on understanding the individual journey through the eyes of patient and practitioner, articulated health pathways or service models can be developed, similar to what has been done for stroke³³, acquired brain injury³⁴ and other chronic health conditions, but on a national level.

Illuminating any service gaps and opportunities, utilising process mapping (into a series of consecutive steps), gathering data on patient experience and outcomes, understanding treatment requirements for best outcomes, and finding consensus based on best practice and research evidence to articulate stronger, sustainable and strategies and frameworks to inform future expenditure and focused resource allocation. Solutions might include hub and spoke outreach models, technology-enabled care and the more cost-effective use of specialist nursing support. New articulated and integrated care pathways could then be costed and resourced against patient outcomes and evaluated accordingly.

This should be a whole of government approach. Solutions should be found across state and territory boundaries. A national approach will be the only way to implement real change, not being subject to inequalities in postcode or other variables such as funding interpretations.

Recommendation 4:

MS Australia recommends the development of disease specific integrated care pathways and models of care through co-design principles.

The role of the MS Nurse

The use of support nurses for specific conditions, such as an MS nurse, can play a key role in improving identification, treatment and management strategies. Whilst other diseases have received much need funding in expanding this priority, diseases such as multiple sclerosis have been left out.

An effective rural health strategy must include consideration of funding specialist disease nurses, such as MS nurses, to assist primary health practitioners and GPs to provide continuity of care and link them with more metropolitan located MS health centres and specialist neurologists.

32 See https://msra.org.au/wp-content/uploads/2018/08/executive-summary_health-economic-impact-of-ms-in-australia-in-2017-report_ms-research-australia.pdf

33 See National Stroke Foundation. National Action Plan for Stroke. Melbourne, Australia, ISBN 978-0-9872830-3-0, <https://strokefoundation.org.au/> and <https://clinicalexcellence.qld.gov.au/improvement-exchange/bld-path-rehab>

34 See https://www.health.qld.gov.au/__data/assets/pdf_file/0029/652628/statewide-abi-rehab-plan-16-26.pdf

Recommendation 5:

MS Australia recommends strengthening the role of the specialist MS nursing workforce in rural and remote Australia.

b. Current state and former Government reforms to outer metropolitan, rural and regional GP services and their impact on GPs, including policies such as:

ii. Distribution Priority Area and the Modified Monash Model (MMM) geographical classification system

The updated 2019 Modified Monash Model (MMM) geographical classification system, endorsed by the Government established the Distribution Working Group (DWG) to address the maldistribution of medical services across Australia and better target financial incentives to attract and retain medical staff in rural and remote areas. It might be able to improve its effectiveness through evaluation and research with participants working in the respective geographical classification areas and benefit both patients and health care practitioners.

b. Current state and former Government reforms to outer metropolitan, rural and regional GP services and their impact on GPs, including policies such as:

iii. GP training reforms

GPs are a vital part of anyone's MS journey. Constraint difficulties in attracting, recruiting and retaining general practitioners to rural and regional settings has been well documented³⁵ causing continuity issues for workforce planning but also patients in rural and remote Australia. Financial and training incentives, and local initiatives to encourage medical graduates to pursue a career in rural practice has not achieved a more secure rural health workforce³⁶ in Australia, resulting in an ongoing reliance of overseas trained doctors³⁷. From a patient perspective, this is wholly unsatisfactory.

The responsibility for policy direction, funding and delivery of education and training for Australia's health workforce is shared across a broad range of players, creating a complexity and inability to respond to changing needs and circumstances - and advocacy and lobbying for change³⁸. Although a number of training programs exist,

35 Ogden, J et al, Recruiting and retaining general practitioners in rural practice: systematic review and meta-analysis of rural pipeline effects, *Med J Aust* 2020; 213 (5): 228-236. doi: 10.5694/mja2.50697

36 See <https://www1.health.gov.au/internet/publications/publishing.nsf/Content/work-review-australian-government-health-workforce-programs-toc~chapter-4-addressing-health-workforce-shortages-regional-rural-remote-australia~chapter-4-rural-recruitment-retention-strategies>

37 O'Sullivan, B., Russell, D.J., McGrail, M.R. et al. Reviewing reliance on overseas-trained doctors in rural Australia and planning for self-sufficiency: applying 10 years' MABEL evidence. *Hum Resour Health* 17, 8 (2019). <https://doi.org/10.1186/s12960-018-0339-z>

38 See: <https://www1.health.gov.au/internet/publications/publishing.nsf/Content/work-review-australian-government-health-workforce-programs-toc~chapter-3-ensuring-capable-qualified-health-workforce~chapter-3-health-education-training> and <https://www.pc.gov.au/inquiries/completed/health-workforce/report/healthworkforce.pdf>

these do not appear to be structured and largely left to the trainee to navigate and coordinate³⁹.

