# Connected Care for People with Multiple Sclerosis

## MS Integrated Care Framework

## Cover image

**Keep Swimming**
by Lucy Smyth, 2025.

> “Having a team that understands you makes a huge difference. When they actually talk to each other, it just works better.”
> Person with MS

# Acknowledgements

## Thanks to

This project was made possible through the support and partnership of many individuals and organisations dedicated to improving outcomes for people living with multiple sclerosis.

The MS Integrated Care Project was funded by the NSW Government through Western Sydney Local Health District, delivered in partnership with MS Plus, and developed in collaboration with Westmead MS Clinic clinicians. Sincere thanks to all partners and contributors who supported its development, engagement, and evaluation.

We thank the health professionals who support people with MS every day. Your expertise and compassion provided valuable guidance on the challenges and opportunities within the current healthcare system.

We are especially grateful to the PwMS and their families who generously shared their time, experiences, and personal stories. Your honesty, insight, and strength have shaped this work and reflect the diversity and resilience of the MS community.

This framework reflects a shared commitment to co-design, collaboration, and continuous improvement, bringing together health services, community partners, and PwMS to create more coordinated, person-centred care.

## Acknowledgement of Country

In the spirit of reconciliation, MS Plus acknowledges the Traditional Custodians of country throughout Australia and their connections to land, sea and community. We pay our respect to their Elders past and present and extend that respect to all Aboriginal and Torres Strait Islander peoples today.

## Project team

The project, including the consultation and framework development, was led by Jess Morris, Integrated Care Project Lead at MS Plus. It was overseen by Kylie Osborne, Senior Manager, Community & Partnerships, with additional support from Dr Justin Garber, Westmead Hospital.

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**Funded by NSW Health**

# Contents

# Executive Summary

**Improving MS care means taking time to understand and respond to what people with MS need across the whole system.**

The MS Integrated Care Project aimed to better understand the experiences and challenges that people with MS (PwMS) face in accessing and navigating healthcare services in New South Wales.

Funded by NSW Health and coordinated by MS Plus, in partnership with Westmead Hospital, the project focused on improving integrated and equitable MS care with input from community and clinical expertise. Throughout the project, people with MS, carers, and health professionals provided ongoing guidance and advice, from identifying key themes and gaps, to co-designing consultations and solutions, and reviewing findings and recommendations for health system partners. This process developed a clinically informed framework grounded in lived experience and shaped by what matters most to PwMS.

**Key insights included:**

- PwMS often manage disjointed care alone due to fragmentation across healthcare, disability, and social support systems
- Where GPs and neurologists work collaboratively, PwMS report greater confidence and better outcomes, but this level of collaboration remains inconsistent
- Communication across providers is often inconsistent, resulting in missed updates, duplication, and PwMS feeling unseen or unsupported in their care
- MS Nurses play a critical role in continuity, education, and access to supports such as NDIS applications, yet availability varies and many PwMS do not have this support
- Neurologists are highly trusted and preferred sources of information, but access is restricted by time, location, and demand on specialist services
- PwMS prefer face-to-face support and want access to MS-specific allied health services close to home
- Emotional and financial concerns are common but often go unaddressed due to time constraints, unclear pathways, and limited resources.
- PwMS face significant barriers to engaging with services including cost, location, and lack of MS-specific knowledge, even those PwMS on NDIS
- GPs were the main point of contact during symptom changes and often the most consistent, but lacked time, support, and MS-specific knowledge
- Early education following diagnosis is inconsistent, leaving many unprepared to understand MS progression or manage their condition with confidence

**Framework Themes**

When exploring experiences of accessing and navigating health services with PwMS and clinicians, findings and recommendations have been grouped under six themes:

MS Specialist Care

Wellbeing Supports

Care Navigation and Coordination

Education and Self-Management

GP, Allied Health and Community Care

Voice and Representation

# Introduction

Multiple Sclerosis (MS) is a progressive neurological condition affecting over 33,000 Australians, with most diagnosed between ages 20 and 40 (Campbell et al., 2023; Multiple Sclerosis Australia, n.d.). It is a leading cause of non-traumatic disability in young adults.

MS occurs when the immune system attacks myelin, disrupting communication between the brain and body. Common symptoms include fatigue, mobility issues, pain, and cognitive changes, which can significantly affect quality of life, independence, and participation in work and social life (Multiple Sclerosis Australia, n.d.)

Currently, MS is classified into three main types: Relapsing-Remitting MS (RRMS), the most common at diagnosis; Secondary Progressive MS (SPMS), which typically follows RRMS after a period of time; and Primary Progressive MS (PPMS), the least common, involving gradual worsening from onset. While multiple disease-modifying therapies exist for RRMS, treatment options for PPMS are limited, affecting access and care planning.

Many PwMS leave paid work within 10 years of diagnosis, often due to the combined effects of symptoms such as fatigue and physical impairment (Conradsson, 2020). This loss of income contributes to increased financial pressure and greater reliance on health services and unpaid carers. In Australia, the economic impact of MS is estimated at more than $2 billion annually, reflecting healthcare costs, lost productivity, and informal care (Campbell et al., 2023). Improving access to coordinated, person-centred care may help reduce these long-term costs and support greater participation and independence.

This report explores MS care experiences in New South Wales and outlines key priorities for a more integrated and responsive system.

# Literature review

**What is integrated care?**

Integrated care provides a foundation for delivering coordinated, person-centred support across health and social systems. It improves access, continuity, and outcomes by enabling collaboration between services and making the system easier to navigate. It is especially important for people with complex needs, including those with chronic illness, disability, or mental health conditions (NSW Health, 2018).

Integrated care is considered best practice for managing complex neurological conditions like MS. Studies show that coordinated, multidisciplinary care improves outcomes, particularly when MS nurses, rehabilitation, and psychosocial supports are involved (Bartolomeu Pires et al., 2023; Sorensen et al., 2019). GPs play a role in MS care and remain essential for general care, however may lack the capacity to coordinate complex, condition-specific needs.

Models such as the MS Care Unit demonstrate how structured, team-based approaches with shared protocols and follow-up systems can improve outcomes, satisfaction, and system efficiency (Sorensen et al., 2019).

The ParkinsonNet model, although developed for Parkinson's disease, also illustrates how regional care networks supported by digital tools and workforce training can improve integration, outcomes, and efficiency (Bloem et al., 2017; 2020). While not directly transferable, it highlights the potential of structured, digitally enabled care coordination in complex neurological conditions.

Workforce limitations remain a key barrier to delivering coordinated MS care. MS Nurses play a vital role in ongoing support, education, and care navigation, yet role inconsistencies, limited availability in public settings, and shortages in regional areas constrain their reach (MS Nurses Australasia, 2022). There is limited access to broader multidisciplinary supports, despite strong support for integrated approaches.

The National Disability Insurance Scheme (NDIS) has reshaped access to disability-related supports, but operates by-design, in parallel to health care, with few mechanisms for coordination. While earlier estimates suggested that only around 30% of PwMS would meet NDIS eligibility (MS Australia, 2021), current data shows that 11,807 PwMS were NDIS participants as of 30 September 2024, representing approximately 36% of the national MS population (National Disability Insurance Agency, 2024).

People not eligible for the NDIS must rely on fragmented health, community, and carer systems with limited coordination or continuity of care (Olney, Mills, & Fallon, 2022). Many previously available state-funded supports were reduced or restructured with the introduction of the NDIS, leaving few alternatives. As the 2023 NDIS Review noted, the lack of foundational supports and inclusive mainstream services continues to push people towards the NDIS, including through referrals from other service systems seeking access to uncapped support (NDIS Review, 2023).

While little is known about how MS care is structured or experienced in Australia, mapping in the Australian Capital Territory found subspecialised services were limited, predominantly health-related, and delivered largely within general neurology settings. There were no dedicated social or coordination services, and overall provision was fragmented, with resources working in isolation and lacking central coordination (Tabatabaei-Jafari et al., 2023).

A 2021 Australian qualitative study explored healthcare experiences among PwMS and their treating clinicians, identifying the importance of communication, decision-making support, and therapeutic rapport (Price, Lucas, & Lane, 2021). However, this study focused largely on individual clinical interactions, rather than how services are accessed, coordinated, or experienced at a system level.

These gaps reinforced the need to examine MS care experiences across other parts of the health system, including in NSW. Despite international models and local initiatives, there remains limited published research assessing whether current systems deliver coordinated, person-centred care. This gap informed the rationale for this project.

# Approach

The project used a mixed-methods approach to explore systemic gaps and co-design recommendations of integrated care that reflect the real-world needs of people living with MS, their carers, and frontline health professionals. Undertaken between July 2024 and June 2025, the project focused consultation on the Western Sydney Local Health District (WSLHD).

### Consultation

Consultation for the MS Integrated Care project included:
- Surveys with PwMS
- online focus groups with PwMS
- Online and in-person interviews with health professionals

### Focus group inclusion criteria

Eligibility for focus groups required PwMS to be engaged in collaborative care within the Western Sydney Local Health District, defined as accessing allied health services through MS Plus Wellbeing Centre in Lidcombe, New South Wales (NSW), and seeing a neurologist based in Western Sydney or nearby.

The project lead confirmed eligibility by reviewing MS Plus client records, identifying 73 potential participants. To be invited, individuals also needed to be aged between 19 and 70 years, have a confirmed diagnosis of multiple sclerosis for at least six months, and not have opted out of communication.

Emails were then sent to 73 PwMS inviting them to participate. Invitations included information about rights, privacy, project aims, and contact details for further enquiries. Eighteen people (16 PwMS and 2 carers) initially expressed interest, with 11 ultimately taking part in the focus groups (10 PwMS and 1 carer).

### Focus groups with PwMS

Initial focus groups were held virtually and facilitated by the project lead. Five small groups (2–3 participants each) explored lived experiences of MS care through semi-structured questions, and sessions were recorded with participants' consent. The participant profile is provided in Table 1 (PwMS n=10, 1 carer).

Following this, 4 secondary focus groups were conducted in which participants (6 PwMS, 1 carer) reviewed a visual summary of the draft framework and provided semi-structured feedback on each theme, using the same evaluation domains as the survey.

**Table 1. PwMS focus group demographics: invited vs participated**

| | Invited (n=73) | Participated(n=10) |
|---|---|---|
| Age (years) | 47.3 years | 51.1 years |
| Female | 55 (75.3%) | 8 (80%) |
| Male | 17 (23.3%) | 2 (20%) |
| Unknown | 1 (1.4%) | 0 |
| Average years since diagnosis | ~12 yrs | ~12.2 yrs |
| NDIS Participant | 18 (24.7%) | 9 (90%) |
| Resident of WSLHD[1] | 30 (41.1%) | 5 (50%) |
| Average IRSD[2] rank | 5.87 | 6.60 |

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[1] Western Sydney Local Health District

[2] Index of Relative Socio-economic Disadvantage (IRSD) ranks range from 1 (most disadvantaged) to 10 (least disadvantaged), based on relative disadvantage within New South Wales.

## Surveys

To build a more comprehensive understanding of PwMS experiences across NSW, two online surveys were conducted and distributed via targeted mailing lists drawn from MS Plus' client management system. Surveys were anonymous and required only minimal identifying information, such as suburb and postcode. Further demographic details are outlined in Table 2 below.

### Initial consultation survey:

- A 55-question survey was distributed to 3,855 PwMS across New South Wales. It explored care experiences, access to neurologists and allied health professionals, communication between providers, symptom navigation, and how wellbeing needs were being met. The survey included both multiple-choice and free-text questions to capture a broad and detailed picture of lived experience.

### Secondary consultation survey:

- A follow-up 49-question survey was sent to 3,721 PwMS across NSW using the same email list as the initial consultation, with unsubscribed or bounced emails excluded. The survey presented the proposed MS Integrated Care Framework, asking PwMS to assess each theme for relevance, usefulness, acceptability, and feasibility. Each section included a brief description, visual summary, and 4–5 targeted questions with optional free-text responses. Participation was open to all PwMS, regardless of prior involvement. Among respondents, 15% had completed the initial survey, 21% had not, and 64% were unsure.

**Table 2. Survey participant demographics and MS profile**

| Survey Demographics | Participated (n=287) |
|---|---|
| **Location classified by Modified Monash Model (MMM)[1]** | |
| MMM1 -MMM2 | 199 (69.3%) |
| MMM3-MMM4 | 40 (13.9%) |
| MMM5-MMM7 | 48 (16.7%) |
| Resident of WSLHD[2] | 29 (10%) |
| NDIS Participant | 142 (50.5%) |
| Average IRSD[3] rank | 6.0 |
| **MS type** | |
| Relapsing Remitting MS | 222 (77.3%) |
| Secondary Progressive MS | 26 (9%) |
| Primary Progressive MS | 18 (6.2%) |
| I haven't been told a specific type of MS | 18 (6.2%) |
| Other[4] | 3 (1%) |
| Average years since diagnosis | ~12.2 yrs* |

[1] The Modified Monash Model (MMM) classifies areas by remoteness and population size: MMM 1–2 = metropolitan and regional centres; MMM 3–4 = large and medium rural towns; MMM 5–7 = small rural towns to very remote areas.
[2] Western Sydney Local Health District
[3] Index of Relative Socio-economic Disadvantage (IRSD), range from 1 (most disadvantaged) to 10 (least disadvantaged).
[4] Includes cases with unclear or conflicting MS diagnoses, such as those described as possibly PPMS but also told RRMS.
* Year of diagnosis based on 154 responses.

### Health professional engagement

Both public and private MS / neurology clinics within metro Sydney were invited to participate.

Individual GP clinics and neurologists within WSLHD were contacted directly. A broader invitation was shared through MS Plus health professional newsletters, and WentWest, the region's Primary Health Network (PHN), supported further distribution through their networks.

Semi-structured, one-on-one interviews were conducted online, each lasting 45 to 60 minutes.

Thirteen clinicians agreed to participate in the first round of consultation, with eleven completing interviews. For the evaluation phase, eight health professionals took part in interviews, and two others provided written feedback.

