



Inquiry into Access to and Affordability of Medical Specialists in Australia

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What is MS?

Multiple Sclerosis (MS) remains one of the most common causes of neurological disability in the young adult population (aged 18–40 years) with over 2.9 million people affected worldwide. More than 37,756 Australians live with MS and over 7.6 million Australians know someone or have a loved one with this potentially disabling neurological condition.

Three times as many women have MS than men. 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. For some, MS is characterised by periods of relapse and remission, while for others it has a progressive pattern of disability. MS can significantly affect quality of life, including through its impacts on pain/mobility, independent living, mental health, relationships and participation in everyday life.

MS Australia is Australia's national multiple sclerosis (MS) not-for-profit organisation that empowers researchers to identify ways to treat, prevent and cure MS, seeks sustained and systemic policy change via advocacy, and acts as the national champion for Australia's community of people affected by MS.

MS Australia represents and collaborates with its state and territory MS Member Organisations, people with MS, their carers, families and friends and various national and international bodies to:

- Fund, coordinate, educate and advocate for MS research as part of the worldwide effort to solve MS
- Provide the latest evidence-based information and resources
- Help meet the needs of people affected by MS

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Executive Summary

MS Australia welcomes the opportunity to provide a submission to the House of Representatives Standing Committee on Health, Aged Care and Disability inquiry into access to and affordability of medical specialists in Australia.

Lived Experience

This submission draws on the experiences and expertise of MS Australia's [Lived Experience Expert Panel \(LEEP\)](#). The LEEP is a panel of people who live with MS or care for someone living with MS, and who provide expert advice to inform MS Australia's advocacy work. Their feedback reflects a diverse range of experiences of ability, disability, health system access and support needs in relation to the Committee's Terms of Reference.

MS Australia recommends practical reforms across the specialist care pathway to improve workforce capacity, regional and outreach services, affordability, referrals, waiting times, communication, care coordination, flexible models of care, travel assistance and carer support. LEEP members' experiences show that access to specialist care for people with MS is uneven across Australia. Established relationships with neurologists, MS nurses, GPs and public MS clinics can support timely care, but many people still face long waits, unclear referrals, limited local services, fragmented communication, high out-of-pocket costs and significant travel demands. These barriers can delay diagnosis, treatment decisions, reassessments and support for changing symptoms, while adding to the fatigue, cognitive changes, mobility impacts, financial pressure and uncertainty already experienced by many people with MS and carers of people with MS.

MS Australia Recommendations

- Invest in the MS specialist and MS nurse workforce, expand affordable public, outreach and shared-care models, publish expected waiting times, establish rapid review pathways when symptoms change, reduce out-of-pocket costs for specialist consultations and investigations, and strengthen continuity, communication and staff understanding of chronic neurological conditions.
- Expand regional, rural and outer-metropolitan access to MS-experienced specialists through visiting specialist clinics, outreach services, shared-care models and flexible hybrid care, supported by transport, parking and accommodation assistance, better private-public coordination, local imaging and pathology, and telehealth where clinically appropriate.
- Standardise referral pathways for MS and related specialist care, enable electronic referral transfer and tracking, clarify responsibility for referral submission and follow-up, provide plain-language information about referral status, wait times, available services and escalation options, and reduce unnecessary administrative barriers.
- Reduce out-of-pocket costs for MS specialist care by improving subsidies and Medicare rebates for specialist consultations, MRIs, pathology, tests and investigations, strengthening bulk-billing incentives, reviewing Medicare Safety Net and concession eligibility, expanding travel-related assistance, and improving private health insurance responsiveness.
- Establish clinically appropriate maximum waiting-time targets for diagnosis, reviews, reassessments and urgent symptom changes, provide transparent information about expected wait times and delays, offer flexible scheduling and rapid rebooking, and ensure people can access MS nurses, neurologists or other clinicians for advice while they wait.

- Routinely identify and follow up with people who miss, cancel, delay or do not book specialist care; provide early support, financial assistance for tests and scans, flexible scheduling, rapid rebooking, practical travel support and escalation pathways; and strengthen clinician training so symptoms and concerns are heard and taken seriously.
- Develop coordinated, multidisciplinary MS care models with a clear point of contact, stronger communication between GPs, neurologists, MS nurses and other specialists, better links between private and public services, expanded regional and visiting services, written information, patient notes, appointment tools, subsidies, travel assistance and chronic-condition training.
- Expand flexible hybrid-care models that provide genuine choice between telehealth, video and face-to-face appointments, sustain Medicare rebates and clear eligibility rules for specialist telehealth, improve affordability, expand MS clinics, visiting neurologists, outreach, MS nurse-led clinics and navigation support, and ensure flexible care does not replace needed face-to-face assessment.
- Strengthen continuity, care coordination and patient advocacy by supporting long-term GP relationships, multidisciplinary communication and navigation of financial, private health and treatment access systems; build non-clinical barrier support into services; expand home-based, remote, local and respite supports; assess carer burden; improve urgent specialist advice; and invest in travel provisions and visiting specialist models.

Access to medical specialists: Experiences of getting timely and appropriate specialist support for MS and related health concerns

To address inequitable access to medical specialists, MS Australia recommends the Government invest in the MS specialist and MS nurse workforce, expand affordable public, outreach and shared-care models, improve waiting-time transparency and rapid review pathways, reduce out-of-pocket costs, and strengthen continuity, communication and understanding of chronic neurological conditions.