It has also been found that structured rural training and career pathways is not well covered for allied health professionals⁴⁰.

Individual patients and patient advocacy groups do not seem to have a seat at the table to inform GP and health workforce training priorities.

There appears to be a structural disconnect between health workforce planning, workforce education and training and the patient voice.

GP training cannot exist in a vacuum and should be intrinsically linked with service needs (industrial and health service environment) in rural facilities, but also supplemented by high quality supervision and support⁴¹. The determination of service needs should include a continuous improvement cycle that includes patient experience and feedback.

MS Australia have partnered with Royal Australian College of General Practitioners (RACGP) in the past succeeded in the inclusion of short GP directed publications, focussing on improving GP's understanding of Multiple Sclerosis diagnosis and support. We are also speaking with our partners in the Australian and New Zealand's Association of Neurologist's (ANZAN) MS chapter representatives to update the existing training modules and articles available for GPs on MS.

Australia has no national clinical guidelines or developed health pathways to manage MS. National clinical guidelines can greatly inform GP training and development.

MS Australia would like GP training and professional development models to support GPs and other primary health care practitioners in understanding MS, how to identify and recognise it early and how to recognise their crucial and important role in the diagnosis and management of this disease. MS Australia remains concerned that delay in identification of early symptoms can have a profound impact on health outcomes. Improved structured training and support for GPs can address this concern.

A super-alliance of support groups for patients with chronic disease have recently been formed to lobby government to do more for patients living with chronic health conditions, called the Australian Patient Advocacy Alliance (APAA)⁴². A big focus of this group, of which MS Australia is a member, is on preventative health strategies. The training curriculum for GPs should include the importance of sharing information and referral pathways with patients suspected of having MS or for those who are diagnosed, and the importance of addressing modifiable health and lifestyle behaviours that can greatly impact on their overall brain health and prevent the acquisition of other chronic health conditions or comorbidities.

³⁹ See Securing a Stable Medical Workforce for NSW Rural Communities NSW HEALTH.
<https://www.health.nsw.gov.au/workforce/Publications/stable-med-workforce.pdf>

⁴⁰ See <https://www.acn.edu.au/wp-content/uploads/NRHC-rural-allied-health-options-discussion-paper-2019.pdf>

⁴¹ Young, L., Peel, R., O'Sullivan, B. et al. Building general practice training capacity in rural and remote Australia with underserved primary care services: a qualitative investigation. BMC Health Serv Res 19, 338 (2019).
<https://doi.org/10.1186/s12913-019-4078-1>

⁴² See <https://mednews.com.au/new-patient-alliance-magnifies-voice/>

Recommendation 6:

MS Australia recommends that patients and patient advocacy groups be included in the development of training and professional development material for GPs and primary health care providers as part of a continuous improvement approach.

b. Current state and former Government reforms to outer metropolitan, rural and regional GP services and their impact on GPs, including policies such as:

iv. Medicare rebate freeze

Most people living with a chronic condition or disability, including those living with MS or other neurological conditions, can attest that the need to spend money on doctors, allied health professionals and medication is expensive. Out of pocket expenses, including gap payments, and the financial challenges that comes as a result of the rebate freeze impact both practitioner (rising practice and operational cost) and patients, and is becoming unsustainable⁴³.

‘Since its 2014-15 Budget the Government has pursued an agenda of fiscal policy – not health policy – to strip \$3.5 billion out of Medicare and shift these costs on to patients.’ (statement by the AMA)⁴⁴

A recent People with Disabilities Australia (PWDA) survey identified that the two main difficulties for people accessing healthcare services are cost and waiting times⁴⁵. MS Australia conducted a needs analysis of people living with MS in Australia in 2019⁴⁶. This survey, conducted by KPMG, highlighted that the biggest barrier to accessing services was affordability.

Currently, Medicare do not subsidise for a GP referred MRI for MS diagnosis and therefore diagnosis confirmation and early response (is delayed).