Participants (n= 11):

- 2 neurologists
- 6 MS Nurses or Nurse Practitioners
- 1 MS dietitian
- 2 GP Liaison Officers

### Data collection and analysis

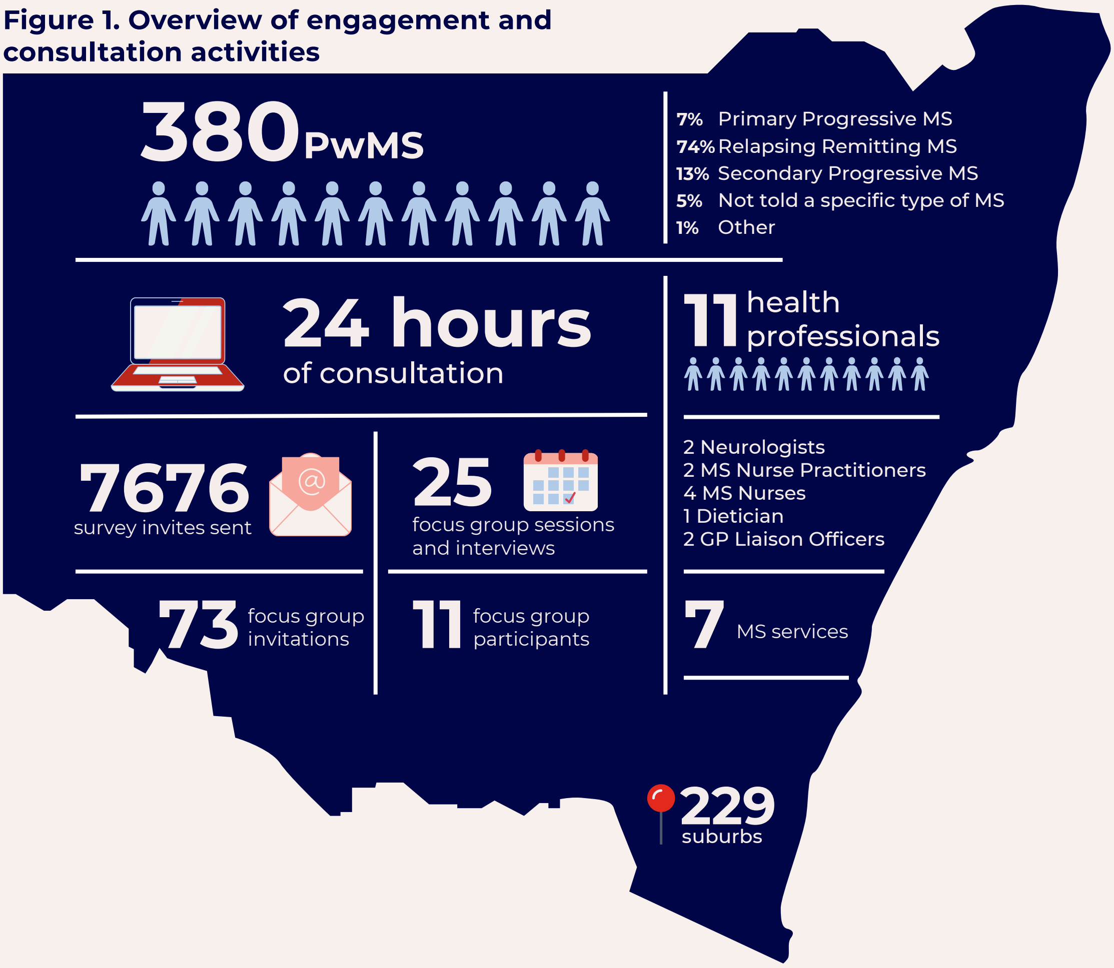
Quantitative survey data were analysed descriptively. Open-ended survey responses and transcripts from focus groups and interviews were thematically analysed to identify key patterns in care access, coordination, and support needs. These were grouped into core domains spanning service delivery, individual experience, and systemic enablers.

### Framework development and consultation

Themes and insights from the consultation were synthesised into a draft integrated care framework structured around three levels of action:

- **People:** Strategies directly impacting or led by PwMS and their carers
- **Services:** Approaches to improve referral pathways, care navigation, and professional roles
- **Systems:** Higher-level policy and funding enablers to support integration and sustainability

**Figure 1. Overview of engagement and consultation activities**



# MS Specialist Care

## Snapshot

MS specialist care is essential to support PwMS in managing their condition effectively. Many described neurologists as trusted, knowledgeable, and central to their care. However, short appointments, limited follow-up, and fragmented communication sometimes left people feeling unsupported. Stronger referral pathways, greater access to MS Nurses, and more tailored support for underserved populations, including people in rural and remote areas and living with Primary Progressive MS, were identified as key improvements to strengthen MS specialist care and reduce pressure on clinicians. Both PwMS and clinicians emphasised the need for consistent, coordinated, and respectful care built on trust, good communication, and shared understanding.

# 1. MS Specialist Care

This section focuses on the core clinicians who provide neurological care to PwMS, including neurologists, MS Nurses, and others working within or alongside MS services. While many of these clinicians are based in hospital neurology clinics or formal MS units, others operate in private practice or community settings. In this context, MS specialist care refers to the type of care provided, not just the provider's title or expertise level.

## 1.1 Neurologist type and specialisation

### Neurologist setting

PwMS access neurologists through public clinics or private practices. Public MS clinics are bulk-billed but sometimes can involve longer wait times and less continuity, with rotating clinicians. Private care offers shorter waits and more consistent providers but incurs higher out-of-pocket costs.

As outlined in Table 3, there was no notable difference in the proportion of PwMS accessing care through public or private systems.

### Neurologist specialisation

Neurologists may have general or MS-specific focus. All can diagnose and manage MS, but some specialise through dedicated clinics or research roles. Both contribute to care, though access varies by location, workforce, and funding. Most PwMS saw an MS-focused neurologist, while a small number were unsure of their neurologist's area of focus, if any (see Table 3).

**Table 3. Neurologist care setting and MS specialisation as reported by survey participants**

| Neurologist setting and type | Participants (n=290)* |
|---|---|
| **Neurologist setting** | |
| Seen through public service | 140 (48.4%) |
| Seen through private service | 141 (48.8%) |
| Not sure/ Unknown setting | 8 (2.8%) |
| **Neurologist specialisation** | |
| Neurologist with a focus on MS | 210 (72.4%) |
| General neurologist | 48 (16.6%) |
| Unsure/Unknown area of focus | 32 (11%) |

*Figures reflect first-round survey engagement only

## 1.2 MS specialist care lived experience

### Trauma and diagnostic experiences

The diagnostic experience can shape how people engage with care after an MS diagnosis. A number of PwMS described feeling their symptoms were dismissed or misattributed to psychological causes. For some, these early encounters left people feeling invalidated and contributed to lasting hesitancy in seeking or trusting healthcare support.

Clinicians acknowledged the lasting impact of negative diagnostic experiences and emphasised the importance of validation and clear communication. An MS Nurse in particular noted that high-quality specialist care following diagnosis can help rebuild trust and support re-engagement. Several PwMS also described the sense of relief that came with finding a clinician who believed them and made them feel seen.

### A closer look at collaboration

Throughout this report, we compare insights from two groups of PwMS, based on how well their health professionals worked together. Collaboration consistently shaped care experiences across all themes.

- The **high collaboration group** felt their GP and neurologist worked *very collaboratively.*
- The **low collaboration group** felt their GP and neurologist *did not work collaboratively at all.*

Look for this icon to compare experiences across collaboration groups as you read.

### Care experiences in MS specialist settings

Many PwMS spoke positively about interactions with neurologists who listened and provided tailored support, noting that feeling known and experiencing continuity across appointments helped build trust and encouraged ongoing engagement.

Several PwMS described more challenging interactions, particularly during early appointments or when continuity was lacking.

These included:

- feeling dismissed, rushed, or unheard
- limited time to ask questions
- symptoms being dismissed when not reflected on scans
- anxiety from delays in receiving MRI results

> “When I was first diagnosed, ...I was basically dismissed... I went to my GP, absolutely bawling, because I knew it wasn't in my head...and he referred me back to another neuro where they were more supportive and a lot more understanding.”
> Person with MS

### PwMS expectations of their neurologist

PwMS see their neurologist as responsible for coordinating key aspects of their care, including:

- monitor disease progression and explain treatment options,
- manage relapses,
- being aware of relevant supports and linking them in
- help coordinate care and communicate with GP’s and other providers, and
- provide education, information and updates

A number of PwMS expressed uncertainty about what their neurologist was responsible for, particularly when care involved rotating clinicians.

Neurologists and MS Nurses acknowledged this, noting that PwMS often view the neurologist as responsible for all aspects of care, rather than part of a broader team.

> “People think we’re in charge of it all, but we’re just part of the team.”
> Neurologist

While clinicians commonly described role confusion among newly diagnosed PwMS, findings suggest role confusion continues long after diagnosis, highlighting the need to revisit role clarity over time to support engagement.

## 1.3 Appointment preferences and PwMS reported satisfaction with care

### Access and appointment preferences

Most PwMS **(73%)** are willing to travel 30 minutes or more to see a neurologist, reflecting the high value placed on specialist care.

**1 in 5**

Would travel any distance to see a neurologist

However, this willingness was often accompanied by frustration, as many PwMS expressed a desire for support closer to home and felt that long travel should not be the only option to access care.

### Neurologist appointment format preferences

The majority of PwMS **(61%)** preferred face-to-face neurology appointments only, with only **1 in 3** PwMS interested in a hybrid model of telehealth and face-to-face support. Few PwMS would consider telehealth-only appointments.

While some PwMS valued telehealth for routine check-ins, it was not seen as a substitute for in-person care. Rural PwMS who relied on telehealth due to limited options highlighted issues such as missed calls and poor follow-up, reinforcing the need for flexible models that consider both appointment type and individual needs.

## PwMS reported satisfaction with neurologist care

As neurologists often remain a consistent point of contact throughout the MS journey, PwMS were asked to rate their experiences across four domains: communication, expertise, non-clinical management and accessibility. The following sections summarise these findings.

### Communication

As outlined in Figure 2, most PwMS (73%) were satisfied with neurologist communication, which covers things such as whether neurologists took the time to listen, explained things clearly, showed empathy, and allowed space for questions.

PwMS consistently emphasised the value of being listened to and feeling like their concerns or views were taken seriously. One PwMS described how their neurologist took their needle phobia into account, adjusting treatment and monitoring decisions to accommodate this while still ensuring their care needs were met.

Clear communication helped improve understanding, support shared decision-making, and built trust and ongoing engagement.

Almost

**3 in 4**

were satisfied to some degree with their neurologists communication

> “He has a fantastic bedside manner and I genuinely feel like he does care and he does listen. He's never dismissive even though I'm sure he's extremely busy. I really appreciate that.” Person with MS

### Expertise and knowledge

PwMS expressed high levels of confidence in their neurologist’s expertise, with 83% reporting some degree of satisfaction, the highest-rated domain. This underscores the neurologist’s central role as a trusted expert in diagnosis, treatment planning and medication decisions.

Many PwMS saw disease management and monitoring progression as the neurologist’s primary area of expertise. One PwMS noted that, because of this specialised focus, they did not expect their neurologist to have the same depth of knowledge in other areas of care.

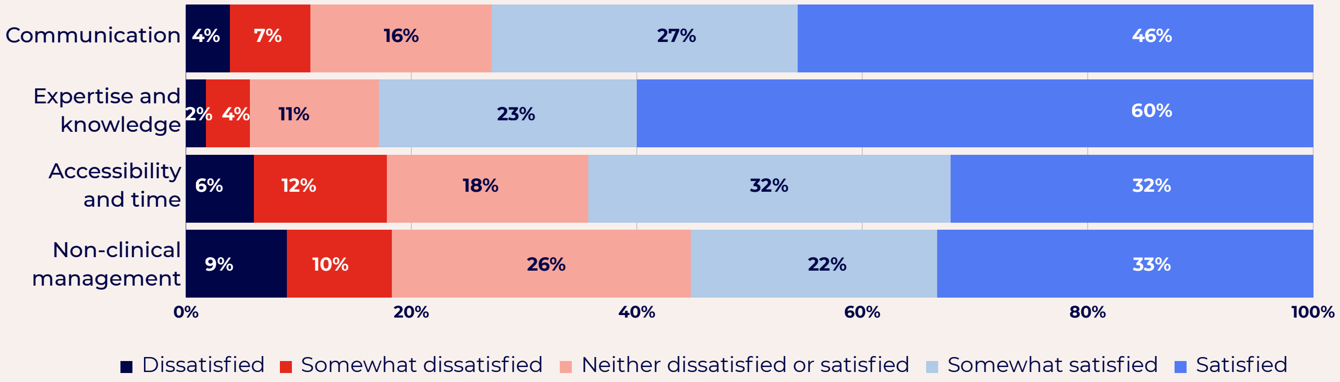
Almost

**4 in 5**

were satisfied to some degree with the level of expertise from their neurologist

> “I find my neuro mainly focuses on my disease progression and management. I think that is where his expertise lies. He lacks the skills or understanding to relate to my social situation. But I am fine with that.” Person with MS

**Figure 2. PwMS reported satisfaction levels across domains of neurologist care**



## Non-clinical MS management

While clinical management is a core part of the neurologist's role and an area where confidence is high, many PwMS felt their broader needs were not as well supported. Non-clinical management explored how well neurologists addressed areas such as emotional wellbeing, social support and overall quality of life, and whether these were considered in care planning and discussions.

**55%**

Were satisfied to some degree with support for non-clinical needs from their neurologist

Non-clinical management was the lowest-rated of all four domains, with nearly **1 in 2** PwMS **(45%)** either neutral or dissatisfied. This suggests that many felt their broader wellbeing was overlooked or not adequately addressed. Some PwMS did not see value in raising these concerns with their neurologist, suggesting this aspect of care may not be consistently recognised or responded to in practice.

> "They don't get it so why bother bringing it up" Person with MS

PwMS in high collaborative care:

- over **5 times** more likely to feel satisfied with communication and non-clinical management
- **2.5 times** more likely to be satisfied with neurologist expertise and knowledge, and time and accessibility

PwMS in low collaborative care:

- Over half **(57%)** reported no satisfaction with communication
- **5 times** more likely to be dissatisfied with neurologist expertise
- Nearly **1 in 2** were dissatisfied to some degree with accessibility and time, and with non-clinical management

What does this mean?

Collaborative care is linked with higher satisfaction across all areas of neurologist support, suggesting that coordination and communication between providers may play a key role in shaping positive experiences.

## Accessibility and time

Satisfaction with neurologist accessibility and time varied. This domain covered factors such as appointment length and the availability of follow-up support between visits when questions or concerns arose. While the majority **(64%)** reported a level of satisfaction, just over a third were either neutral or dissatisfied.