LEEP members reported that access to medical specialists for MS and related health concerns is highly uneven. Some members described medical specialists as easy to access, particularly where they had established relationships with neurologists, regular six-or twelve-month review appointments, the ability to book well in advance, or email access for advice between appointments. Others had no major barriers beyond occasional waits. However, many members described long and uncertain waiting times for neurologists and other medical specialists, including waits of several months for diagnosis, treatment decisions, follow-up after a neurologist retired, MRI scans, cognitive assessment, psychiatry, cardiology and other medical specialists. For people whose symptoms change or whose condition is progressing, these delays can create significant risk, uncertainty and distress.

"I don't have a publicly available specialist, and there are no private specialists within 700km taking new patients - however, I am lucky, my neurologist has been with me since the early days and thus has kept me as a patient, he is also 700km away." – **LEEP Member Rachel K.**

"It's more difficult for me as the one living with MS because of my rural location. I feel you cannot beat 'in person' appointments as my PPMS changes regularly so its best my specialist see me in person placing more pressure on me with time management, financial pressure, work/life balancing and of course managing the fatigue getting to and from appointments. FYI, I have 14 regular specialists in my corner, from Cardiologist, to Neurologist, to Physiotherapist to Psychologist. It's certainly full on but not a lot of choice when not giving up easy."

– **LEEP Member Jo**

The feedback also highlights a clear equity gap. LEEP members who live in rural and regional Australia report living hundreds of kilometres from the nearest medical specialist, reported limited public options, few private medical specialists accepting new patients, and reliance on long-distance relationships with existing neurologists. Some members felt they could only access timely or appropriate care by paying privately, while others expressed empathy for people who could not afford to do the same. Out-of-pocket costs for medical specialist consultations, scans, hospital transfers and related care were described as substantial and particularly difficult for people on a disability pension, even when Medicare or private health insurance covered part of the cost.

“When I was first chasing answers, pre-diagnosis following an MRI Request from a GP that showed signs of MS I was told that there could be a 6 month wait. Instead, I had the ability to pay out of pocket for a private neurologist which I am very lucky to do... then able to get in the following week. Now, it definitely takes time to see a neurologist each year and when I do, it usually is a 5-10 minute appointment and sent for another MRI with another few months wait.”

– **LEEP Member Alex**

“Initially when going through the diagnostic process, there was a wait to see a neurologist, approximately 4 weeks. I now see him regularly each 6 months and book my appointments well in advance. Initially I was also travelling for treatment every 4 weeks. This continued for some years, but thankfully now I can get my treatment at the local public hospital.”

– **LEEP Member Julie**

Access to medical specialists is not just a question of whether an appointment exists. For people with MS, care also needs to be timely, affordable, geographically reachable, consistent, empathetic and responsive when symptoms change, or other health concerns emerge. Several described very brief neurology appointments, repeated contact with different registrars rather than a consistent neurologist, and long waits for follow-up investigations.

“I have experienced some difficulties accessing medical specialists for MS. I was initially placed on a six-month waiting list for an appointment with a neurologist to confirm my MS diagnosis, although this appointment was brought forward due to the progression of my condition. I also experienced a lengthy wait when my first neurologist retired, and I was referred to another neurologist. Both experiences were made more difficult by telephone interactions with reception staff who appeared to lack empathy and understanding of the challenges associated with living with a chronic health condition.” – **LEEP Member Connie**

“Apart from my neurologist, I only seek paid professionals because I know I'd be waiting forever. I have huge empathy for those who not in a fortunate position to do the same.”

– **LEEP Member Rowena**

Others noted that administrative interactions can compound stress when reception staff do not understand the urgency, complexity or emotional impact of living with a chronic neurological condition. Overall, the feedback shows that access is not only about whether an appointment can be obtained, but whether access to medical specialists is timely, affordable, geographically reachable, continuous, empathetic and responsive to changes in a person's MS or broader health needs.

MS Australia recommends the Government:

- invest in the MS specialist and MS nurse workforce
- expand affordable public, outreach and shared-care models
- publish expected waiting times and establish rapid review pathways when symptoms change
- reduce out-of-pocket costs for medical specialist consultations and investigations
- strengthen continuity of care, improve communication with patients while they wait
- ensure clinical and administrative staff understand the complexity and urgency of chronic neurological conditions such as MS.

Geographic barriers and service availability: How location, including living in metropolitan, regional, rural or remote areas, affects access to medical specialists

To address geographic inequities, MS Australia recommends expanding regional, rural and outer-metropolitan access to MS-experienced specialists through visiting, outreach, shared-care and hybrid models, supported by practical travel assistance, local diagnostics, better public-private coordination and clinically appropriate telehealth.

LEEP members reported that geography has a major influence on access to MS medical specialists, but the impact varies considerably depending on where a person lives, whether they can drive, and whether they have support to travel. Members living in inner-city or major metropolitan areas generally described access as easier, with medical specialist care, MRI services and other related appointments more likely to be nearby and accessible by public transport. However, even in cities, access can still be difficult when services are concentrated on the other side of the city, when public transport is not suitable, or when MS fatigue, reduced mobility, inability to drive or reliance on carers makes travel physically and logistically challenging.