Comment from Allied health practitioner working with people living with MS

Recommendation 7:

MS Australia recommends that the Government reconsider the impact of the Medicare rebate freeze and the number and value of the indexation of items on the Medicare Benefits Schedule on the ability of GPs to provide free or very-low-cost healthcare to people with chronic conditions.

c. The impact of the COVID-19 pandemic on doctor shortages in outer metropolitan, rural, and regional Australia

MS Australia has provided a summary⁴⁷ of general advice and information on Covid-19 and MS since the epidemic began based on advice from ANZAN and the Multiple

⁴³ See <https://www.ama.com.au/media/new-figures-show-impact-years-medicare-freeze>

⁴⁴ See <https://www.ama.com.au/article/medicare-indexation-freeze-support-materials-practices>

⁴⁵ See <https://pwd.org.au/experiences-of-people-with-disability-during-covid-19-survey-results/>

⁴⁶ See <https://www.ms.org.au/attachments/living-with-multiple-sclerosis-in-2019-report-emba.aspx>

⁴⁷ See <https://www.msaustralia.org.au/about-ms/covid-19-and-ms>

Sclerosis International Federation (MSIF). With our member organisations we have also provided emotional and social support to assist people living with MS in Australia to address their mental health needs and risks of loneliness through our connections hub and other similar peer support initiatives.

We also support a global data sharing initiative⁴⁸ collecting and sharing data on the impact of the novel coronavirus virus on people with MS.

2.5 million Australians do not have access to an internet connection⁴⁹. In rural remote locations in Australia where doctor shortages exist and people might not have access to the internet and reliable web-based resources, people with MS have little other options for accessing evidence based and informed advice on what health decisions to make regarding Covid-19 and its impact on MS but also how to manage their other MS-related health needs during the pandemic. It has been well documented that people do not tend to prioritise and keep their regular health care appointments during periods of restrictions⁵⁰. Not being located to other specialists supports or not being aware of how to access such supports can cause serious health implications.

d. Any other related matters impacting outer metropolitan, rural, and regional access to quality health services.

Chronic health plan utilisation

MS Australia strongly advocates that GPs improve their utilisation of GP Management Plan (GPMP) and Team Care Arrangements (TCAs)⁵¹ to support people living with chronic health conditions such as MS. This is particularly important for the cohort of people that does not have eligibility to the National Disability Insurance Agency supports. These types of structured plans and supports provide essential support for those living in rural and remote locations and who might not have easy access to metropolitan based specialist MS clinics. These plans can especially assist with affordability issues already identified as it provides eligibility for Medicare rebates for specific individual allied health services, as identified by the GP.

They can also assist patients with MS in symptom management, managing other comorbidities - particularly where the patient experiences a compounding effect on their mental health.

Shared care models in MS

Combined with the more structured support and planning approach to managing MS, MS Australia would like to explore how shared care models might work for especially those patients living with MS in rural and remote Australia.

⁴⁸ See <https://www.dropbox.com/s/wj1oo9o8weh2v2y/MS%20Data%20sharing%20initiative%20-%20MS%20organisation%20overview.pdf?dl=0>

⁴⁹ See <https://www.smh.com.au/politics/federal/digital-divide-2-5-million-australians-isolated-with-no-internet-connection-20200327-p54egn.html#:~:text=The%20most%20recent%20data%20from,or%20lack%20of%20digital%20literacy.>

⁵⁰ See <https://www.health.gov.au/news/health-alerts/novel-coronavirus-2019-ncov-health-alert/ongoing-support-during-coronavirus-covid-19/accessing-health-services-during-coronavirus-covid-19-restrictions>

⁵¹ See <https://www1.health.gov.au/internet/main/publishing.nsf/Content/mbsprimarycare-chronicdisease-pdf-infosheet>

MS is a complex chronic illness which can vary significantly from person to person. MS symptoms can be managed to varying extent and success, depending on the severity of the disease and the symptoms experienced. Given the wide spectrum of clinical manifestations that MS can produce, patients may require consultations with a variety of specialists; indeed, patients with MS are often best served by a multidisciplinary approach. MSA has endorsed the Brain Health: Time Matters in Multiple Sclerosis⁵² report, launched in late 2015, which presents consensus recommendations on diagnosis, therapeutic strategies and access to treatment and needs to be fully implemented in Australia.

A recent consultation with an allied health manager working in a specialist MS organisation highlighted “the importance of supporting rural GPs to understand MS, its management and keeping up to date on DMTs and treatment options. Our MS nurses often get queries from patients living with MS seeking advice about ‘GPs who know MS’. This is obviously more critical in rural areas where there is limited access to specialists.”