**1 in 3**

Were fully satisfied with neurologist accessibility and time

PwMS frequently described difficulty securing appointments and limited time during consultations to raise concerns beyond urgent issues. Many felt rushed, with one PwMS and their carer noting the walk to the consultation room sometimes lasted longer than the appointment itself.

> "I feel like the neurologist is walking us out the door before I'm even finished talking." Carer of Person with MS

Some PwMS said they would be willing to wait longer between appointments if it meant having more time with their neurologist, suggesting that longer, more meaningful consultations were worth the trade-off.

## Understanding perceptions of neurologist care

Most PwMS were satisfied across the four key domains of neurologist support. However, satisfaction was lower in relation to time and accessibility, and non-clinical management. Collaborative care was linked with higher satisfaction for all domains. These findings reflect PwMS's perceptions of care and are shaped by a range of factors. The following section explores broader system-level and service-related barriers that contribute to how MS specialist care is experienced.

### Support following diagnosis

PwMS expressed a strong desire for more information from their MS clinicians after diagnosis, with many supporting dedicated education early in the post-diagnosis period.

While most PwMS found early education helpful, some felt too much information at diagnosis would have been overwhelming. This highlights the importance of tailoring information to each person's stage, needs, and readiness.

Clinicians also supported this, with MS Nurses seen as best placed to deliver or coordinate it. However, this would likely place additional pressure on already stretched nursing roles.

Stronger support after diagnosis, better communication during symptom changes, and flexible education approaches are all needed to close the gap between clinical intent and lived experience.

### Uncertainty between visits and the ongoing need for guidance

PwMS described limited engagement with health teams outside of relapse events, often feeling uncertain or unsupported during periods considered 'stable'. PwMS felt appointments typically focused on treatment updates or MRI results, with less attention given to ongoing symptoms, daily challenges, or what to expect between visits.

Many expressed uncertainty about whether things were genuinely on track or if what they were doing was right, or enough, to manage their condition, leading to a sense of second-guessing and self-doubt.

> "I've relapsed every year, but I don't feel like my neurologist provides much information beyond saying *'you're stable'* or *'you need an MRI.'*" Person with MS

This uncertainty was not limited to those newly diagnosed. PwMS four or more years post-diagnosis described still learning how to understand and manage their MS, and continued to look to their neurologist for direction.

These expectations often reflected a perception of the neurologist as the central figure in MS care, reinforcing the need for clear communication and proactive guidance, particularly in the early years.

## 1.4 Unmet needs and access limitations in MS Specialist Care

### The essential role of MS Nurses in MS Specialist Care

MS Nurses were consistently viewed as essential by PwMS, particularly in helping navigate care, interpret treatment options, and coordinate services following diagnosis. However, access was uneven. Those seeing private neurologists often lacked MS Nurse support, which is more commonly available in public clinics or through medication support programs.

Many PwMS reflected on limited or lost access over time, with some noting that consistent MS Nurse contact early on would have made a substantial difference. Despite their vital, multi-faceted role, an estimated one third of PwMS do not have access to MS Nurse care (Chen et al., 2022). Nurses in this project reported managing 40–150 non-clinic contacts weekly, much of it outside appointments, covering education, coordination, and complex tasks such as NDIS paperwork.

There was overwhelming recognition from PwMS of the value MS Nurses bring to care. PwMS consistently described their positive impact and expressed a strong desire for access. Even those who no longer had access to an MS Nurse due to changing services, often recalled positive interactions from years earlier, highlighting the lasting difference MS Nurses can make when they are available.

> "My neurologist changed the access to the MS nurse. It has had adverse impacts. I would be happy to pay for this service." Person with MS

### Unmet needs in Progressive MS care

People with Primary or Secondary Progressive MS (PPMS/SPMS) often described infrequent, passive neurologist contact, feeling symptoms were overlooked or dismissed as ageing. Many felt unsupported in managing wellbeing, exercise, or function, and sensed little could be offered to help.

> “I've got PPMS…they just say, ‘*hey, how are you going?… we'll get you back here in six months.*’” Person with MS

Clinicians widely recognised people with progressive MS as underserved. Some linked reduced contact to limited treatment options but stressed this should not mean reduced care.

Clinicians saw standard six-monthly reviews as inadequate and supported tailored, co-designed pathways including housing, functional supports, and allied health. Broader support from physiotherapy, urology, and rehabilitation was considered essential. One clinician noted that unhelpful or inaccessible appointments could lead Progressive PwMS to disengage.

### Catchment rules restrict care

Access to neurology services was often determined by where people lived. Several PwMS reported that public MS clinic access was restricted by local health district boundaries. Some were unable to attend preferred clinics, even if willing to travel or pay, due to catchment rules, which was especially difficult in rural areas with limited options.

Some felt forced to attend local clinics that had dismissed their concerns or they felt lacked MS expertise. For some clinics, rising demand has led to stricter referral rules, with most out-of-area referrals redirected. Clinicians acknowledged the difficulty of turning people away and noted that access was often shaped by system limits rather than clinical need.

### Location barriers to neurologist access

PwMS in rural and regional areas reported major challenges accessing neurologist care. Long travel distances, limited local services, and disrupted continuity contributed to reduced access and increased burden.

Many PwMS regularly travelled three hours or more, often due to trust in a particular neurologist or dissatisfaction with local options. Some felt the travel was worthwhile for high-quality care.

> “It is now a 3+ hour drive for MS appointments and treatments, but it is worth it as the care is exceptional.” Person with MS

Lack of local specialists and long wait times, sometimes up to a year, compounded these challenges. Relocating from metropolitan to regional areas often disrupted established care relationships and weakened coordination with GPs.

Neurologist care in rural areas was often unreliable, with PwMS outlining missing referrals and specialists failing to attend telehealth appointments. Access was described as hit and miss, with few options and inconsistent service leaving many feeling uncertain and unsupported. As one PwMS said, “you don't have many choices or options.”

> “They [Neurologist] have consistently failed to respond to queries from my GP or attend pre-arranged telehealth consults. I have been left for days wondering if they will call as arranged.” Person with MS

These experiences point to ongoing geographic inequities in access to specialist MS care, with rural and remote residents facing longer wait times, limited continuity, and reduced service responsiveness.

> “The local health district zones being enforced means I cannot access the specialists I wish I could… My plan was to attend the [MS Clinic] because I want health professionals who are at the forefront of my condition… However, wait times and being out of area mean I do not have that option…” Person with MS

## 1.5 Integrated Care Framework – MS Specialist Care

Access to consistent, high-quality MS Specialist Care is widely recognised as essential, yet current experiences remain variable. While most PwMS value their neurologist's expertise, gaps in follow-up, non-clinical support, and service availability undermine continuity and trust. As outlined in Table 4 below, the framework prioritises clearer neurologist and MS Nurse roles, alongside strengthened coordination, to address unmet needs and reduce the burden on clinicians and PwMS. A logic model outlining recommended implementation steps is included in Appendix A.

**Table 4. Integrated Care Framework – MS Specialist Care**

| What we learned: | What we recommend: |
|---|---|
| Neurologist care was valued but siloed, with rushed appointments, and limited support beyond clinical care. PwMS often navigated services alone, while clinicians faced system barriers. | • **Care standards.** Set clear minimum standards for follow-up, check-ins, and care.<br>• **Post-diagnosis support.** Offer early support and education post-diagnosis. |
| PwMS wanted MS-specific communication, proactive care, and follow-up. People with PPMS felt overlooked, with clinicians calling for dedicated support. Neurologists were expected to manage all care, highlighting the need for clearer roles and team-based approaches. PwMS reported anxiety while waiting for MRI scan results, often made worse by delays and lack of communication. Clinicians also faced challenges accessing scans across systems, limiting timely follow-up. | • **MS-specific framing.** Use condition-relevant language and real-life examples.<br>• **National guidance.** Promote standards such as MS Brain Health to clarify roles, timeframes, and steps in specialist care.<br>• **Review pathway.** Use telehealth and MS Nurse-led escalation pathways to ensure people can stay connected and respond to changing symptoms.<br>• **Reminders and follow-up.** Provide timely updates after events like MRIs to help PwMS feel informed and supported between appointments. |
| PwMS faced long waits and limited access, especially in rural areas, due to high demand and stretched services. | • **Boost public clinic capacity.** Strengthen public services to enable timely, consistent access through better resourcing. |
| MS Nurse access was limited despite high demand, especially in rural areas. | • **Access to MS Nurses.** Give more PwMS access to MS Nurse support. |
| PwMS and clinicians saw coordinated access to MS Nurses, allied health, and mental health as essential for holistic, team-based care. | • **Fund multidisciplinary teams/service.** Support funding for multidisciplinary MS teams or services to enable coordinated, holistic care. |

**Key takeaways**

- Neurologists were trusted, but care was limited by short appointments and unclear roles
- PwMS are often unsure who to contact during symptom changes, and had trouble contacting their provider, with GPs most commonly contacted
- MS Nurses are essential but not consistently available, and more tailored post-diagnosis education and between-visit support is needed
- Underserved groups include PwMS with progressive MS and those in rural areas, facing persistent access and support gaps
- When care was collaborative, PwMS reported greater satisfaction and more positive outcomes

# Care Navigation and Coordination

## Snapshot

Effective care navigation and coordination are key to ensuring PwMS receive timely, appropriate, and connected care. However, many described the current system as fragmented, difficult to access, and heavily reliant on individual effort. This section examines the factors that influence how PwMS seek and access care, including their confidence navigating the system, understanding of different health professional roles, and the personal and systemic barriers that affect follow-through on referrals. It also outlines the support needed to enable more integrated, responsive care.

# 2. Care Navigation and Coordination

PwMS often navigate input from multiple providers, including neurologists, GPs and allied health, making effective care coordination essential. Care navigation and coordination refer to how these services are linked and how PwMS move between them, knowing who to contact, how care is followed up, and how information is shared. When well supported, this process reduces confusion and ensures care is timely, consistent, and responsive. This section explores the supports and barriers to that process for both PwMS and providers.

## 2.1 Communication across the care team

### How PwMS navigate and manage care

PwMS often felt solely responsible for navigating disconnected services, with little support or guidance. Repeating information, managing referrals, and coordinating care added stress, especially when dealing with fatigue, memory issues, or cognitive symptoms.

> "It is overwhelming managing the many supports I need... It is exhausting constantly monitoring, consulting, comparing, evaluating, staying objective while wanting to make it all go away, to feel a 'normal' person instead of a tired robot bouncing from one week's appointment to the next." Person with MS

### System-driven self-management

Among those living with MS for over a decade, some appeared highly skilled in managing their care. This confidence seemed to emerge not from structured support, but from repeated trial and error, learning to self-refer and navigate fragmented systems after facing gaps and setbacks.

> "I think my experience differs from others in that I have worked hard to find a consistent team to work with me and now the support is quite stable. Initially it was really hard to navigate." Person with MS

Many of these PwMS had built what they described as a well-established team of trusted providers and had learned to work around the system. However, this sense of stability was fragile. A single change, such as a neurologist retiring or a key provider relocating, could quickly unsettle even those with strong networks.

> "So while I'm in charge of the train, and all the cabooses are working merrily behind, I'm ok, but as soon as somebody wants to tip it off the rails... I go and find somebody else." Person with MS

Fragmented systems left PwMS carrying the burden of coordination. While this kept some on track, it often led to fatigue, disengagement, and declining trust when follow-up depended solely on their efforts.

## 2.2 Navigating symptom changes

### Confidence in care discussions

Most PwMS **(76%)** reported always or often feeling confident navigating and discussing their care with their neurologist.

**1 in 4**
did not consistently feel confident participating in care discussions with their neurologist

### Confidence in knowing where to go during symptom changes

Confidence among PwMS in knowing where to go during new or changing symptoms was inconsistent. While just over half of PwMS **(54%)** felt confident about who to contact, many still expressed uncertainty, raising concerns about timely access to appropriate care.

Almost
**1 in 2**
were not fully confident in knowing who to contact when symptoms changed

Neurologists and MS Nurses in the public system commonly reported that PwMS were provided with clinic contact details and encouraged to make contact when experiencing changing symptoms. Most of the MS Nurse workload reportedly occurs outside clinic sessions, with high volumes of contact from PwMS.

However, survey data suggests this support does not always translate to confidence. Over **40%** of PwMS in both public and private neurology care said they would feel unsure who to contact during a symptom change. Uncertainty was even higher among those unsure whether they saw a public or private neurologist, pointing to broader difficulties navigating the system.

Given the demand on MS Nurses, it is possible that their time is consumed by tasks beyond their clinical scope. This may reflect gaps in system coordination, and highlight the unmet needs PwMS are left to manage alone.

### First point of contact

During symptom changes PwMS would contact:
- GP **(44%)**
- Neurologist **(41%)**
- MS Nurse from clinic or neurology service **(30%)**
- Other MS Nurse service eg: phone based **(6%)**
- Wouldn't contact anyone **(7%)**

When experiencing new or changing symptoms, PwMS contacted a range of services. Although neurologists are typically viewed as leading MS care, GPs were more commonly the first point of contact. While many PwMS valued access to MS Nurses, only a small proportion reported using telephone-based nursing services during these situations.

These findings highlight the need to strengthen GP involvement and clarify roles during change. Low use of telephone-based services may reflect a preference for known providers or a view that remote support suits non-urgent issues, though reasons remain unclear.

### Access is inconsistent

PwMS **(65%)** often relied on a single provider as their main contact, making that access point critical. However, many reported difficulty contacting them, highlighting a barrier to timely support.

**1 in 2**
report sometimes or often having trouble getting in touch with their healthcare professional

PwMS in high collaborative care:
- nearly **3 times** more likely to always feel confident participating in care decisions with their neurologist
- nearly **twice** as likely to feel confident about what to do during symptom changes

PwMS in low collaborative care:
- **1 in 2** felt only occasionally or never confident participating in care decisions
- **11%** wouldn't contact anyone about symptom changes (vs **0%** in high collaborative care)

What does this mean?

PwMS in collaborative care report more confidence navigating care and knowing what to do. Those in low collaborative care may face more uncertainty, or not engage in care.

### Emotional considerations when seeking help

An area that may need greater recognition is the emotional process PwMS go through when experiencing new or changing symptoms. Many described trying to rationalise these symptoms, attributing them to poor sleep, stress, or other unrelated causes, as acknowledging they might be MS-related felt too confronting.