“Living on the border between rural and metro areas has affected my access to a specialist. Although I can access metropolitan services, travelling to specialist appointments can take significant time and planning. There are fewer specialist services closer to home, so I may need to travel further for MS related care. This can be challenging when appointments are frequent and can involve taking time away from work and family responsibilities.” – **LEEP member Deize**

“There is no choice of specialist, it is simply finding one that will agree to take on a new patient and then accepting the cost of both a private appointment, and travel to same. Also, there are logistical issues with a private doctor referring to the public system for an MRI or scan, so more often you will also be out of pocket with them too. In short, if you don't have at least \$800 to spend for each appointment, you are at the mercy of the stretched public system and their wait lists.” – **LEEP member Rachel K.**

“We live in suburbs just outside the city. The only way you can see a specialist fast in WA, is to end up in hospital and hope that they aren't ramping. Current ramp time for people to be admitted from ambulance attendance is 4 hours. That's a long time in an ambo if you're in a bad way.” – **LEEP Member Jody C.**

“Living in a rural area has meant that I must travel for neurologist appointments, lumbar puncture, MRIs as well as the JCV blood test. I travel a round trip of 4 hours approximately 5 times a year, if my MS is staying relatively stable. This takes a fair amount of planning around work, my partner and other events.” – **LEEP member Julie**

For members living in regional, rural, remote or outer metropolitan areas, geographic barriers were more pronounced. Some described living on the border between rural and metropolitan areas, where metropolitan services were technically available but still required significant planning, travel time and time away from work and family responsibilities. Others reported travelling long distances for neurologist appointments, lumbar punctures, MRIs and blood tests, including round trips of around four hours several times a year when MS was stable. Members also noted that if they could not drive, limited public transport in rural areas would make access substantially harder.

The feedback also shows that geography and affordability are closely connected. Some members reported that limited local medical specialist availability meant there was little or no choice of medical specialist, and that the practical options were to accept long public wait lists or pay privately for faster access. For people who need to travel for private appointments, the costs of consultations, imaging and transport can be substantial. Members also raised concerns about logistical barriers when private medical specialists refer patients back into the public system for scans, which may result in further delays or additional out-of-pocket costs. These barriers can be especially difficult for people on lower incomes or those managing disability-related costs.

Members' experiences also show that access cannot be reduced to a simple city-and-regional divide. People in major cities may still face long and exhausting travel across metropolitan areas, while people in rural and regional areas may be dependent on a small number of distant medical specialists, carers for transport, or hospital-based escalation when timely specialist access is not otherwise available.

"I'm lucky to be live the inner city of Melbourne. Access to specialist care is very easy for me, accessible by public transport." – **LEEP member Louis**

"Good access living in major city. For some specialties even living in Sydney, I still need to travel across the other side of the city sometimes which is very inaccessible with my MS fatigue and lack of driving." – **LEEP member Jodi M.**

"City living certainly helps! I am dependent on a carer providing transportation to appointments as public transport has challenges. Most associated specialist like the Urologist or MRI scanning are also concentrated in cities." – **LEEP member Gavin**

These differences affect timely diagnosis, monitoring and treatment, particularly for people with MS fatigue, cognitive symptoms, mobility limitations or fluctuating health. Improving geographic access requires more locally available services, better transport support, and flexible models that reduce unnecessary travel while preserving access to face-to-face care when clinically needed.

MS Australia recommends the Government:

- expand regional, rural and outer-metropolitan access to MS-experienced medical specialists through visiting medical specialist clinics, outreach services, shared-care models and flexible hybrid care
- fund transport, parking and accommodation assistance
- improve coordination between private and public services
- improve access to local imaging and pathology
- provide telehealth options where clinically appropriate, while ensuring people can still access face-to-face medical specialist care when needed.

Referral pathways and system navigation: Experiences of being referred to specialists, including whether pathways are clear, timely and easy to follow

LEEP members reported mixed experiences of referral pathways and system navigation. Some found the process straightforward, particularly when referrals were made through a GP, an emergency department, inpatient hospital care, or an integrated hospital service where medical specialists were connected under the same health system. For these members, referral to a neurologist or related specialties was generally clear and timely enough, although there could still be a wait before the first appointment.

"Could have been clearer. Most of the information was verbal and it was stressful at that time so retaining that information was difficult." – **LEEP member Muskaan**

"Overall, my experience was positive, and I was able to access the specialist care I needed. However, the referral process was not always straightforward, and it was sometimes unclear what the next steps were or how long I would need to wait for an appointment. Having clearer information about referral process, expected waiting times and available specialist services would make the experience easier." – **LEEP member Deize**

However, other members described referral pathways as unclear, stressful and more complicated than they needed to be. Several noted that most information was provided verbally at a time when they were distressed, overwhelmed or trying to understand a possible MS diagnosis, making it difficult to retain details about next steps, expected waiting times or available medical specialist services. Members said the experience would be easier if people received written, plain-language information explaining the referral process, what to expect, how long they may need to wait, who is responsible for each step, and how to follow up if symptoms worsen or no appointment is received.

The feedback also highlights that referral pathways can be shaped by affordability and service availability. Some members were told they could face long public waiting periods but were able to pay out-of-pocket to see a private neurologist much sooner. Others had little choice of provider and moved between the only available medical specialists. Members also described medical specialist screening processes that can delay access, particularly when patients are asked to submit referrals themselves in a particular format or through a particular technology, rather than this being managed by the referring practitioner. Confusion about referral validity, including differences between standard Medicare rules and individual medical specialist practices such as not accepting indefinite referrals, can add another layer of complexity for people already navigating a chronic health condition.