In lieu of having structured training modules for doctors in training or those seeking additional professional development in understanding MS or complimenting such training, a shared care model in MS can assist in linking GPs with specialist MS centres who can provide a type of satellite supervision and support to GPs in managing someone with MS in a rural and remote setting. This can be especially valuable in activities such as:

- DMTs assessment
- Immunisations schedule prior to DMTs
- Safety monitoring, adverse events and interactions with
- Shared health records and health information across health network of support – encouraging use to support person with MS in communicating appointment/pathology outcomes
- Facilitating improved access to Telehealth options where appropriate
- Access to patient transport when needed
- Symptom management
- Relapse management
- And accessing specialist support with other MS related health needs.

Access and referral support from GPs

When seeking to access the NDIS, or support with an application for the Disability Support Pension (DSP) or other Centrelink supports, patients and carers will often ask their GP for support, from general information and advice on eligibility to evidence gathering and documentation.

One in six people with a disability lives in poverty according to an ACOSS/UNSW report in 2018⁵³. These numbers are likely to be under-estimations as the report did not adjust for additional costs resulting from living with a disability day to day i.e. modifications at

⁵² <https://www.msbrainhealth.org/recommendations/brain-health-report/>

⁵³ See <https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/contents/employment/employment-rate-and-type>

home, personal support and care, medical and pharmaceutical expenses and additional transport costs.

Although there are safety nets, such as the DSP and some people living with disability do maintain some level of employment, “people with disability generally have a lower level of personal income than people without disability. Having a person with disability living in the household is also associated with lower levels of household income.” They are also more likely to experience poor health, discrimination and violence than those without disability. For those effected by the current DSP process, the impacts are profound. DSP is seen the last resort, a sober point of facing up to the irreversible impacts of MS - and not something anyone wish upon for themselves or their families.

I have had several clients who have requested their GP complete part of the Access Referral Form (AFT) to apply NDIS funding and the GP has informed the client that they are “working the system as they are not disabled enough to need that funding”. This has also occurred twice with GPs refusing to support clients to apply for the Mobility allowance when they cannot use public transport during an MS flare. I think more education about these funding schemes is needed for GPs to support clients to access all options available to support their health and wellbeing as early as possible in their MS journey.

Comment received from an occupational therapist treating a person with MS

Similarly, given the diversity in disease presentation and progression, people with MS require a broad and diverse range of support that may include care delivered by family and friends; recognition, acknowledgement, and support for the vital role of these carers are crucial components of maintaining them in this role.

GPs, in lieu of access to other HCPs in rural and remote locations, are crucial in assisting people with MS in these access issues.

Mental Health: Better Access Services

The Better Access Initiative was set up to provide patients with access to mental health professionals and team-based mental health care. GPs and primary health care practitioners are key partners in providing people with MS support, information, referral and advice to address their mental health needs.

Some people with disability, including those living with MS, face day to day challenges to actively participating in everyday life. 32% of adults with a disability experience high/very high levels of psychological distress compared to only 8% of those living without a disability⁵⁴. Over 50% of people living with MS will experience a major depression at some point in their lives. ⁵⁵While people with other chronic disorders also have high rates of depression, the rate is higher among people with chronic disorders — such as MS — that are inflammatory in nature.

⁵⁴ See <https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia-2020-in-brief/contents/income>

⁵⁵ <https://www.msaustralia.org.au/living-with-ms/expert-blog/multiple-sclerosis-and-depression-%E2%80%93-it-seriously-complicated>

Identification and supporting people with MS with their mental health needs, particularly those living in rural remote locations, are as an essential part of their overall health as any physical ailments or conditions.

Palliative and end of life care

Improving the inconsistent provision of palliative and end of life care for people with MS and other neurological diseases in rural and remote locations requires systematic solutions, to address the gaps, but also inequalities in access.

Innovative models exist⁵⁶ and should be considered for further implementation in other regions in Australia.

Conclusion

The role of the GP in recognising the early signs and symptoms of MS and facilitating a speedy referral and diagnosis of MS is vital. Given that there are many more GPs in Australia than there are people living with MS, it is likely that many GPs will have never treated a person diagnosed with MS and will not have any experience in recognising symptoms, which may lead to delays in referral and diagnosis. Any delay in identification of early symptoms can have a profound impact on health outcomes and cause irreversible damage.

Awareness of the early symptoms of MS and effective ongoing treatment and management is therefore dependent on improved education and training about MS by GPs and also a willingness to be involved in a multidisciplinary healthcare team to provide optimal healthcare to the person diagnosed.