> “.. the first thing I want to think is, ‘no, it's not’... I want it to be something else before it is MS.” Person with MS

This pattern was seen not only in those recently diagnosed, but also in PwMS who had lived with MS for many years. Emotional responses, including fear of progression, often delayed help-seeking, highlighting the need for care responses that address both clinical and emotional needs.

## 2.3 Understanding care needs

Understanding and navigating MS care requires more than general confidence in speaking to health professionals. PwMS must also know which providers to contact for specific issues, and whether those providers have the MS-specific expertise needed to offer appropriate care.

### Confidence in identifying the right type of health professional

Most PwMS **(69%)** said they felt confident knowing the right type of health professional for a given issue, such as whether to see a physiotherapist, psychologist, or other discipline.

For example, someone experiencing changes in bladder function may recognise they need to see a continence nurse.

Almost

**1 in 3**

were unsure or not confident knowing the right type of health professional to see

### Confidence in identifying the right provider for MS needs

Most PwMS **(66%)** felt confident identifying the right provider for their MS-specific needs. For example, knowing to seek a dietitian familiar with chronic illness and MS-related fatigue, instead of one focused mainly on sports nutrition.

Almost

**1 in 3**

were unsure or not confident identifying the right provider for MS-specific needs

### Likelihood of seeking out a provider for MS care

Most PwMS **(70%)** would proactively seek out a health professional to support their MS management.

Almost

**1 in 3**

were unsure or unlikely to proactively seek out a health professional to support their MS care

### Understanding care needs: What this tells us

Most PwMS reported confidence in knowing which type of health professional to contact, identifying MS-specific providers, and said they would seek support when needed. However, as the next section shows, this confidence does not always translate into action.

> “...you get a bit of information, but you do actually have to look a little bit. Not everything's going to be laid to you on a platter. Doing a little bit of research yourself helps, and within that research, discussing it with your health care providers. You can't be static and not do anything...there are some responsibilities for your own health.” Person with MS

## 2.4 Referral pathways and care follow-through

Referrals play a critical role in connecting people to the right supports. While most PwMS reported confidence in identifying the right provider and intention to seek care, this does not always translate into access, and many still encounter gaps or barriers that prevent them from following through.

### Motivation to engage with care

PwMS reported high motivation, with over **90%** indicating they were likely or very likely to act on referrals or care suggestions from their neurologist or GP.

### Direct referrals from neurologist

Despite strong motivation to act on care recommendations, many PwMS reported limited support from neurologists in connecting to additional services.

As shown in Figure 3, most **(60%)** had received at least one direct referral, where they were connected with a specific provider or given contact details. However, few received more than one.

### Referral recommendations from neurologist

Somewhat unexpectedly, general referral recommendations were less common than direct referrals (Figure 3). Just under half of PwMS **(47%)** had been advised to see another provider without being told who to contact.

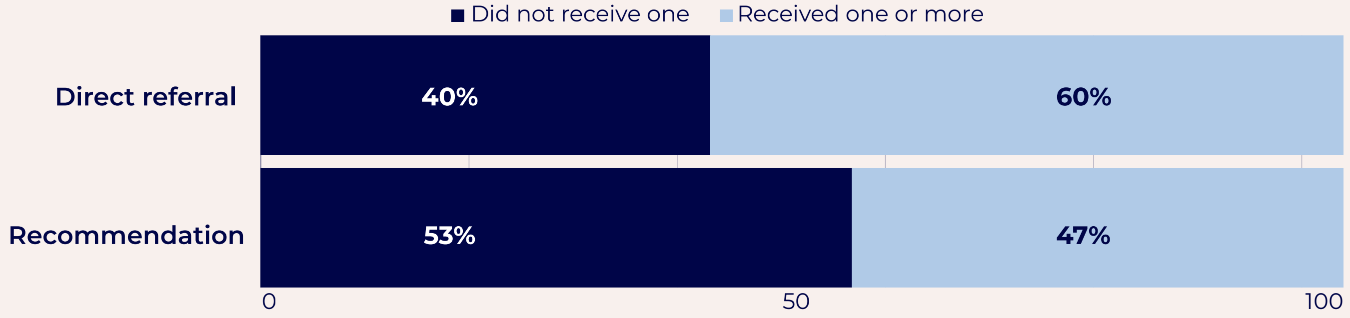
This may suggest that neurologists are more likely to act when a clear service pathway or provider is known, rather than offering a general referral recommendation. However, the survey question did not specify a time period, limiting interpretation of whether responses reflect recent experiences or referrals received at any point in the care journey.

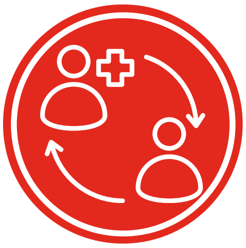
More than

**40%**

of PwMS have not received a referral or recommendation from their neurologist

**Figure 3. PwMS reported referral types received from neurologist - direct vs recommendation**





PwMS in high collaborative care:

- were **3 times** more likely to get a direct referral from their neurologist compared to PwMS in low collaborative care

### Barriers to acting on care recommendations

For those who were referred to other services, many faced practical and systemic barriers that made follow-through difficult.

While a small minority of PwMS (10%) reported they always followed up on referrals, most PwMS faced one or more obstacles. The most common barriers reported were:

- 46% cost
- 35% inconvenient locations
- 24% other time commitments (e.g. work, family, school)
- 18% too many appointments
- 17% difficulty finding a suitable time
- 18% impact of MS symptoms (e.g. fatigue, cognition)

Other barriers cited included mental health concerns, lack of confidence in themselves or in services, or lack of wheelchair-accessible facilities.

### Access and affordability in allied health

When considering allied health in particular, cost was both a common and frequent barrier. Nearly 63% of PwMS reported that cost limited their access to allied health at least half the time, highlighting how financial pressure consistently interferes with care. The broader impact of financial barriers on MS care is explored in more detail in the Wellbeing Supports chapter.

### Clinician insights on referral barriers

Clinicians echoed many of these challenges. Cost and access were frequently raised, particularly in areas with high service demand such as Western Sydney.

> "In the Western suburbs, not a lot of people could afford that… you knew that if they had all of this input, they could do much better." MS Nurse

Neurologists also highlighted the difficulty of keeping up with referral options.

> "I still don't understand all the services that are available for me to refer to… I learn week to week, and it changes." Neurologist

This limited awareness of referral options, combined with informal referral practices, often led to reactive care, leaving PwMS to self-manage complex systems with few safeguards if support was missed.

## 2.5 PwMS perspectives on care communication

Poor communication between healthcare professionals left many PwMS feeling that their care team operated in silos. PwMS frequently had to update each clinician separately, unsure whether information was passed on or valued.

> “You have to navigate it yourself. Not many people speak to each other within your health professionals.” Person with MS

### PwMS role in sharing allied health updates with neurologist

Although allied health plays a key role in MS care, only 1 in 3 (33%) PwMS consistently share updates about allied health involvement with their neurologist, whether verbally updating or through sharing formal reports.

Almost

**1 in 3**

rarely or never share these allied health updates with their neurologist

Clinicians noted that allied health professionals often see PwMS more regularly and gather valuable insights. While they valued being kept informed, they acknowledged that updates are rarely shared unless prompted.

### PwMS perceived value placed on allied health updates by neurologists

Despite clinicians valuing allied health updates, only 46% of PwMS felt their neurologist considered them important, highlighting a disconnect in communication and in the perceived value of shared input across the care team.

**1 in 5**

PwMS felt their neurologist didn’t see allied health updates as important

PwMS in high collaborative care:

- were **4 times** as likely to always share allied health information
- were **3 times** as likely to feel their neurologist saw this information as important

PwMS in low collaborative care:

- were **5 times** more likely to rarely or never inform their neurologist about allied health care
- were **12 times** as likely to feel their neurologist did not view allied health updates as important

What does this mean?

PwMS in more collaborative care settings are more likely to share allied health updates and feel these are valued than those in low-collaboration settings, suggesting that the level of collaboration may influence communication and trust.

> “I have to tell them what I’m doing with the exercise physiologist… I don’t feel like they see the link as important.” Person with MS

## 2.6 Gaps and enablers in care navigation and coordination

### Coordination gaps and the burden on MS Nurses

MS Nurses are central to MS care and often provide key continuity, but their coordination role is rarely formalised, resulting in overwork, inconsistent follow-up, and variable access.

In many settings, care coordination is undefined and unfunded, often falling to MS Nurses or individuals, leading to inconsistent follow-up and hidden gaps. For PwMS without access to an MS Nurse, these coordination gaps are even more pronounced, with no clear fallback for navigating referrals, follow-up, or care transitions.

To support referral coordination for PwMS, many MS Nurses maintained personal lists of trusted providers. However, this workaround was fragile, time-consuming, and difficult to sustain. When staff leave, service knowledge is often lost, particularly in regional areas with high turnover and limited provider options.

> “I had a book I would take to clinic… but gradually that’s not perfect either. They change or move suburbs or their clinics close, and then you’re back to square one.” MS Nurse

The current approach is unsustainable. MS Nurses carry essential but unsupported responsibilities. Sustainable care requires formalising coordination roles through investment, reducing duplication, and relieving MS Nurses of unsupported tasks.

### Priorities for effective care navigation and coordination

PwMS valued clear care pathways, known contacts, reliable provider communication, and follow-up on referrals. MS-informed professionals and simple ways to check in between appointments were seen as helpful to stay engaged in care. Coordination was seen as essential during relapses as well as in periods between active symptoms, when support needs still remained.

Digital tools like secure messaging were supported by both PwMS and clinicians but remain largely unavailable. While many saw potential to improve real-time communication, concerns were raised about privacy, provider capacity, and poor system integration. Simple solutions like shared provider directories were also endorsed to improve visibility and reduce coordination burden.

> “This position needs to be truly accessible, e.g., if the coordinator is not available in person there needs to be a system for the 'patient' to leave a message and for the coordinator to follow-up within a fixed period. Or if they can't answer the phone, then they also return the call within a certain timeframe. No point providing a Care Coordinator function if its unreliable, intermittent and/or has no follow-through. That is disappointing.” Person with MS

> “It's often left to MS Nurses to wear so many hats. Because they're the person wearing the hat of the physio, the dietitian, the psychologist, the life coach… and that's why they're so swamped and overwhelmed. Nursing isn't just poor man's medicine. It's a real art form in itself.”
> MS Nurse

## 2.7 Integrated Care Framework – Care Navigation and Coordination

There is strong consensus that improved care navigation and coordination are essential for high-quality MS care. PwMS need to know who to contact, when, and how, particularly during periods of change or crisis. As outlined in Table 5, the proposed Framework focuses on embedding roles, tools, and communication systems into routine care to reduce fragmentation, improve continuity, and lessen the burden currently carried by individuals. A logic model outlining recommended implementation steps is included in Appendix B.

**Table 5. Integrated Care Framework – Care Navigation and Coordination**

| What we learned: | What we recommend: |
|---|---|
| Many PwMS are unsure who to contact during symptom changes and lack confidence navigating the system. Uncertainty and emotions like fear or denial often delay help-seeking. | • **Care team connections.** Make sure people know who to contact and how to reach their care or support team across services.<br>• **Shared planning.** Involve PwMS and carers in care planning using checklists or tools. |
| Fatigue, symptoms, and short appointments make it hard for PwMS to share updates. PwMS may forget what to say or lack confidence that updates are valued. | • **Update tools.** Encourage people to share symptom and health changes with their team via secure messaging, symptom trackers, or apps. |
| Allied health updates are often not passed on to neurologists. PwMS are unsure whether shared information is acknowledged or used. | • **Team communication.** Help all parts of the care team share updates and stay connected. |
| Without shared systems, coordination relies on workarounds. MS Nurses carry this burden without support, limiting follow-up and leaving PwMS to chase referrals, repeat their story, and miss check-ins. | • **Integrated care roles.** Fund MS care coordinator positions in community or hospital settings.<br>• **Care coordinator check-ins.** Support regular check-ins from care coordinators to help manage follow-up, appointments, and referrals.<br>• **Care coordination.** Digital tools to help services track referrals and follow-ups across services. |
| Clinicians and PwMS both struggle to identify MS-informed providers. | • **Workforce access.** Build and maintain a national directory of MS-trained providers. |

### Key takeaways

- PwMS often manage fragmented care alone, especially during symptom changes
- PwMS feel confident seeking help from other providers, but barriers like cost often prevent follow-through
- MS Nurses are regarded as central to care coordination, but many PwMS experience inconsistent or limited access due to high demand and workforce constraints
- Few PwMS received referrals from neurologists, but when they did, these were more often direct than general suggestions
- PwMS often don't share allied health updates, and are unsure if this is valued by neurologists
- Service gaps and fluctuating availability made referral pathways difficult to sustain

# GP, Allied Health and Community Care

## Snapshot

PwMS often engage with GPs, allied health, and community supports alongside specialist care, but preferred providers with MS knowledge and were willing to wait for them. Poor coordination and unclear roles contributed to gaps, delays, and frustration, while strong GP–neurologist collaboration improved care. Face-to-face care was strongly preferred, with rural PwMS facing additional barriers from distance and limited local services. Addressing these issues will require early engagement, clear pathways, and MS-specific training, supported by a coordinated network to connect people with MS-aware providers and improve access and continuity.

# 3. GP, Allied Health and Community Care

GPs, allied health professionals, and community services play a central role in supporting the day-to-day health and wellbeing of PwMS. These providers often complement specialist care, though access and coordination vary widely. This section explores how PwMS interact with these providers, clinicians' insights, barriers to informed care, and what's needed to strengthen shared care.

## 3.1 General practice: Access, roles and experiences

### The role of GPs in MS care

While not always seen as central to MS care, GPs are a consistent point of contact for prescriptions, referrals, paperwork, and general health concerns. Many PwMS, particularly those in rural areas, rely on GPs between neurology visits. MS Nurses highlighted the vital role GPs play in maintaining continuity of care, even if their contributions are often under-recognised.

Experiences with GPs were mixed. PwMS often reported limited MS knowledge and inconsistent follow-up, with some expected to explain treatments or prompt action themselves.

> "My GP has to rely on my knowledge of MS to tell her about medications."
> Person with MS

Others reported positive experiences, describing their GP as a central part of their MS care team and, for some, the key to making everything work. In contrast, some PwMS struggled to find a regular GP at all, particularly in rural areas, where long waits to see the first available doctor were a barrier to continuous care.