“Referrals are more complicated than they need to be. Specialists often have a screening process which delays things, especially when they ask you as the patient to send the referral in a particular format or using a particular technology, when this should be done by the referring practitioner. It can also be confusing to know how long a referral lasts for when there is the standard Medicare process and then some specialist have their own standards on top of that e.g. not accepting indefinite referrals.” – **LEEP member Jodi M.**

MS Australia recommends the Government and health services:

- Standardise referral pathways for MS and related medical specialists
- Enable electronic referral transfer and tracking
- Ensure responsibility for referral submission and follow-up sits clearly with referring practitioners and health services rather than patients
- Provide written, plain-language information about referral status, next steps, expected waiting times, available medical specialist services, referral validity and escalation options if symptoms worsen or appointments are delayed
- Reduce unnecessary administrative barriers, align referral requirements with Medicare rules where possible, and provide clear communication throughout screening and triage processes.

Out-of-pocket costs and affordability: The impact of appointment fees, tests, treatments, travel and other costs on access to medical specialists

LEEP members reported that out-of-pocket costs can have a direct and significant impact on access to medical specialist care, tests, scans and related supports. Some members had relatively low costs because appointments were bulk billed or because insurance reduced the financial burden. However, many described costs for private medical specialist appointments, MRIs, pathology, travel, parking and time away from work as substantial, particularly when care required travel further from home or when public waiting times made private care the only realistic option for timely access.

Members' experiences show that affordability barriers can arise even when people are insured or partially subsidised. One member described not having Medicare at the time and relying on private health insurance that did not initially cover MS-related appointments and tests, requiring a change of insurer and an additional waiting period before MS-related care was covered. Others noted that some medical specialist costs were manageable, but related investigations such as MRIs could be prohibitive if not bulk billed. The feedback also highlights that the Medicare Safety Net may not provide support early enough for people with MS who need to see multiple medical specialists but sit just above eligibility thresholds for concession cards or other assistance.

“Costs and travel impact my ability to get specialist care. I cancel approx. 1 in 3 appointments with my specialist purely for cost reasons.” – **LEEP Member Rachel K.**

“Getting sick and needing specialist scans and tests costs lots when on a pension. I've been forced to say no to tests because I haven't had the money to do it then and there.” – **LEEP Member Jody C.**

“Costs and travel impact my ability to get specialist care! I didn't have Medicare at the time and was relying on private health. It didn't cover me for the appointment and tests at the time, so I had to switch private health providers and MS has a waiting period, so it took me a long time before I was covered for MS-related things.” – **LEEP Member Muskaan**

“Because it is so expensive, specialist care needs to be rationed, and I will sometimes save up inquiries for my next appointment, delaying care until then. The Medicare safety net doesn't kick in early enough for people who need to see multiple specialists like those of us with MS but might be just on the border of receiving healthcare cards or other support.” – **LEEP Member Jodi M.**

“Yes, costs and travel massively impact my ability to get specialist care. Even the out of pocket expenses add up when living with health challenges. Add that on top of what my other family members also need to manage at times, I feel very guilty about what my MS has cost us. As I said Private Health has enabled us to be more in the ‘driver's seat’ but that's only one component of the financial pressures. Getting to and from appointments are costly when they are required in-person, including scans, treatment etc, nothing is available locally. Plus, I have a reduced capacity to earn a wage to help with general living costs. Professionally my world got the curve ball too which has its own pressures. Thankfully Medicare and PBS are major support, however options are limited with travel etc due to where I live. But make it work regardless.” – **LEEP Member Jo**

For some members, cost meant care had to be rationed, delayed or declined. Members described cancelling medical specialist appointments for financial reasons, saving up multiple concerns for the next appointment instead of seeking timely advice, and being forced to say no to scans or tests when they could not afford the cost at the time. These impacts were especially acute for people on a disability pension or those managing multiple disability-related expenses. Several members also reflected that they were fortunate to be able to budget for private care, travel or scans, while recognising that many people with MS do not have that option and may be left waiting in an already stretched public system.

MS Australia recommends the Government:

- reduce out-of-pocket costs for MS medical specialists by improving subsidies and Medicare rebates for medical specialist consultations, MRIs, pathology, tests and related investigations.
- Strengthen bulk-billing incentives for people with chronic neurological conditions;
- Review Medicare Safety Net and concession eligibility settings so people who need frequent medical specialist care are not excluded from support because they sit just above income or concession thresholds.
- Expand practical assistance with travel, parking, accommodation and time-related costs.
- Make private health insurance arrangements clearer and more responsive to the needs of people newly diagnosed with MS or seeking MS-related care.

Waiting times, travel and delays: How delays in appointments, long travel distances and service shortages affect timely diagnosis, treatment and support

LEEP members reported that lengthy, unpredictable and inflexible waiting times can make medical specialist care harder to access and can delay diagnosis, reassessment, treatment decisions and support for changing or unexplained symptoms. Some members described waiting several months for neurologist appointments, including being initially placed on a six-month waiting list to confirm an MS diagnosis. Even when appointments were later brought forward because of disease progression, members emphasised that the delay caused not only clinical risk but also a significant psychological burden, including prolonged uncertainty, anxiety and worry about their health and future.