According to a report of the RACGP “the concentration of GPs working in major cities is higher than the national average, whereas regional, rural and remote areas all have below average numbers”⁵⁷ makes the likelihood of knowledge about MS even less likely. This combined with the fact that “patient experience data shows that there are longer waits to see a GP for patients outside major cities”⁵⁸, means that people with MS living in rural and regional communities will experience less than optimal care pathways.

Of major concern are the anecdotes and stories provided to us by the MS community of difficulties in having their symptoms understood and timely referral and diagnosis being performed.

We hope that this review will provide an opportunity to improve the initial phases of the MS journey and lead to better health outcomes for the MS community.

56 <https://www.phrp.com.au/issues/march-2020-volume-30-issue-1/improving-palliative-and-end-of-life-care-for-rural-and-remote-australians/>. <http://dx.doi.org/https://doi.org/10.17061/phrp3012001>

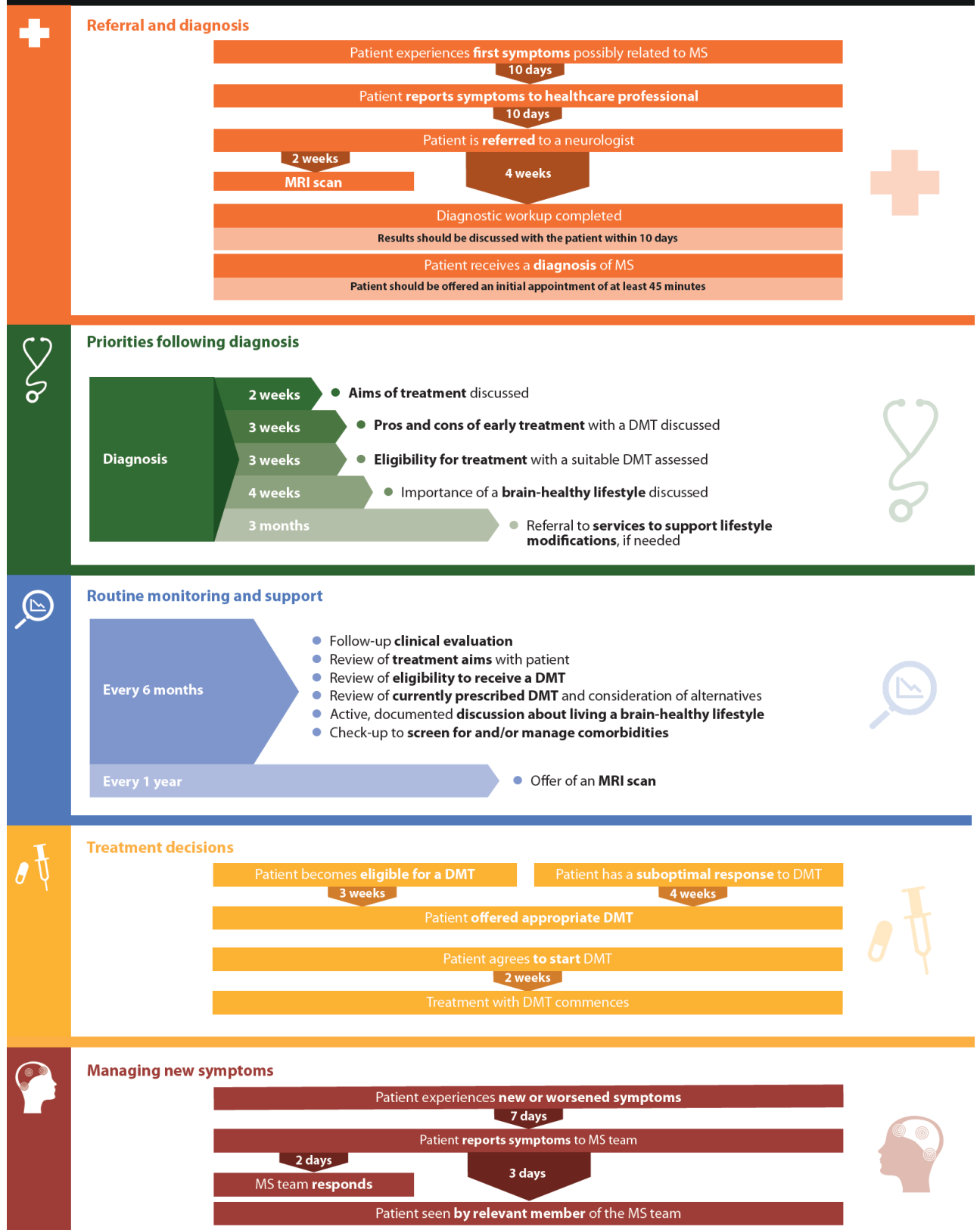
57 The Royal Australian College of General Practitioners. General Practice: Health of the Nation 2020. East Melbourne, Vic: RACGP, 2020. P22