> "There is a GP shortage in my town. I see any doctor who is available as there is often a 3-4 week wait for appointments. This does not foster good continuous healthcare."
> Person with MS

Some PwMS viewed their GP as a reliable fallback when other providers were unavailable. While not MS specialists, GPs were appreciated for being accessible and responsive to everyday needs, making them a valued part of the broader care network.

### System pressures and communication breakdowns

General practice operates under substantial time and funding constraints. GP Liaison Officers pointed to Medicare's bulk billing incentives, which reward high-volume output. Many GPs must complete up to six appointments per hour to remain financially viable, leaving little time for in-depth care planning or coordination. For PwMS, this model is a poor fit.

Health professionals acknowledged these constraints, but stressed that even small actions, like brief outreach or timely follow-up, can support better care continuity. PwMS expressed a strong desire for clearer roles across their care team and more direct communication between GPs and neurologists. While they did not expect every provider to have deep MS knowledge, they wanted symptoms to be taken seriously and appropriately escalated when needed.

Both clinicians and PwMS reported that GP referrals often lacked detail, and that neurologist letters were delayed or omitted, placing the burden of information-sharing on the individual.

### Improving shared care

Where GPs were described as proactive and collaborative, care felt more connected. However, this was not the norm. Missed opportunities for shared care often stemmed from unclear referral pathways and delayed updates rather than a lack of goodwill. Clear escalation protocols, regular communication, and practical tools, not just MS-specific training, were identified as key enablers of better GP involvement.

> "they're not very knowledgeable on MS, but ... my GP has been great at helping me access stuff, like getting a disability permit ... My GP is very readily accessible, if I was really sick and I couldn't contact my neurologist, I know I could get to the GP pretty quickly." Person with MS

## 3.2 GP–Neurologist collaboration and care integration

### PwMS rating of collaboration between GP and Neurologist

As outlined in the previous chapters, many PwMS described having to manage disconnected care pathways, often acting as the primary link between services. This was particularly evident in the relationship between GPs and neurologists, where communication gaps, unclear responsibilities, and inconsistent follow-up left PwMS acting as the only point of connection between their GP and neurologist.

When asked how well they felt their neurologist and GP communicate and work together in managing their MS care, PwMS reported:

- 15% very collaboratively
- 30% somewhat collaboratively
- 25% neither collaborative nor uncollaborative
- 29% not very collaboratively or not at all collaborative

Almost

**1 in 3**

felt there was minimal or no collaboration between their neurologist and GP

Few PwMS felt their GP and neurologist worked collaboratively. While some described a degree of coordination, only a small number reported strong collaboration. A similar number felt there was little or none, and many were unsure or described it as neutral. This inconsistency often left PwMS responsible for bridging gaps between services.

### Common barriers and experiences in care between GP and Neurologist

Many PwMS described frustration when GPs dismissed their concerns or redirected them to the neurologist, even for non-MS issues.

> "I find it frustrating that whenever I have any sorts of symptoms of anything, even if they might not be related to MS, my GP just tells me to talk to my neurologist."
> Person with MS

Others noted that while neurologists often shared reports or summaries, these were not always received or followed up by GPs. Where communication failed, care felt fragmented, and PwMS were left to act as the sole link between providers, managing updates, chasing referrals, and navigating conflicting advice.

Despite these challenges, some described positive experiences with collaboration. PwMS who had consistent teams in place, or GPs who were proactive in engaging with neurologists, reported more integrated care.

> "My GP is key to making everything work. She is amazing, but the others seem to operate in isolation and rely on me bringing everything together."
> Person with MS

Others shared that neurologists encouraged transparency and included the full care team in correspondence when possible, improving communication and shared decision-making.

### Common barriers and experiences in care between GP and Neurologist

Health professionals acknowledged persistent gaps in collaboration between GPs and neurologists. MS Nurses observed that many GPs lacked familiarity with MS and were hesitant to manage MS-related concerns, often redirecting these to neurology. This contributed to fragmented care and placed additional burden on both PwMS and specialists.

One neurologist noted that communication breakdowns are not solely a general practice issue, and that specialists also need to take greater responsibility for improving shared care. Without clear, two-way communication, PwMS are often left navigating their own care across disconnected providers.

> "...we need to be honest that many specialists don't communicate well with GPs. That has to change too." Neurologist

Both PwMS and clinicians called for shared documentation, role clarity, and defined protocols to reduce the coordination burden that currently falls on individuals. In rural and regional areas, where specialist access is limited, GPs play a critical role in maintaining continuity of care. Strengthening collaboration between these core providers remains essential to delivering integrated, person-centred support for PwMS.

Insights from GP Liaison Officers highlighted the growing complexity of general practice, where GPs manage multiple chronic conditions with limited time and no reimbursement for work outside consultations. While neurologists typically provide adequate MS-specific information, they are often not involved in broader health issues affecting PwMS.

GPs are left to manage overlapping concerns, such as vaccine safety, medication interactions, and comorbidities, without direct input. With multiple specialists referring back to general practice, the workload is increasingly unsustainable. Liaison Officers stressed that expecting GPs to develop specialist-level MS knowledge is unrealistic and called for clearer shared care arrangements to support more coordinated management.

> "And so when it comes to ringing or emailing the neurologist and saying, '*What should I be thinking about?*'...I'm less likely to go '*Yes, I can spend the time investigating that.*' And if that time's out of the consultation time, that's in my admin time, which I get no money... [If they are a] 10 minute doctor, '*Speak to your neurologist*'".
> GP Liaison Officer

## 3.3 Allied health & community supports in MS care

### Factors shaping access to allied health support

Most PwMS preferred nearby allied health services, with **78%** unwilling to travel more than 30–60 minutes. While provider expertise was valued, practical factors like travel time, transport availability, and cost often shaped decisions, particularly for those relying on NDIS transport funding or support workers. Several PwMS described choosing less specialised providers to make limited resources stretch further.

> “My physio (specialised in MS) is far away from home. I am using Ubers and I am paying 2/3 of the total fare as NDIS only covers 1/3. I have thought on stopping going to that physio and look for just any physio closer to home.” Person with MS

Although **86%** of PwMS said they preferred to wait for an allied health professional with neurological expertise, some made trade-offs when symptoms required urgent attention. This reflected a desire for MS-informed care that is also timely and accessible.

### Appointment preferences and service format

Over half of PwMS (**54%**) preferred a mix of face-to-face and telehealth allied health appointments. Format preferences were discipline-specific; telehealth was seen as appropriate for services like psychology and dietetics, while physiotherapy and ‘hands-on’ therapies were expected to be delivered in person. This highlights the importance of tailoring hybrid models to both the type of service and the stage of treatment.

### Frustrations with poorly tailored or unrealistic care

Many PwMS reported disengaging from allied health services when care did not reflect their needs. Common concerns included exercise programs that failed to accommodate MS symptoms, limited understanding of fatigue, and emotionally taxing expectations.

> “I get long lists of exercises and stuff that I need to do… I just get so overwhelmed. I can barely do that… then I think, *‘oh, there’s no point going back because I haven’t done the exercises.’*” Person with MS

Some also expressed frustration at having to educate providers on basic aspects of MS. PwMS supported improved training and practical resources for health professionals to reduce the education burden falling on them and enable more meaningful engagement.

> The physio I attend has a recumbent bike but it doesn't have foot straps so my feet just slip off and its pointless. “ Person with MS

### Improving early engagement with supports

Clinicians and PwMS highlighted the need for plain language information at diagnosis to explain the role of allied health and support early, confident engagement. Practical tools such as brochures, symptom checklists, and role summaries were recommended to help people understand who is involved and why. This may ease confusion and reduce fear that referrals signal disease progression. Framing allied and community health as a routine, preventative part of MS care could encourage earlier and more sustained engagement.

### Making training practical and accessible

There was broad agreement that improving allied health integration requires more than individual upskilling. Project participants recommended a national MS Learning Hub, led by a trusted organisations, to provide CPD-accredited micro-training, factsheets, and practical tools. Clinicians emphasised that training must be relevant, time-efficient, and easily incorporated into daily practice.

### Recognising underused allied health roles

Greater recognition of allied health contributions was also seen as essential. While roles like physiotherapy are more commonly integrated into MS care, others such as dietetics remain underutilised. One dietitian noted that nutrition plays a key role in managing bladder and bowel symptoms, yet referrals from neurologists and GPs are rare. Improving awareness of these roles, and referral options across the care team could help PwMS access more comprehensive, coordinated support.

### Community supports

PwMS emphasised that the supports that matter often extend beyond formal care teams. It is important to recognise who else contributes to a person's day-to-day support network, as many rely on workers outside the traditional health system to maintain independence and manage fluctuating symptoms.

Several PwMS described the value of having support from people who understand their mobility needs, or who assist with tasks like gardening and meal preparation. While these community-based supports were seen as part of living well with MS, they are often paid for privately or rely on NDIS funding, which is not accessible to everyone. Recognising and including these everyday supports in care planning may help build a more complete picture of what PwMS need to live well.

> "I have a hairdresser who understands that I have MS, and so I can sort of rely on her to help me in and out of chairs without making a fuss..." Person with MS

## 3.4 Embedding MS-specific expertise across local health services

### Embedding MS capability in local services

PwMS strongly supported embedding MS knowledge into local services through consistent training and system-level enablers. A national online directory of MS-trained providers was widely endorsed as a way to improve visibility, ease referrals, and help people find appropriate care closer to home. Clinicians also supported the concept but raised practical concerns, including workforce mobility, directory maintenance, and uneven regional uptake.

### Learning from international models

Across health systems internationally, structured models have been developed to embed condition-specific expertise into local services. One of the most established is ParkinsonNet, a nationally coordinated model from the Netherlands designed to improve care for people with Parkinson's disease. It was developed in response to challenges that closely mirror those in MS care, including fragmented communication, inconsistent referral pathways, and poor coordination across allied health services.

ParkinsonNet connects health professionals across disciplines through accredited training, regional networks, and a public directory, all supported by a digital platform that enables communication, referrals, and transparency (Bloem, Munneke, & The ParkinsonNet Team, 2017; Bloem et al., 2020).

### ParkinsonNet: A model for specialist allied health integration

ParkinsonNet was established to embed condition-specific knowledge within local systems and improve the quality and coordination of care. Over more than 10 years, the model has supported 66 regional networks involving around 3,000 trained professionals from 15 disciplines.

Core components include:

- Accredited training and quality standards with ongoing requirements
- A public online directory searchable by location and provider discipline
- Standardised care pathways and referral protocols
- Regional multidisciplinary networks to support collaboration
- A digital platform enabling education, patient access, and telehealth

Evaluations have shown reduced hospitalisations, fewer hip fractures, better adherence to care guidelines, and lower overall healthcare costs. The model also empowers patients through transparent access to trained professionals and tools that support self-referral and shared decision-making.

### Why this model is relevant to MS

ParkinsonNet was created to address system gaps that are also common in MS care: limited access to trained providers, unclear referral processes, and siloed service delivery. Like Parkinson's disease, MS is progressive, complex, and requires sustained, multidisciplinary input across both health and community settings. Modelling an MS-specific approach on ParkinsonNet offers a practical and evidence-informed strategy that could be tailored to the Australian context.

### Implications for MS care in Australia

Clinicians and PwMS supported a scalable model to embed MS capability across services. Backed by national directories, coordinated training, and standardised pathways, such a platform could reduce fragmentation, improve access to trained providers, and support consistent, MS-informed care. While implementation would require significant time and investment, it could extend beyond MS specialists to include allied and community-based providers, improving access particularly in rural and under-served areas.

## 3.5 Integrated Care Framework – GP, Allied Health and Community Care

Coordinated MS care must extend beyond specialists to include GPs, allied health, and community services. While PwMS value these supports, access is often inconsistent and lacks MS-specific expertise. As outlined in Table 6, the proposed Framework focuses on strengthening visibility, communication, and workforce capability to improve continuity, reduce fragmentation, and enable earlier, more effective care. A logic model with implementation steps is provided in Appendix C.

**Table 6. Integrated Care Framework – GP, Allied Health and Community Care**

| What we learned: | What we recommend: |
|---|---|
| Limited communication between providers and unclear referral pathways often left PwMS and carers coordinating care alone, highlighting the need for a clear MS care and referral resource. | • **Shared protocols.** Clarify GP and neurologist roles in MS care.<br>• **Standardised referrals**. Use shared templates and care plans between neurologists and GPs.<br>• **MS info sheet.** Create a simple handout with MS care information and key resources to give to providers. |
| MS-specific knowledge is inconsistent among GPs, allied health professionals and community supports. Non-specialist health professionals need easier access to targeted MS education. | • **Digital Learning Hub.** Create an online portal that offers comprehensive MS health professional resources.<br>• **Build workforce capability.** Collaborate with peak bodies and relevant allied health associations to develop targeted MS education for health professionals. |
| PwMS want to understand the role of allied health early in their diagnosis, and how this is part of proactive management. | • **Support early.** Develop resources to help clinicians explain that allied health services are a standard part of proactive MS care, not only for periods of decline. |
| PwMS want simple tools to track key updates and understand who is in their care team and what each provider does. | • **Care summary prompts.** Provide a simple tool or checklist to help track and share key updates.<br>• **Know your team.** Create a resource to help people map their care team and understand each provider's role. |
| PwMS have difficulty finding providers with MS knowledge, which is highly valued. | • **Workforce access.** Build and maintain a national directory of MS-trained providers. |

**Key takeaways**

- While GPs are often not viewed as central to MS care, they play an important role in providing ongoing support, prescriptions, and referrals
- Time pressures, short appointments, and unclear roles make it difficult for GPs to follow up, with PwMS often redirected between providers
- 1 in 3 PwMS reported little or no GP–neurologist collaboration, while stronger collaboration was associated with better outcomes
- PwMS want access to MS-informed allied health professionals close to home and prefer face-to-face care, with telehealth seen as a limited alternative
- Many PwMS disengage from services that lack MS knowledge, often having to educate providers themselves and support a national directory to help find MS-trained professionals

# Wellbeing Supports

## Snapshot

PwMS consistently described wellbeing supports, including emotional, social, and financial needs, as central to managing their condition. However, these needs are inconsistently addressed in routine care. Barriers such as cost and unclear pathways limited access to mental health and social supports. Many PwMS felt unsure what was appropriate to raise with clinicians. While health professionals acknowledged these challenges, limited time and system pressures reduced their ability to respond. Both groups supported more proactive, integrated support, particularly during major life transitions.