Members also described the practical effects of waiting times on day-to-day life. Long waits limited options and made some people scared to reschedule appointments in case they were pushed further back in the queue. Clinics running significantly late made it difficult to anticipate how much

time would be needed away from work, while long travel distances added further stress, fatigue and inconvenience, particularly for people living between rural and metropolitan areas. For some, appointments outside a regular six-month review cycle could take up to two months unless the situation was treated as an emergency.

“Waiting times to see specialist care could be relatively long if they are not pre-booked in advance. I typically see my specialist once every six months. Bookings are made in advance. However, to see them out of the cycle may take up to 2 months if it's not an emergency.”

– **LEEP Member Louis**

“At the diagnosis stage, the wait time was unavoidable but added to the extreme stress and worry I was already feeling.” – **LEEP Member Julie**

“Waiting times are often long which delays care. Depending on the specialist this might not have any impact, or it might mean that I am living with pain or an unknown symptom during months of waiting. Often the delays if they are there are caused by me because my MS takes priority over other issues and I might delay seeking care or following up on a referral.” – **LEEP Member Jodi M.**

“You just accept that most appointments are 6 weeks out if required asap, or you head to emergency. Fortunately, I am able to contact the MS nurse and ask for information to be provided to the neurologist, lucky I have a good one.” – **LEEP Member Rowena**

“It has made it harder in the sense that I have limited options, I am scared to reschedule because of the waiting times, and the specialist appointments are always running significantly late so I can never anticipate how much time it will take me off work and the waiting and uncertainty drains me too.” – **LEEP Member Muskaan**

“The anxiety that comes from being sick and not knowing why is extremely hard to deal with as a patient and as a carer. It causes stress which in turn is bad for MS.” – **LEEP Member Jody C.**

“Beyond the physical consequences of delays in diagnosis and treatment, I should not have had to endure the psychological impact of prolonged uncertainty about my health and what the future might hold.” – **LEEP Member Connie**

“Waiting times and travel sometimes made it harder to access specialist care. Living between rural and metropolitan areas means I may have to travel a considerable distance for MS specialists, and appointments can involve long waiting periods. This can be stressful and inconvenient, particularly when symptoms change or treatment decisions are needed.”

– **LEEP Member Deize**

Some members reported that when medical specialist care was needed quickly, the only realistic option was to wait several weeks or present to emergency, while others benefited from being able to email their consultant or contact an MS nurse who could provide advice or raise concerns with the neurologist. This kind of interim support was highly valued because it reduced uncertainty and helped people avoid being left without guidance while waiting. Members also noted that delays can mean living with pain, unexplained symptoms or untreated health concerns for months, and that MS may cause people to deprioritise or delay follow-up for other health issues when their capacity is already stretched.

MS Australia recommends the Government and health services:

- Establish clinically appropriate maximum waiting-time targets for diagnosis, reviews, reassessments and urgent symptom changes.
- Provide transparent information about expected wait times and delays.
- Offer flexible scheduling, practical options for people who need to reschedule, and better communication when clinics are running late so people can plan work, care and travel.
- Provide clear escalation pathways when symptoms change or treatment decisions are needed, including timely access to MS nurses, neurologists or other clinicians for advice while people wait.
- Ensure waiting-time reforms recognise the combined impact of delays, travel, fatigue,

uncertainty and psychological distress on people with MS and their carers.

Missed or delayed care due to barriers: The consequences for people with MS and their carers when medical specialist care is postponed, missed or avoided because of cost, distance, waiting times or other barriers

LEEP members reported varied experiences of missed or delayed care. Some had not missed, postponed or gone without medical specialists because of cost, distance or other barriers, particularly where care was bulk billed, distance was not an issue, or they had access to responsive medical specialist support. Several members described themselves as fortunate because they could afford private care, access urgent hospital referrals when waiting times were long, or contact a neurologist's office and receive timely advice when concerns were important.

"I have had to push appointments as I'm not able to miss work commitments at certain times when the Neurology clinic and other clinics are only open in the morning." – **LEEP Member Alex**

"It took close to a decade for me to receive my diagnosis because my symptoms and concerns were repeatedly dismissed and invalidated within the medical system. Although I received my diagnosis almost five years ago, experiences like mine continue to occur despite significant improvements in the diagnosis and treatment of MS." – **LEEP Member Connie**

However, other members described serious consequences when care was delayed, avoided or deprioritised. One member reported that it took close to a decade to receive an MS diagnosis because their symptoms and concerns were repeatedly dismissed within the medical system. This experience highlights that missed or delayed care is not only caused by cost or geography, but can also result from poor listening, clinical assumptions, or failure to take people's symptoms seriously. Members noted that while diagnosis and treatment of MS have improved, experiences like this continue to occur and can have long-term consequences for people's health, confidence and trust in the health system.

Members also described postponing or cancelling care because of practical barriers. Some had to push appointments because neurology and other clinics were only available during morning hours that conflicted with work commitments, while others cancelled appointments because of immediate health and wellbeing issues related to MS. Cost also led to delayed investigations, including scans that were postponed because they could not be paid for at the time. Long waiting periods sometimes made care feel pointless or poorly timed, such as being referred for pregnancy-related eye care with a nine-month wait. These examples show that delayed care can arise when appointment timing, cost, symptoms, work responsibilities and long waits combine in ways that make attending care difficult or unrealistic.