58 *ibid*

KEY FACTS ABOUT MS:

- Multiple sclerosis (MS) is a neurological condition affecting the central nervous system (brain and spinal cord) that affects more than 25,600 people throughout Australia
- It is the most common chronic neurological condition diagnosed in young adults.
- MS is most commonly diagnosed between the ages of 20 and 40
- 75% of people diagnosed are women.
- MS varies significantly from person to person. For some people, it is a disease that comes and goes in severity with periods of unpredictable relapse and remission. For others it means a progressive decline over time. For all, it is life changing.
- Symptoms vary between people and can come and go; they can include severe pain, walking difficulties, debilitating fatigue, partial blindness and thinking and memory problems.

Achievable standards* for the timing of key events in the MS care pathway








Reproduced from Hobart *et al.* International consensus on quality standards for brain health-focused care in multiple sclerosis. *Mult Scler*2018; doi:10.1177/1352458518809326. *Achievable grading reflects good standards of MS care. DMT, disease-modifying therapy; MRI, magnetic resonance imaging; MS, multiple sclerosis.

⁵⁹ <https://www.msbrainhealth.org/healthcare-professionals/ms-brain-health-consensus-standards/>

MS BRAIN HEALTH CONSENSUS STANDARDS

ATTACHMENT 1 (CONTD)

Expert consensus on standards for timely MS care				
	Core	Achievable	Aspirational	Reporting first symptoms
Referral and diagnosis 	4 weeks	10 days	5 days	■ Anyone experiencing for the first time symptoms that might be related to MS should report them to a healthcare professional within [] of noticing them
	4 weeks	10 days	5 days	■ Anyone who reports symptoms that might be related to MS to a healthcare professional should be referred to a neurologist within []
	4 weeks	2 weeks	5 days	■ An initial MRI scan should be performed within [] of first referral to a neurologist for diagnosis (if not performed earlier)
	2 months	4 weeks	7 days	■ The MS team should complete a diagnostic workup for MS within [] of referral to a neurologist
	4 weeks	10 days	5 days	■ The results from a diagnostic workup for MS should be discussed within [] of completion, during an appointment with the patient
	2 months	4 weeks	2 weeks	■ An accurate diagnosis of (uncomplicated) MS should be made and communicated to the patient within [] of their referral to a neurologist
	30 minutes	45 minutes	1 hour	■ Following MS diagnosis, patients should be offered an initial appointment of at least [] to discuss the implications of the diagnosis
Priorities following diagnosis 	Diagnosis			
	4 weeks	2 weeks	7 days	■ The MS team should discuss the aims of treatment with each patient within [] of MS diagnosis
	6 weeks	3 weeks	7 days	■ The MS team should discuss the pros and cons of early treatment with a DMT with each patient within [] of diagnosis
	6 weeks	3 weeks	7 days	■ The MS team should assess within [] of an MS diagnosis whether the patient is eligible for treatment with a suitable DMT
	3 months	4 weeks	10 days	■ The importance of a brain-healthy lifestyle should be discussed with each patient with MS within [] of diagnosis
	6 months	3 months	4 weeks	■ Patients with MS who need additional support to make lifestyle modifications, beyond that offered by the MS team, should be referred to appropriate services within [] of diagnosis
Routine monitoring and support 	Diagnosis			
	6 months	–	–	■ Cognitive screening should be offered to all patients with MS within [] of diagnosis
	1 year	6 months	–	■ The MS team should perform a follow-up clinical evaluation of each patient at least once every []
	1 year	6 months	6 months	■ The MS team should review with each patient at least once every [] the aims of their treatment for MS
	1 year	6 months	–	■ The MS team should review at least once every [] whether each patient with MS who is not receiving a DMT is eligible for one, based on applicable guidelines
	1 year	6 months	6 months	■ The MS team should review with each patient at least once every [] their currently prescribed DMT and consider alternatives if appropriate
	1 year	6 months	–	■ The MS team should engage patients with MS in an active, documented discussion about living a brain-healthy lifestyle at least once every []
Treatment decisions 	Diagnosis			
	1 year	6 months	6 months	■ All patients with MS should have a check-up with an appropriate healthcare professional to screen for and/or manage comorbidities at least once every []
	2 years	1 year	1 year	■ All patients with MS should be offered an MRI scan at least once every []
	Patient becomes eligible for DMT			
2 months	3 weeks	10 days	■ A DMT should be offered to a patient with MS within [] of their becoming eligible for one	
Patient decides to start DMT				
4 weeks	2 weeks	7 days	■ Treatment with a DMT should commence within [] of a patient with MS agreeing this approach with their neurologist	
–*	4 weeks	2 weeks	■ If a patient's response to their current DMT is judged to be suboptimal, an appropriate, alternative DMT should be offered within []	
New symptoms 	Diagnosis			
	New or worsening symptoms			
	2 weeks	7 days	3 days	■ Patients with MS should report new or worsened symptoms to their MS team within [] of experiencing these symptoms
	Reporting new or worsening symptoms			
3 days	2 days	1 day	■ The MS team should respond within [] to a patient with MS reporting an acute deterioration of symptoms	
7 days	3 days	2 days	■ Patients with MS who experience an acute deterioration of symptoms should be seen by the relevant member of their MS team within [] of reporting these symptoms	
Additional statements	<ul style="list-style-type: none"> ■ Aspirational standard: Regular cognitive screening should be offered to all patients with MS ■ Core standard: The MS team should give all patients the opportunity to participate in informed, shared decision-making about their care ■ Achievable standard: The MS team should regularly enter patient data into an MS database ■ Core standard: Neurologists should use the latest accepted diagnostic criteria when diagnosing MS 			