# 4. Wellbeing Supports

Wellbeing supports in this context include emotional and mental health, social connection, and financial stability. These were the most commonly raised areas by PwMS, though it is acknowledged that other aspects of wellbeing also matter. This section explores how PwMS and health professionals experience and navigate these needs, and what is needed to address gaps more proactively.

## 4.1 Emotional wellbeing in MS care

Depression affects PwMS at up to three times the rate of the general population (MS Australia, n.d.), underscoring the need for routine recognition and response in clinical care. Emotional wellbeing was seen by PwMS as central to their overall health, yet many felt it was frequently overlooked in practice.

### Emotional wellbeing in clinical care

Despite growing recognition of mental health as central to wellbeing, support remains inconsistently offered. Nearly half of PwMS **(44%)** said they were rarely or never offered help, even when requested or clearly needed, while only **29%** said they usually or always received support.

> “I tried to speak to my neuro about mental health and he just said he had a lot of patients waiting when I asked if I could have a bit more of his time!!”
> Person with MS

**1 in 2**
PwMS report that mental health support was rarely or never acknowledged

Many found it difficult to raise these concerns with their neurologist or GP, particularly in short or rushed appointments. Carers also noted inconsistent attention to emotional wellbeing, with needs often overlooked unless explicitly raised. Some felt they were the only ones recognising distress and prompting referrals, adding pressure to advocate within a system lacking proactive screening.

### Referral or expertise limitations

Clinicians acknowledged the importance of mental health in MS care but emphasised key limitations. Many noted they are not trained mental health specialists and described a lack of clear referral pathways, with services often fragmented or unavailable.

> “We don't necessarily have the expertise to manage mental health problems...it's not in our wheelhouse necessarily, but then the referral pathways are just so woeful.”
> Neurologist

MS Nurses highlighted the difficulty of finding mental health professionals with MS or chronic health expertise, noting that suitable providers were scarce and quickly overwhelmed. Cost, rapport-building, and stigma were also key barriers.

Clinicians often relied on GPs to manage mental health needs, as Mental Health Care Plans must be initiated by a GP and appointments with them are generally more frequent than with neurologists. However, this was not always suited to complex or urgent cases. Mental health support was seen to be more available during crises, while longer-term or preventative care remained limited, particularly in rural areas.

Clinicians encouraged broader supports like lifestyle changes and mindfulness, but noted uptake was highly variable and depended on a range of factors including self-motivation and access.

**PwMS in high collaborative care:**

- 1 in 2 (56%) were usually or always offered mental health support

**PwMS in low collaborative care:**

- 1 in 6 (17%) were usually or always offered mental health support

**What does this mean?**
PwMS in high collaborative care were more likely to be offered mental health support. This suggests that stronger team communication may help ensure these needs are addressed.

### Financial barriers to mental health support

Cost was one of the most common barriers to accessing care across the system. Many PwMS needed mental health support but could not afford to fund this privately. Without access to subsidised services through Medicare or the NDIS, PwMS reported this support was often out of reach.

> “I really would love mental support, but psychologists are so expensive. Even when you work full time, it's so much money for a session.” Person with MS

### Systemic barriers to funded psychological support

PwMS described major challenges accessing funded psychological care. Many reported that mental health supports were routinely excluded from NDIS plans, even when recommended by clinicians. Several PwMS reported that emotional needs were often deprioritised by NDIA Planners in favour of physical function. Further, where support was approved, clinicians noted it could take sustained advocacy to activate.

> “there is lots of pushback from the NDIS [Planner]... they're pretty quick to go, ‘*why have you got psychology in there?*’” Carer of Person with MS

Under Medicare, Mental Health Care Plans are limited to a capped number of subsidised sessions each year, and often involve gap payments that many cannot afford. This made them a less viable option for ongoing support, leaving many PwMS without timely or affordable care.

### Quality of mental health support

For those who went on to access mental health support, most PwMS reported mixed experiences. Fewer than half were satisfied, with many unsure of its benefit or finding it unmet their needs. These findings suggest a need for more consistent, MS-relevant mental health care and reflect wider gaps in service availability and specialisation.

> “Just finding the right person that can actually help [PwMS] has been a challenge” Carer of Person with MS

## 3.2 The role of financial stress in MS care

### Cost barriers to essential MS services

While the financial burden of MS is well recognised, this section explores how broader financial strain affects care decisions, service access, and wellbeing. PwMS described delaying or forgoing therapies due to competing costs, with many health professionals unaware of the financial pressures influencing these choices. This mismatch often left PwMS feeling guilty or helpless when trying to prioritise their care.

> "She kept going on about how every fortnight, it's very important, and I said, *'yes, but I'm not earning money, so therefore it becomes a luxury.'*" Person with MS

### Hidden costs of living with MS

Many PwMS described financial strain from indirect costs such as transport to appointments, time off work to attend care or support groups, medical treatment after falls, and the high cost of items like shoes to fit orthotics. Even those in paid work reported difficulty affording regular appointments for supports.

Some rationed or skipped recommended therapies due to out-of-pocket costs. For those not eligible for NDIS, few alternatives existed to fund essential care. These pressures impacted long-term management, especially for those in insecure work or receiving Government income support such as the Disability Support Pension.

### Centrelink and financial insecurity

For PwMS who were eligible for government income assistance, access to Centrelink payments was described as inconsistent and demoralising. PwMS spoke of the emotional toll of needing to 'prove' disability despite obvious challenges, with delays and assessments often failing to reflect the lived experience of MS.

For those unable to work, financial insecurity extended to an inability to maintain basic independence, including transport or vehicle costs. Several PwMS described the psychological impact of relying on others for financial and practical support, despite wanting to remain self-sufficient.

> "Being on welfare is quite difficult. I would love to be able to work for my own living… I can't even afford to maintain my own vehicle… Being dependent on others is demoralising." Person with MS

> "I'm needing to get a scan on my shoulder because I keep falling on that side. And if I want to get the scan done, the doctors don't have the right to bulk bill, to send you to have an MRI as the neurologist would… I'm going to wait to see my neuro, and she will hopefully write me to have a scan. I can't afford four hundred dollars on a disability pension."
> Person with MS

### Perceptions of NDIS as a pathway to affordable care

Many PwMS shared that without NDIS funding, allied health support was unaffordable. For some PwMS, cost was the primary reason they applied to the NDIS, seeking access to consistent, affordable care, particularly for allied health.

One PwMS expressed that without this support, they feared being unable to manage their daily responsibilities while working and caring for family.

> “Due to the cost of allied health…I have submitted an NDIS application as without funding I fear that I will not receive the care I require to manage my MS symptoms…” Person with MS

### NDIS funding gaps

For PwMS who were NDIS participants, there were repeated frustrations over NDIS funding exclusions. This was particularly the lack of support for services PwMS considered essential to their wellbeing, such as massage and chiropractic care.

Many expressed feeling forced to make decisions based on financial constraints rather than MS needs, weighing the cost of care against its emotional, mental, and physical benefits. In some cases, PwMS shifted to local non-MS specialist providers when transport was not fully funded or unaffordable.

PwMS also reported being charged higher rates as an NDIS client despite receiving the same service, which was viewed as unfair.

> “Don't charge extra for people on NDIS, except for a report (which usually is charged extra) you don't do anything different to another client.” Person with MS

### Cost barriers persist, even with NDIS support

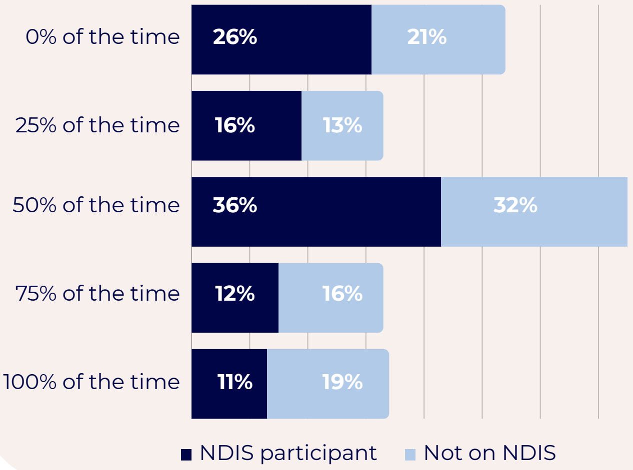
While the NDIS has improved access to supports for eligible PwMS, allied health services remained financially challenging, even for participants in the scheme.

Most PwMS reported cost as a significant barrier to allied health, even for those on the NDIS. Almost **40%** of PwMS receiving NDIS support reported cost as a barrier to allied health, rising to **53%** among those PwMS not on the NDIS.

Cost was not only a common barrier to allied health access, but also a *frequent* one. As detailed in Figure 4, among PwMS who faced cost barriers, nearly **59%** of NDIS participants and **67%** of non-NDIS participants said it limited their access at least half the time or more.

**Figure 4. Proportion of time that PwMS reported cost as a barrier to allied health, by NDIS status**

n=233 (NDIS = 121, non-NDIS = 112)



While unexpected, this finding may reflect how the question was interpreted. Several people on the NDIS described limited funding within their plans, requiring them to prioritise some therapies over others. In this context, cost-related barriers likely reflect gaps between what is funded and what participants believe is needed.

**3 in 4**
NDIS participants experienced cost as a barrier to allied health at some point

### Financial concerns and the scope of MS care

Many PwMS are unsure whether financial concerns that impacted their MS care can be raised with their neurologist or GP, leading them to remain silent even as cost pressures impact their care. Nearly **1 in 3** PwMS feel financial issues were outside the role of their neurologist, and **1 in 4** said the same of their GP.

**3 in 4**
were unlikely to raise financial issues with at least one key member of their healthcare team

### Discomfort raising financial issues with clinicians

Many PwMS want financial support in the form of information or referrals to financial support organisations but do not feel comfortable asking for it, particularly from neurologists.

57% of PwMS would welcome financial support from their neurologist, but of those, **2 in 3 (65%)** would not feel comfortable raising the issue. **73%** of PwMS would be unsure or unlikely to discuss financial issues with their neurologist.

66% of PwMS would welcome financial support from their GP, but more than half of them **(56%)** would not feel comfortable raising the issue. **61%** of PwMS would be unsure or unlikely to discuss financial issues with their GP.

**1 in 3**
would appreciate financial resources and information from their GP or neurologist, but wouldn't feel comfortable asking

PwMS in high collaborative care:

- were **3 times** as likely to feel comfortable asking their neurologist for financial resources and support
- more than **twice** as likely to say they'd ask their GP for financial resources and support

PwMS in low collaborative care:

- 70% were unlikely to ask their neurologist for financial resources and support (vs 30% in high collaborative care)

### Clinician perspectives on financial barriers

Clinicians acknowledged that financial hardship directly affected access, adherence, and the ability of PwMS to access supports.

One neurologist described financial context as integral to care planning, noting that when therapies or supports were unaffordable, essential MS management became out of reach.

MS Nurses frequently identified cost as the reason referrals were not followed up. While some PwMS disclosed this, many required prompting. Nurses observed that when daily living costs were overwhelming, healthcare was often understandably deprioritised.

Despite these insights, survey findings showed a disconnect. Many PwMS were unsure if financial concerns were appropriate to raise or felt uncomfortable doing so, contrasting with clinician perceptions that such issues were often openly discussed. This may reflect the more personal nature of nursing roles.

Because survey questions focused on neurologists, comfort levels with other providers, such as MS Nurses, were not captured. This may have overlooked important differences in how and where PwMS feel safe raising financial concerns.

Clinicians also cited structural barriers, including limited public services, unclear referral pathways, and persistent out-of-pocket costs. Some turned to creative strategies, such as linking PwMS into research trials as a means to access supports, though many still felt constrained by systemic limitations. One MS Nurse observed that many PwMS could not access support services without NDIS funding.

> "If they don't have NDIS, forget about it..."
> MS Nurse

These reflections emphasise that financial hardship is a system-wide challenge that limits care delivery. Clinicians highlighted the importance of understanding financial pressures to provide realistic, effective support.

## 4.3 Social wellbeing in MS care

### The social impacts of MS and need for support

Most PwMS viewed social wellbeing as essential but felt it was often overlooked compared to emotional or physical health. Many described experiences of isolation and invisibility, with some avoiding community settings due to mobility limitations, safety concerns, or fear of judgement. These issues were rarely discussed with clinicians, often seen as outside their scope or too complex to explain.

While some PwMS reported having strong support networks, others faced challenges alone, including grief, domestic violence, job loss due to MS symptoms, or housing insecurity. Many expressed a desire for peer support and tailored social connection, but access was frequently limited by cost, geography, or lack of information.

> “I am lucky to have very good family and friends support to work around my disability. My husband is amazing and is always finding ways to make my life easier. I realise not everyone has that level of support.” Person with MS

### Life transitions and triggers for support

Major life changes, such as leaving work or starting a family, were commonly described as high-stress periods where support was most needed. PwMS and carers highlighted a lack of coordinated assistance during these times and called for clear, accessible support linked to key transitions.

Health professionals echoed this, noting stress is often discussed but not fully recognised until symptoms worsen. Events like moving house or changing jobs were sometimes only raised after crisis had begun, limiting early intervention.

Clinicians also noted broader social needs were often missed in standard, time-limited appointments. While some screening may occur during pregnancy, emotional wellbeing, social support, and financial stressors frequently went unaddressed. There was strong support for proactive, trigger-based support before stress escalates.

> “[PwMS] kind of went from working to not working and then feeling shit about that because [they] wasn't financially contributing. In hindsight, we probably should have gotten some psychology then... as it was happening would've been better. I think [PwMS] definitely needed more support at the time.” - Carer of PwMS

### Confidence in discussing social needs impacting on MS care with clinicians

PwMS often lacked confidence in raising social challenges related to managing their MS, such as work issues or family support, with their care team, regardless of provider. While GPs were seen as slightly more approachable, confidence levels remained mixed. Less than half of PwMS **(42%)** felt extremely or very confident discussing social issues with their GP, and **1 in 6** reported low confidence.

Nearly **1 in 3** PwMS felt unsure or uncomfortable discussing social issues with their neurologist, similar to patterns seen around financial concerns, reinforcing the need for proactive, whole-person conversations.

Many said their social context was only addressed in specific settings like getting assessments for NDIS applications, not as part of routine care. Some wanted these conversations to happen more often but did not feel comfortable initiating them. Others said trust and continuity were essential before opening up, highlighting the role of rapport in enabling more integrated care.