MS Australia recommends the Government and health services:

- Routinely identify and follow up with people who miss, cancel, delay or do not book medical specialists.
- Offer early support to address the reasons care is being postponed.
- Provide financial assistance for tests and scans, flexible scheduling outside narrow clinic times where possible, rapid rebooking and practical travel support.
- Provide clear escalation pathways when symptoms change or waiting times are clinically unsafe.
- Strengthen clinician training in listening to and validating patient concerns, particularly during diagnosis, so symptoms are not dismissed and people with MS are not left for extended periods without answers, treatment or support.

Improving access and support: Practical changes that would make it easier for people with MS and their carers to access the medical specialists they need

LEEP members identified practical changes that would make medical specialist care easier to access, understand and navigate. These included shorter waiting times, clearer referral processes,

more affordable appointments, better travel support, and more regional, rural and visiting services. Members emphasised that written, plain-language information is particularly important for people with MS, because fatigue, brain fog and cognitive changes can make it difficult to remember verbal information provided during appointments, especially at stressful points such as diagnosis or treatment changes.

Members also highlighted the value of being able to access patient notes, with one member describing this as a “game changer” because reviewing recent appointment notes helped them remember what was discussed and increased confidence in the transparency of their care. Members suggested that people with MS and their carers should be supported with practical resources to record questions, symptoms and key discussion points before and during medical specialist appointments. Where these resources already exist, medical specialists and health services should actively make people aware of them and encourage their use.

Members strongly supported more coordinated and multidisciplinary care, including a single point of contact, better communication between GPs, neurologists and other health professionals, and stronger links between private and public services. Some noted that having one main health service coordinating referrals and medical specialist care made access much easier, while recognising that this is not available to everyone. Members also emphasised the need for ongoing GP education so GPs can support timely referral and do not become an unintended roadblock to care. Education should also extend to reception and administrative staff, who are often the first point of contact and play an important role in communication, referral processes and patient experience.

For people outside major metropolitan centres, members called for more local and visiting services, including visiting neurologists at regional hospitals, MS clinics in more hospitals, and medical specialist services closer to home. Telehealth and video appointments were described as highly valuable, particularly when travel was unaffordable or unnecessary, although members still valued seeing the medical specialist's face and maintaining connection. Members also called for functional travel support, community transport, and community carers or home-visiting services for people with higher support needs. Existing travel schemes were described as difficult to navigate or incomplete when they did not cover the real costs of getting from home or airport to hospital.

When asked what would make it easier for people with MS and carers to get the specialist care they need; LEEP members had the following suggestions:

“Written information and plain language, if possible, will help, especially with MS that can bring mental fatigue, brain fog or cognition changes. Also, being able to access your patient notes is a game changer. I can do it, thanks to Alfred, and I always find it helpful to skim through the last 1-2 appointment notes to jog up my memory of what we discussed. It also makes me feel like I can trust them since accessing my notes shows they're transparent. I also feel like there should be resources for people living with MS or their carers to be able to record their question or key discussion points, something they can carry to each specialist appointment. If resources for people with MS exists, the specialist should encourage them or at least make people aware of them.” – **LEEP Member Muskaan**

“I'd love to see drs in a new area of study look after chronic or life diseases specifically, so a doctor can specialise in paediatrics they need a sector for life disability diseases. There aren't enough neurologists anywhere”. – **LEEP Member Jody C.**

“It would be great to have the option of a visiting neurologist that came to the hospital throughout the year. Even once a month depending on the need.” – **LEEP Member Julie**

“Making specialist care more accessible would include shorter waiting times, clearer referral processes, affordable appointments and better travel support for people who live further from metropolitan services. Telehealth could also make big difference by reducing the need to travel for appointments when an in-person consultation is not necessary. Better coordination between GPs, neurologists and other health professionals would also help people with MS receive timely and continuous care.” – **LEEP Member Deize**

Continued...When asked what would make it easier for people with MS and carers to get the specialist care they need; LEEP members had the following suggestions:

"The healthcare system needs to change to better support people living with chronic health conditions. From my own experience, I believe the system needs to move away from operating in silos, with greater communication and collaboration between specialists involved in a patient's care. I also believe that all healthcare staff should have an understanding of chronic physical health conditions, including reception and administrative staff, who are often a patient's first point of contact and can play an important role in communicating with specialists and facilitating the referral process." – **LEEP Member Connie**

"More virtual/ video appointments where possible. I find seeing the face of the specialist valuable in making a connection." - **LEEP Member Alex**

"I have been fortunate to have access to a local GP who is thoroughly familiar with my medical history. I am aware that others are not so fortunate and the GP can be an unwanted roadblock to accessing care. GP education should be an ongoing priority." – **LEEP Member Gavin**

"Functional travel support would be so helpful- in QLD, the PTSS exists however it's increasingly difficult to get a response from their office, even when all of the forms are completed and submitted. It also doesn't cover surface transport so that can add up fast as the 50c travel fares aren't available from the airport to the hospital. Telehealth has been a saviour for me here, at least I am able to see my specialist when I can't afford to travel. That said, the Medicare rebate on specialist appointments is atrocious and so I am religiously at least 200 out of pocket for each visit which of course isn't claimable on private health - this is regardless of physical or telehealth attendance. So, in order, ideally, we would have a specialist here, or closer than 700-odd kms. Otherwise, functional travel support would help." – **LEEP Member Rachel K.**

"Standardised referral processes and systems so there was no gap any more between referral and specialist. Greater access to subsidised clinics when standard specialist care is not affordable. MS clinics in a lot of the hospitals are a good example of this working well." – **LEEP Member Jodi M.**