Reproduced from Hobart *et al.* International consensus on quality standards for brain health-focused care in multiple sclerosis. *Mult Scler* 2018; doi:10.1177/1352458518809326. Standards were agreed by at least 75% of the Delphi Consensus Panel. Core, achievable and aspirational grading reflects minimum, good and high standards of MS care, respectively.

*Time frame of 3 months was agreed by the Delphi Panel after completion of the Delphi process.
DMT, disease-modifying therapy; MRI, magnetic resonance imaging; MS, multiple sclerosis.

Time matters in multiple sclerosis: diagnose early to maximize brain health

A guide for general practitioners and primary care providers

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Why MS matters

Multiple sclerosis (MS) is a leading cause of disability in young adults.¹ Disability cannot be reversed, but early treatment with effective anti-inflammatory disease-modifying therapies (DMTs) can protect brain health and improve outcomes for people with MS. Therefore, general practitioners (GPs) and primary care providers (PCPs), who are usually the first to encounter people with symptoms suggestive of MS, play a critical role in establishing a timely diagnosis and referring patients promptly to a neurologist.

MS Brain Health, a global initiative based on the internationally endorsed report *Brain health: time matters in multiple sclerosis*,² recommends a therapeutic strategy for people with MS that aims to maximize lifelong brain health. This concise guide explains how the recommendations from that report can be put into practice by GPs and PCPs.

Role of GPs and PCPs

1. Ensure a high index of suspicion of MS

Symptoms of MS vary among individuals and can be difficult to identify; however, the time course of an MS attack (relapse) is characteristic in patients with relapsing–remitting MS (85% of patients, typically aged 20–40 years). The classical presentation is of a gradual increase in symptom number and intensity over several days, followed by a stable period lasting days to weeks, with subsequent partial or full resolution.¹ The remaining 15% of patients have primary progressive MS; these individuals are typically aged 40–50 years and present with progressively worsening symptoms that do not resolve.¹

Symptoms for both groups of patients can be wide ranging (Figure 1), but particular neurological manifestations to look out for include:

- optic neuritis – reduced visual acuity, colour desaturation, sometimes preceded by periorbital/orbital pain on eye movement
- transverse myelitis – ascending sensory changes in one or both legs, sometimes with muscle weakness affecting legs, trunk, arms and bladder, Lhermitte's sign (electric-shock-like sensations, often down the spine, brought on by neck flexion, which may precede or follow a relapse)
- brainstem inflammation – vertigo, double vision, dysarthria, ataxia.

MS also has many symptoms that are more difficult to distinguish from those of other conditions, including fatigue, depression, anxiety and cognitive impairment.¹ These symptoms may precede or accompany more obvious physical signs.