### Addressing social wellbeing in MS care: Neurologist perspectives

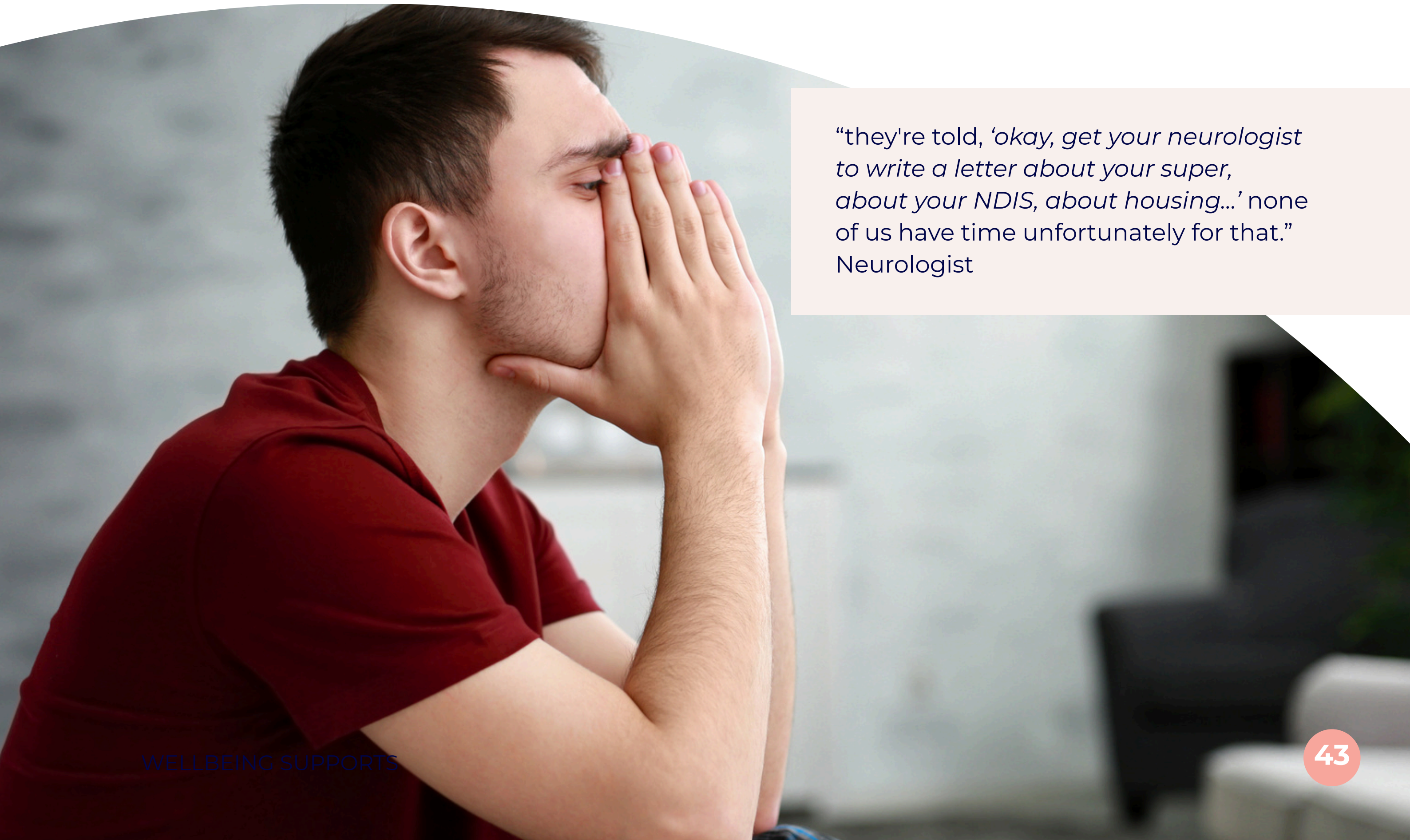
Neurologists acknowledged the importance of social wellbeing but cited key barriers to addressing it in practice. It was acknowledged that supporting social care needs falls outside their clinical training, making it challenging to navigate these conversations effectively. As a result, some preferred to avoid the topic altogether.

> “We don’t have real training in social work… the conversation shies away because of a lack of knowledge of how to manage it.”
> Neurologist

Without clear referral pathways or follow-up options, identifying social needs often felt unmanageable. Even 30-minute appointments were rarely enough to address both clinical and social concerns.

Episodic reviews, often spaced 6 to 12 months apart, made it harder to build continuity and respond to emerging issues.

Administrative demands added further strain. Frequent requests for letters to support superannuation, NDIS, or housing claims contributed to unsustainable workloads. One clinician noted that they, like many others, were already working several hours on evenings and weekends to keep up.



> “they're told, *‘okay, get your neurologist to write a letter about your super, about your NDIS, about housing…’* none of us have time unfortunately for that.”
> Neurologist

### MS Nurse perspectives

MS Nurses echoed neurologists' concerns about screening for social needs, noting that even when issues are identified, capacity to respond is often limited.

> "It's a Pandora's box... they don't have the time and resources to deal with the answer, so they don't go there." MS Nurse

MS Nurses reported consistently high administrative workloads, particularly in supporting NDIS and social support documentation. Tasks included preparing letters, gathering evidence, and coordinating input across services, often filling gaps left by time-poor GPs and neurologists. Some clinics introduced templates or patient-led tools to manage this demand, while others were forced to decline new requests due to limited capacity.

There was also widespread frustration with the NDIS process itself. MS Nurses described inconsistent decision-making and a lack of transparency when NDIS applications were rejected despite detailed, appropriate evidence.

One MS Nurse estimated that a quarter of their time is now spent on NDIS-related tasks, while others described the work as "constant," with some applications requiring "another hour and a half" to complete.

### GP perspectives

While GPs were seen by PwMS as slightly more approachable than neurologists when raising social concerns, their capacity to provide support is limited by structural and financial pressures.

A GP Liaison Officer noted that most GPs need to see four to six patients per hour to remain financially viable, leaving little time for complex discussions. This was echoed by an MS Nurse, who shared, "The GPs just put their hands up. They won't do it. They don't have the time."

Administrative tasks, such as supporting NDIS applications, often fall outside paid appointment time. For GPs who are willing to support an NDIS application, they may spend hours completing paperwork, only to have applications rejected without clear or consistent reasoning, a concern also shared by MS Nurses.

Communication with agencies like the NDIS was also described as difficult.

> "You can't get them [NDIS] on the phone."
> GP Liaison Officer

Combined with the prioritisation of neurologist input in formal processes, these challenges have led some GPs to limit their involvement.

### Seeking social connection and support

Many PwMS expressed a strong desire to connect with others who understood their experience, with around **50%** engaged in or seeking formal peer support.

**1 in 3**

Tried to connect with others but didn't know where to start or couldn't find something suitable

Other PwMS wanted to connect with peers but faced barriers such as transport, work and family commitments, few local options in rural areas, shyness, or uncertainty. For some, choosing not to disclose their diagnosis, even to family, added emotional strain and reinforced isolation.

> "I have kept my MS hidden from my family and my job, so it is quite stressful at times." Person with MS

Many noted that their social wellbeing was rarely discussed in clinical appointments, especially with neurologists. While **30%** said they did not need additional social support, this may reflect satisfaction with current networks or disinterest in MS-specific groups, rather than a lack of connection overall.

### Why social context matters

Both clinicians and PwMS emphasised the importance of understanding social context in care. PwMS described how family or peer support directly affected how they managed their condition. Clinicians also acknowledged the need for more flexible, respectful ways to connect people to support, noting that preferences, privacy, and practical barriers must be taken into account.

### What this means

Mental and emotional health, social wellbeing, and financial circumstances are widely recognised as central to MS care, yet remain poorly integrated due to structural and practical barriers. Access is further constrained in rural and regional areas. Addressing this will require system-level investment in workforce capacity, embedded roles, and clear, accessible referral pathways.

> "Reflecting on these questions, I've never realised how little my social life is discussed with my medical doctors. My allied health team discuss it all the time but GP and neuro, rarely. It's definitely something I think should be included in patient conversations in future" Person with MS

## 4.4 Integrated Care Framework - Wellbeing Supports

There is strong consensus that emotional, social, and financial wellbeing must be addressed as core components of MS care. Many PwMS reported that support in these areas was inconsistent, crisis-driven, or difficult to access due to cost, system fragmentation, and unclear pathways. As outlined in Table 7 below, the proposed Framework focuses on strengthening pathways, proactive screening, and coordinated funding models to improve access to key wellbeing supports. A logic model outlining recommended implementation steps is included in Appendix D.

**Table 7. Integrated Care Framework – Wellbeing Supports Framework**

| What we learned: | What we recommend: |
|---|---|
| Complex NDIS processes and cost barriers led many PwMS to delay or avoid care, even though most wanted support but felt uncomfortable asking for it. | • **Helpful resources.** Tools to help people apply for NDIS and access low-cost service.<br>• **Financial navigation.** Help health professionals and services guide people to financial supports. |
| Mental health support was often hard to access due to cost, limited provider options, and unclear referral pathways. | • **Mental health matters.** Provide information to help PwMS manage their mental and emotional wellbeing.<br>• **Mental health support.** Help clinicians connect PwMS with mental health support. |
| PwMS valued connecting with others who share their experience, but many felt their social needs were often overlooked in care. | • **Connection.** Use brief check-ins to spot stress and stay socially connected.<br>• **Resilience & peer support.** Provide programs led by professionals and PwMS. |
| PwMS wanted care to reflect major life transitions, but these were often overlooked and rarely prompted proactive support. | • **Social screening.** Include questions about things like housing, transport, and relationships in MS health reviews.<br>• **Triggers for support.** Set up pathways for support during big life events like pregnancy or changes in employment. |
| PwMS want more joined-up support. When services and funding are siloed, access becomes fragmented. Shared approaches could improve coordination. | • **Connected funding.** Help services (health, mental health, disability) work together and share funding so people can access more joined-up support in one place. |
| Clinicians face time pressures, high admin demands, and limited resources to address broader support needs. | • **Workforce support.** Build staffing capacity through training, shared tools, and dedicated roles to reduce admin burden and improve continuity of care. |

**Key takeaways**

- Mental health needs are often unmet, with nearly half of PwMS rarely or never offered support despite its impact
- Cost limits access to mental health, allied health, and social supports, even when on NDIS
- PwMS are unsure or unlikely to raise financial or social concerns, despite wanting support
- During stressful life events like pregnancy or job changes, PwMS want support yet events rarely trigger proactive support or referrals
- Collaborative care makes a difference, PwMS in high-collaboration care were 2–3 times more likely to feel confident raising concerns and were more often offered mental health support
- Clinicians face barriers to addressing wellbeing, including time constraints, admin burden, and unclear referral pathways

# Education and Self-Management

## Snapshot

Many PwMS expressed a strong desire to better manage their health but described receiving limited, inconsistent, or poorly timed information, particularly at diagnosis. Without consistent access to the right knowledge or tools, PwMS faced additional barriers in understanding their condition and making informed decisions. This section explores PwMS preferences for information and the importance of practical tools and supports in building the knowledge and confidence needed for effective self-management.

# 5. Education and Self-Management

Education and self-management help PwMS understand their condition, make informed decisions, and take an active role in their care. This includes timely, tailored information and practical tools to support day-to-day health decisions. This section explores what PwMS need to manage their health confidently and effectively, alongside health professionals' experiences in supporting this.

## 5.1 Building health literacy and early understanding

### Improving education after diagnosis

Most PwMS reflected that they did not receive enough information at diagnosis to feel well informed. Many wanted personalised, paced education to support decision-making without confusion or fear. A small number preferred minimal information early on, relying on their neurologist to provide it gradually. While intended to reduce overwhelm, this approach was not seen as adequate by most.

Neurologists confirmed they often provided limited information early to avoid overwhelm, favouring a gradual approach. However, this informal and inconsistent method often left PwMS unprepared. Although many reflections came from years beyond diagnosis, the overall message was clear: early education must be structured, relevant, and responsive to individual needs.

One MS Nurse Practitioner described spending over an hour with a person 12 months post-diagnosis who was engaged in care but still didn't understand what MS was, what demyelination meant, or what to expect. They noted this level of support was only possible due to differences in time allocation, with MS Nurses having more time than the neurologists. The example highlights how information gaps can persist well beyond diagnosis, the structural barriers limiting in-depth education, and the critical role MS Nurses play in ongoing support.

### Health literacy and information gaps

Health literacy refers to a person's ability to find, understand and act on health information to make informed decisions about their care (World Health Organisation, 2024). Health professionals emphasised that this must be built early, particularly at diagnosis. Without clear explanations, many PwMS may not fully understand the purpose of medications, MRIs, or follow-up appointments, leading to disengagement from care. Some only grasped the seriousness of MS after experiencing functional decline.

Clinicians noted that low health literacy often combines with time pressure and emotional overwhelm, reinforcing long-term barriers to engagement. Several also highlighted a systemic issue, that making assumptions about a person's ability to navigate the health system can result in confusion and costly errors. Education must extend beyond MS-specific content and include practical guidance on navigating services, referrals, and care coordination.

> "I've had MS for 25 years and still feel I've learned very little about how the system works." Person with MS

> " I think sometimes we think we know it all, and we think we know how to deliver education...and you walk in with a preconceived idea of how this appointment's going to go, and...you fall flat on your face when that happens. That's the barrier, you actually have to stop talking and listen to the patient. Ask questions, but open questions so you can actually listen to what they need and what they want and what will make them get to the point that you've agreed upon is their treatment management plan." MS Nurse

### Perceptions of MS information and advice

Lifestyle and wellbeing information from neurologists and GPs was often perceived by PwMS as inconsistent. Only **1 in 4 (25%)** PwMS reported often or always receiving this, compared with **36%** who sometimes did and **39%** who rarely or never did.

Additionally, almost half of PwMS **(44%)** reported receiving conflicting advice, which added to the sense of fragmented information. Many felt left to navigate information alone, often unsure where to begin or how to determine what was credible.

> "It's all coming back to the same thing… move around more, eat better… the information can be pretty repetitive."
> Person with MS

### Reframing wellbeing and bridging disconnects

While some appreciated reminders about diet and exercise, others described the advice as vague or repetitive. Clinicians acknowledged this disconnect. Although lifestyle advice may be clinically sound, it can feel generic if not clearly linked to MS progression or tailored to the individual.