"I believe that having one main point of contact, in this case, the Royal Melbourne Hospital, makes referrals and specialist care much easier and more convenient. I understand that this is not the case from most people." – **LEEP Member Louis**

MS Australia recommends the Government and health services

- Develop coordinated, multidisciplinary MS care models that include a clear point of contact, stronger communication between GPs, neurologists, MS nurses and other medical specialists, and better links between private and public services.
- Expand regional and visiting medical specialist services, MS clinics, telehealth and video appointments, nurse-led care, outreach, community transport and home-visiting supports.
- Provide people with MS and their carers with written, plain-language information, easy access to patient notes, and practical appointment preparation tools to record questions, symptoms and key discussion points.
- Improve subsidies, Medicare rebates and access to affordable medical specialist clinics.
- Strengthen functional travel assistance, standardise referral processes, and fund ongoing chronic-condition training for GPs, medical specialists, nurses, reception and administrative staff.

New and flexible models of care: Experiences with telehealth, outreach clinics, nurse-led care, MS services and other alternative ways of accessing medical specialist support

LEEP members described new and flexible models of care as important ways to improve access, reduce travel and support more timely medical specialist advice. Telehealth and video appointments were widely valued for follow-up appointments, allied health appointments, GP care, urology and routine neurology reviews, particularly where the appointment was expected to be straightforward or focused on questions rather than physical examination. Members said telehealth saved time, energy and money, reduced the need for long travel, and made it easier to fit appointments around work, family responsibilities or a lunch break.

“I have used telehealth and MS services. Telehealth has worked well for follow up appointments or having questions answered because it reduces travel time and makes it easier to fit appointments around work and family responsibilities. However, it is not always suitable when physical examination or face to face assessment is needed. Having the choice between telehealth and in person appointments would provide greater flexibility and access to care.”

– **LEEP Member Deize**

“I use telehealth quite often with my specialist and G P appointments. This saves me time and energy.” – **LEEP Member Louis**

“I've used telehealth for a couple of neurologist appointments, when I know the check in will be straightforward and fairly quick. This saves a lot of time and expense with not having to travel. I can even schedule these to coincide with my lunch break, so I don't have to take a day off work.”

– **LEEP Member Julie**

“Telehealth works great for me and has really helped. I am unsure if the Medicare rule is still in place that means you need an in person appointment once every 12 months to continue being able to access a Medicare rebate for telehealth - that was a hold up for my neuro for a while, however in fairness that doesn't seem unreasonable when we don't have any other means of taking physical measure and tests here. In an ideal world it would be MS nurse led through a clinic here as the best of both worlds. I don't have access to an MS Nurse sadly, though I would be absolutely delighted if that option landed here in any format. In fairness, we are so short of any care options here, I wouldn't say no to any of the above.” – **LEEP Member Rachel K.**

At the same time, members emphasised that telehealth is not suitable for every situation. Physical examination, assessment of new or changing symptoms, scans, tests and some treatment decisions still require face-to-face care. Members therefore strongly supported having a choice between telehealth and in-person appointments, rather than one model replacing the other. Some also noted that video appointments are preferable to telephone-only care because seeing the medical specialist's face can help build connection, trust and confidence.

Members also valued MS medical specialist clinics, particularly where they were embedded in public hospitals and connected to other referrals and services in one familiar place. For some, attending the same hospital created a sense of continuity and confidence because they knew the setting, understood where to go, and felt they were being cared for by people with MS expertise. MS nurses and MS practice nurses were also identified as highly valuable. Members described nurse-led care as helping investigate symptoms, identify issues that may not be MS-related, provide advice, avoid unnecessary medical specialist appointments, and reduce long waits or out-of-pocket costs.

"I attend an MS specialist clinic. It makes me feel like I can trust them since they are the experts. I like that the MS specialist clinic is part of a public hospital since all the referrals I get, I have to go to the same place, which becomes a safe space for me, and I know my way around so there's that little comfort." – **LEEP Member Muskaan**

"MS clinics often use residence and registrars who are training which I Access. For MS in particular I will go through my MS practice nurse first because that can avoid an expensive appointment or long wait time." – **LEEP Member Jodi M.**

The feedback also highlights the importance of service navigation and equitable access to flexible models. Some members found MS support services difficult to navigate or were unaware of them at diagnosis, suggesting people need earlier, clearer information about what is available and how to access it. Regional and remote members called for local MS nurse-led clinics, visiting neurologists, outreach services and any additional care options closer to home, particularly where the nearest medical specialist is hundreds of kilometres away. Members also raised concerns about Medicare rebate rules and ongoing out-of-pocket costs for medical specialist telehealth, noting that telehealth can reduce travel costs but does not necessarily make appointments affordable if rebates remain inadequate.

MS Australia recommends the Government and health services:

- Expand flexible hybrid-care models that give people with MS a genuine choice between telehealth, video and face-to-face appointments according to clinical need, preference, disability impacts and travel burden.
- Sustain Medicare rebates for medical specialist telehealth and video appointments, provide clearer rules about eligibility and in-person review requirements, and improve affordability so remote access does not still leave people significantly out-of-pocket.
- Expand public MS medical specialist clinics, visiting neurologist services, outreach models, MS nurse-led clinics and MS practice nurse roles, particularly in regional and remote areas.
- Ensure people are told about MS services and navigation supports at diagnosis and key transition points.
- Ensure flexible models strengthen, not replace, coordinated medical specialist care, timely physical assessment and access to face-to-face care when needed.