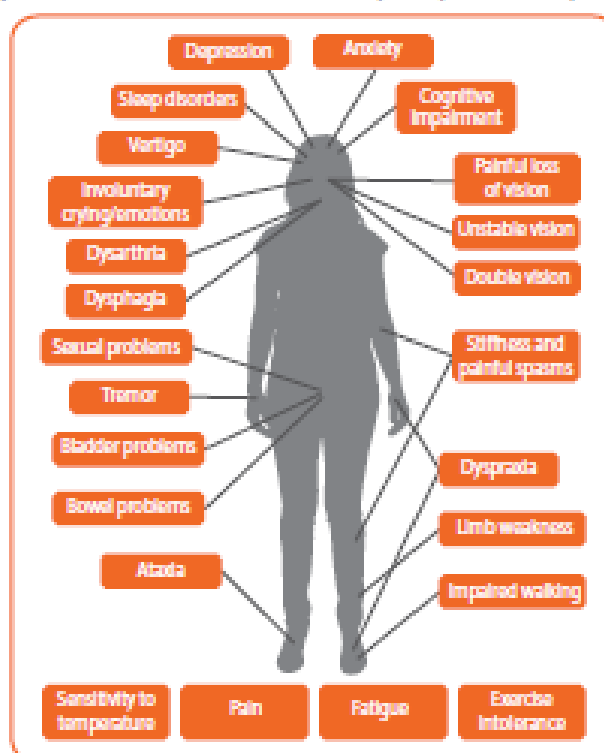


Figure 1. MS can present with a wide range of symptoms.

⁶⁰ <https://www.msbrainhealth.org/healthcare-professionals/brain-health-in-multiple-sclerosis-a-gp-and-pcp-guide/>

2. Refer people with suspected MS to a neurologist

Increasingly lengthy delays in referral to an MS neurologist are associated with greater levels of disability at the time of specialist evaluation.¹ Therefore, patients presenting to their GP/PCP with symptoms suggestive of MS should be referred promptly to a neurologist, ideally one who has a special interest in MS.

The face of relapsing MS has changed – it is now a highly treatable disease. The pace of changes in treatment options and monitoring processes is fast and exciting, with many highly effective DMTs now available. Regular specialist contact is needed to treat to target and to prevent long-term disability; neurologists who specialize in MS, together with their multidisciplinary teams, are best placed to provide diagnostic evaluation and specialist care and management.

First-person account²

I started getting a lot of pain in my legs and lower back. Along with the pain, I was getting weird nerve sensations in my legs and my legs felt as though they were getting weaker and weaker. This continued from 2003 to this day. I saw orthopaedic specialists on nine occasions and they put the problems down to the sciatic nerve. In 2010 ... I registered with a new doctor. He told me he was referring me to a neurosurgeon (sic) to get this checked out properly. In early 2011, I was sent for full body magnetic resonance imaging scans and lumbar punctures ... finally ... (in) February 2012, I was diagnosed with primary progressive MS ... I have fought for 9 years to try and work out what was going on in my legs.

With permission from the Multiple Sclerosis Trust

3. Provide shared care, support and monitoring

Symptomatic treatments

Once MS has been diagnosed and treatment with a DMT established, GPs/PCPs will ideally collaborate with the MS team in providing treatments to reduce symptoms such as pain, constipation, bladder dysfunction, anxiety and depression.

Prevention and treatment of infections and comorbidities

People with MS may be at increased risk of infections and significant comorbidities. Immunizations should be updated before DMT treatment starts, and common infections (e.g. urinary tract infections) should be treated quickly and appropriately. Comorbidities including obesity, hypertension, diabetes, depression and anxiety have been associated with poor outcomes in people with MS.³ Therefore, comorbidities should be managed by health promotion, screening and early treatment, as appropriate.

Monitoring of MS therapies

Patients receiving DMTs will be monitored by the MS team for safety events; the requirements for each drug and each individual will vary. GPs and PCPs need to be vigilant and look out for signs of rare events that warrant referral of the patient to an MS specialist. These events often present as fever/malaise and include progressive multifocal leukoencephalopathy (presenting with altered cognition, personality changes and/or focal neurological symptoms), cytomegalovirus, herpes zoster, herpes simplex, meningitis, liver toxicity and secondary autoimmune conditions.^{4,5} Patients experiencing potential relapses or DMT side effects should be urgently assessed by their MS team, who will evaluate the need for possible acute treatment.

Pregnancy in patients with MS

In pregnant women with MS, most DMTs should be stopped and some may require an accelerated elimination protocol. Pregnancy should be discussed with all women with MS of childbearing potential, and those who are considering pregnancy should discuss this with their neurologist.

Lifestyle factors

Patients should be encouraged to exercise, to keep their weight under control, to adopt a healthy diet, to avoid smoking, to limit alcohol intake and to keep their minds and bodies as active as possible. For more information, see *Six ways to lead a brain-healthy lifestyle* (available from: www.msbrainhealth.org/resources).

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