Additional lived experience insights: Other experiences, concerns or suggestions from people with MS and their carers

LEEP members' additional insights reinforced the importance of trusted relationships, consistency of care, practical advocacy and system navigation support. Members described the significant difference that an engaged medical specialist or GP can make when they understand a person's circumstances, medical history and care needs. One member described a medical specialist using their expertise and position to advocate with private health and financial systems so the member could afford medication, which substantially improved access to treatment and helped prevent further disease progression. While members did not suggest that all medical specialists should be expected to provide advocacy beyond their clinical role, this experience illustrates the value of clinicians understanding the broader barriers that affect treatment access and using their knowledge of the system to support patients where appropriate.

"The specialist who diagnosed me was a big advocate for me and he spoke for me with the finances and private health to cover up my medication costs fully. Without him and his advocacy, I wouldn't be getting the care and treatment I'm getting now, and I know MS would have progressed further if not for the treatment, I'm now able to afford. So, it meant a lot to me that the specialist (who knows more about the system than I do) used his place and expertise to advocate for me. I'm not saying that all specialists should be expected to do something like this, which could be considered out of scope, but it's nice to see a specialist understanding your care needs and helping you with something that might be seen extra but is actually helping you in a way that drastically improved your treatment and care." – **LEEP Member Muskaan**

Members also emphasised that an involved GP can be critical to continuity and timely care, particularly when the GP has known the person for many years and understands their changing needs. More broadly, members felt that Australia's health system compares favourably with many others but still needs to better support people living with chronic health conditions. This includes moving away from siloed care, improving communication between health professionals, and recognising that timely, affordable and flexible access to medical specialists should not depend on where a person lives or whether they can pay privately.

"I believe people with MS should have timely, affordable and flexible access to specialists, regardless of where they live. Stronger coordination between healthcare professionals could make a significant difference." – **LEEP Member Deize**

"Generally, specialists do not come to home visits which sometimes will create stress and burden on carers. Telehealth or email contact are usually effective but it is easy to imagine a scenario where face to face contact is preferable." – **LEEP Member Gavin**

"It would be just nice to skip lines and waiting lists to ease off the pressure and stress that comes with being ill and living with disease. I have a friend who waited for oncology appointment and now the cancer has spread throughout her body but if she saw someone earlier, they could have caught it in time. Scary!!" – **LEEP Member Jody C.**

Members also raised concerns about the burden created when medical specialist services do not offer home visits or local alternatives. While telehealth and email contact can often be effective, members noted that there will still be circumstances where face-to-face care is preferable or clinically necessary, and the lack of home-based or local options can place additional stress on carers. Some members expressed the need for faster access to urgent medical specialist care to reduce the pressure and fear that can come with serious illness and linked this to broader concerns about delayed care across the health system. Members also reiterated that many access problems could be reduced through better travel provisions, including considering whether visiting medical specialists to regional communities may be more efficient and equitable than repeatedly transporting patients' long distances to metropolitan centres.

MS Australia recommends the Government and health services

- Strengthen continuity, care coordination and patient advocacy for people with MS by supporting long-term GP relationships, multidisciplinary communication and clearer navigation of financial, private health and treatment access systems.
- Recognise the role clinicians can play in identifying and addressing non-clinical barriers to care, while ensuring this support is built into systems rather than relying on individual clinicians.
- Expand home-based, remote, local and respite supports.
- Routinely assess and address carer burden and improve access to urgent medical specialist advice.
- Invest in practical travel provisions and visiting medical specialist models that reduce the need for people in regional and remote communities to repeatedly travel long distances for care.

Conclusion

LEEP members' experiences show that access to medical specialists for people with MS is too often shaped by geography, income, service availability and the ability to navigate complex systems. While some people benefit from established relationships with neurologists, MS nurses, GPs or public MS clinics, others experience delays in diagnosis, treatment decisions and support for changing symptoms. These barriers compound the physical, cognitive, emotional and financial impacts of MS, particularly for people in regional, rural and remote areas, people on low incomes or disability pensions, carers, and those managing fatigue, mobility limitations, cognitive changes or fluctuating health.

The feedback also highlights that improving medical specialist access requires more than increasing appointment numbers. Reforms must address the whole pathway of care: clear and standardised referrals, transparent waiting times, affordable consultations and investigations, functional travel assistance, timely escalation when symptoms change, accessible written information, access to patient notes, and better support for people to prepare for appointments and remember key information. Care must be coordinated across GPs, neurologists, MS nurses, allied health, hospitals, private providers and community supports, with stronger chronic-condition training for both clinical and administrative staff. Flexible models such as telehealth, video appointments, nurse-led care, outreach, visiting medical specialists, MS clinics and home-based supports should expand choice and reduce unnecessary travel, while preserving access to face-to-face assessment when clinically needed.

MS Australia urges the Government to use this inquiry to drive nationally consistent reforms that make medical specialist care timely, affordable, geographically accessible, person-centred and responsive to the realities of living with MS. People with MS and their carers should not have to rely on luck, private means, individual clinician advocacy or their own persistence to receive the care they need. A stronger medical specialist care system should provide clear pathways, equitable access, continuity, empathy and support from diagnosis through ongoing monitoring, treatment and management of broader health needs. Embedding lived experience in the design and implementation of these reforms will be essential to ensuring they are practical, accessible and effective for people with MS and their carers.