> "…because it's not branded as MS specific, people are sort of like…"*everybody knows that…*" I think they're wanting something which is, *'Oh, the MS diet is this.'*"
> MS Nurse

MS Nurses noted that general health advice can seem irrelevant unless clearly linked to outcomes that matter to PwMS. Reframing it around MS-specific impacts may improve its relevance. Clinicians also highlighted a lack of support to help PwMS apply this advice in practice.

The disconnect between clinician perceptions and PwMS experiences may reflect differences in recall, expectations, or comfort asking for information. The survey asked how often PwMS received advice but not whether they sought it, so those who didn't ask may have missed out. MS Nurses consistently described education as core to their role, but the question only referred to GPs and neurologists, meaning their input was not captured. Not all PwMS have access to an MS Nurse, which may also explain some of the reported gaps and warrants further exploration.

### Missed opportunities for brain health education

Despite increasing emphasis on brain health in MS care, clinicians noted that the concept was not always well understood or retained, noting that advice on brain health was rarely reinforced beyond initial appointments. One allied health professional emphasised that while diet, lifestyle, and overall management are key to preserving brain health, the concept is often not communicated to PwMS in a way that feels relevant or actionable.

## 5.2 Supporting self-management and confidence

### Self-management and unmet support needs

PwMS expressed a strong desire to actively manage their condition but often felt unsupported. A lack of plain-language, early-stage guidance left many unsure how to navigate care or trust services. Even terms like "allied health" were unfamiliar to some, and roles across the system remained unclear.

> "You just feel like you're left alone."
> Person with MS

Clinicians reinforced that information alone is not enough. Empowerment requires the capacity to act; knowing what to do, when to act, and how to get help.

Barriers such as cost, time, digital access, language, and fragmented care disproportionately affect people from culturally and linguistically diverse (CALD) communities or with lower health literacy. These groups often need more time and personalised support to engage meaningfully. A lack of translated resources was identified as a major gap. One neurologist suggested that central websites like MS Australia could improve access by adding simple translation tools, such as AI-supported features, to help PwMS read information in their own language.

PwMS in high collaborative care:
- **2 in 3 (64%)** always or often get helpful lifestyle and wellbeing information

PwMS in low collaborative care:
- over **3 times** more likely to rarely or never receive lifestyle and wellbeing information

### Peer support and informal learning

For some PwMS, peer support informally filled critical education gaps, particularly at diagnosis or during times of change. Insights from others who had "been there" were highly valued, with many saying earlier access to someone living with MS would have helped them feel more prepared. Peer settings not only offered reassurance, but also reinforced practical strategies for navigating care. Evidence shows that peer support in chronic illness improves adherence to healthy behaviours and enhances self-management, making information more relatable and actionable (Fisher, 2014). Despite this, access to peer support remains inconsistent and is not routinely embedded in formal care pathways.

> "I think that maybe if I knew someone who had been dealing with it for a long time, I would have gotten some advice from them." Person with MS

### Practical tools to support self-management

PwMS consistently called for reliable, easy-to-use self-management supports to help manage their care.

Commonly requested features included:

- Central access to test results, medications, referrals, provider contacts, and emergency information
- Smarter symptom tracking functions
- Pre-appointment checklists
- Clear explanations of different roles in the health system
- Personal control over information sharing

Accessibility was essential. Tools needed to work across devices, include low-tech formats, and accommodate PwMS with cognitive challenges or low health literacy. Clinicians supported tools that encouraged engagement, particularly those with automated prompts or gamified tracking features.

### Clinician education resource needs

Many PwMS expected their neurologist to provide condition-specific resources, but these often came from external organisations rather than directly through clinical care.

> "There doesn't seem to be enough fact sheets for neurologists to give out."
> Person with MS

Clinicians confirmed that resources they provide to PwMS are often self-sourced or outdated. They called for a centralised, up-to-date library to support education on lifestyle, treatment, and progression. Translated resources were again identified as a major gap.

## 5.3 Access to education and support

### Preferred formats and how PwMS seek information

Survey responses showed a clear preference from PwMS for information provided verbally by a trusted clinician, followed by written material from the same source. Other formats such as factsheets, webinars, and podcasts were also valued but less preferred.

When searching online:

- 84% used Australian MS organisation websites
- 53% used the top results from a Google search
- 47% accessed international MS websites
- 33% used health sites like WebMD or HealthDirect
- 13% used social media

Most people accessed a broad mix of sources, but many struggled to find structured, practical education. Clinicians were viewed as the most credible source to help interpret and prioritise information. Only a small proportion avoided online searches entirely.

## 5.4 Integrated Care Framework – Education and Self-Management

There is strong consensus that education and self-management are essential to effective MS care. Many PwMS reported that information was inconsistent, difficult to access, or lacked clear links to MS, leaving them uncertain about how to navigate the system or make informed decisions. As outlined in Table 8 below, the proposed Framework focuses on improving access to timely, relevant, and easy-to-understand information, and on building the skills and confidence needed for active participation in care. A logic model outlining recommended implementation steps is included in Appendix E.

**Table 8. Integrated Care Framework – Education and Self-Management**

| What we learned: | What we recommend: |
|---|---|
| PwMS felt unprepared and wanted earlier, clearer education, but information was often inconsistent, conflicting, or lacked MS-specific context. They called for clear, centralised, and credible resources. | • **Learn early.** Provide clear, early MS information to support understanding and informed choices.<br>• **Consistent information.** Give everyone access to the same clear, trusted resources.<br>• **Plain language tools.** Make sure information is easy to understand and consistent across all parts of the health system. |
| PwMS and carers had inconsistent access to clear, accessible information to navigate care. Many needed more support to build health literacy, ask questions confidently, make informed decisions, and feel included in their care. | • **Support for everyone.** Provide mentoring, peer support, and tools to build confidence and support active involvement in care.<br>• **Trust and transparency.** Support open, fair processes that help people feel safe and included in their care. |
| PwMS and carers often lacked clear, accessible information to navigate care, especially with low health literacy, leaving many unsure how to ask questions, make decisions, or feel included. | • **Self-monitoring.** Use apps to track symptoms, emotional wellbeing and reminders.<br>• **Care guides.** Use simple tools to explain roles, responsibilities, and contact points. |

**Key takeaways**

- Many PwMS felt under-informed at diagnosis, with early understanding limited at times by emotional overwhelm and low health literacy
- Gaps in understanding persisted without tailored follow-up, with many PwMS receiving conflicting advice and unclear explanations of care roles
- Brain health was emphasised but not always clearly explained or followed up, and many PwMS lacked support to apply health information or navigate care confidently
- Neurologists were the preferred and most trusted source of information
- PwMS and clinicians reported limited access to trusted resources, with CALD communities especially affected by a lack of translated materials
- Peer support was highly valued as a way to learn from others with lived experience

# Voice and Representation

## Snapshot

Voice and representation is essential to addressing the systemic barriers faced by PwMS. This chapter highlights gaps in access, policy, and support, emphasising the need for structural reforms, carer inclusion, clear communication, and accessible plain language information. It also addresses the importance of fostering self-efficacy, building optimism, and empowerment, alongside challenges after diagnosis and key priorities to improve equity and outcomes.

# 6. Voice and Representation

Voice and representation means PwMS having a say in the decisions, services, and systems that affect their care. It includes being listened to in appointments, influencing how services are designed, and being recognised as partners in their care. This section explores how PwMS and carers speak up, navigate barriers, and help shape more responsive, person-centred care. It also highlights the role of self-efficacy, clear communication, and inclusion in improving equity and outcomes.

## 6.1 System-level advocacy and policy reform

### Inclusion in policy and system reform

PwMS identified clear opportunities for systemic advocacy to improve access, equity, and consistency in MS care. This included widespread calls for a national care plan that reflects the complexity of MS, stronger representation in disability and mental health policy, fairer NDIS rules, and better coordination between state and federal systems.

> “The hardest things I have had to deal with since being diagnosed with MS, is I have suddenly become invisible and have lost my voice!!” Person with MS

Co-design was seen as essential to ensure services reflect real needs across diverse settings, yet many PwMS felt excluded from decision-making, particularly within large systems like NDIS and aged care. Health professionals acknowledged this disconnect. One MS Nurse observed that clinical expertise can sometimes overshadow lived experience, reducing the impact of genuine co-design.

> “A lot of clinicians think because they deal with MS all the time, that gives them permission to override co-design, but it doesn’t.” MS Nurse

Many PwMS described how personal advocacy efforts often emerged from system failures, for example, losing access to essential mental health services when NDIS funding changed or was denied. Those under 65 who are ineligible for the NDIS frequently lack viable alternatives, despite the intended role of community-based foundational supports. These supports, scheduled to roll out from 2025–26, are not yet in place (NDIS Review, 2023), leaving many to rely on out-of-pocket costs or unpaid carers.

> “Funding will always be an issue. I need help now but I suppose another 6 months won't worry people who are not affected directly by MS.” Person with MS

PwMS also called for more inclusive representation, especially from rural and regional communities where engagement opportunities are limited and metro-centric decisions often fail to reflect broader needs. These experiences highlight both the systemic nature of unmet needs and the significant impact on individuals and families. Advocacy, in this context, means not only raising personal voices, but also pushing for structural change to prevent exclusion based on age, location, or funding criteria.

## 6.2 Speaking up and navigating service challenges

### Rights, representation, and raising concerns

For many PwMS, raising concerns or changing providers was crucial but difficult. Fatigue, system complexity, and low expectations of being heard were major barriers. Those who self-advocated often needed persistence and assertiveness to fill gaps in support. Some felt overwhelmed or invisible, frustrated by the effort required to access even basic services. Others felt they were dismissed due to assumptions about cognition or communication difficulties.

Self-advocacy was widely seen as necessary but exhausting. Many PwMS felt they had to become the expert in their own care, often acting as the coordinator to access support. There was little room to wait or trust the system to respond. While PwMS recognised the need to take responsibility for their health, navigating disconnected services left many feeling they had to stay constantly alert and speak up at every step just to be heard.

### Building agency and optimism

Some clinicians noted that true empowerment goes beyond education and access, requiring a mindset shift and psychological support, especially early in the MS journey. One neurologist observed that while greater control over care decisions can help PwMS feel more empowered, it does not always make people feel more hopeful. Strong relationships, access to treatments, and trusted research were also seen as key to supporting both confidence and optimism.

**“We shouldn't be pushed away because of disability”**
**Person with MS**

> “I’ve genuinely had to become the expert to survive, and even then, I have to advocate for myself like hell 24/7”
> Person with MS

**Self-efficacy,** defined as a person’s belief in their ability to produce desired outcomes through their own actions (Bandura, 1977), is closely linked to engagement and health outcomes in MS. Clinicians described it as a vital yet under-recognised aspect of integrated care, shaped by trust, consistent support, and communication tailored to individual needs. Higher self-efficacy is associated with better physical function, lower depression, and improved overall health in PwMS, while lower self-efficacy is linked to greater disability and poorer outcomes (Young et al., 2022).

These findings directly support the proposed framework, which emphasises individualised support, clinician communication that builds confidence, self-management education, and co-designed interventions aligned with personal goals (Young et al., 2022). Current models risk excluding those with low self-efficacy, who may be less likely to engage in services or research. The framework addresses this by embedding tailored, proactive support to ensure visibility and inclusion for PwMS with reduced confidence or self-advocacy (Young et al., 2022).

## 6.3 Supporting self-advocacy and decision-making

### Adjustment and overload after diagnosis

Clinicians noted that while many people appear confident, this may reflect necessity rather than empowerment. In early stages of diagnosis, people often contact services frequently as they adjust, learn the system, and try to establish a new sense of normal. This period is marked by uncertainty and information overload, which can undermine decision-making confidence if not well supported.

Clinicians highlighted that the emotional and psychological weight of a new MS diagnosis can also shapes people's ability to engage with care. The diagnosis not only signals a risk of long-term disability, but also introduces a lifelong management process that can fundamentally alter a person's outlook, identity, and confidence in navigating the health system.

> "People need to feel empowered...I'll give them the steps... but I want that to be replicated. I want them to know how to reach out for help and arrange those things themselves." MS Nurse

## 6.4 The role of carers in advocacy and coordination

### Influence of family and friends on healthcare

Most PwMS reported limited influence from family and friends when choosing healthcare providers. Around **58%** said they were only somewhat or slightly influenced, while just **16%** found their networks very influential or important. For some, this reflects autonomy and confidence in decision-making; for others, it may indicate a lack of support or guidance. However, this question did not account for those without close networks, and lived experience feedback confirms that some PwMS have limited informal support networks such as family and friends.

**PwMS in high collaborative care:**

- over **4 times** more likely to say family and friends were influential in their healthcare provider decisions

**PwMS in low collaborative care:**

- only **1 in 13** rated family and friends as influential in their healthcare provider decisions

PwMS who reported high collaborative care between their GP and neurologist were more likely to say family and friends influenced their choice of healthcare providers. It was somewhat unexpected that PwMS in highly collaborative care were more likely to report influence from family and friends. It might be assumed that those in less coordinated care would rely more on informal networks for guidance. Instead, **28%** of PwMS in high-collaboration care said family and friends influenced their provider choices, compared to just **7.5%** in low-collaboration care.

This may reflect stronger informal support networks, greater openness to shared decision-making, or care teams more actively involving families. It is also possible that some people in the low-collaboration group had less access to family and friend support networks, which may have influenced their responses. While the reasons are unclear, it suggests that collaborative care may not only improve clinical outcomes but also support more inclusive decision-making.

### The critical role of carers in advocacy and communication

Carers play a crucial but often background role in helping PwMS navigate services, attend appointments, and communicate needs, especially during relapses or cognitive difficulties. Many PwMS rely on partners, family, or friends to advocate and coordinate care when symptoms make self-management difficult.

> “We had an OT come out… lucky for [carer] having everything on [their] phone… if you asked me straight away, I have no idea.” Person with MS

Health professionals noted the complexity of involving carers in a way that respects consent and the dynamics of the relationship. While carers often attend appointments, they may hold back until the person with MS struggles to explain their situation. Clinicians observed that some carers share concerns privately, which can be helpful, but acknowledged the need for clearer, more sensitive ways for carers to communicate without undermining the PwMS’s autonomy.

Carers also reported administrative barriers, especially in large or unfamiliar settings. One described how a supportive GP clinic became harder to deal with after merging with a larger practice, and despite holding formal authority, they were repeatedly questioned.

> “...the receptionist was quite abrupt. Like, ‘*does [PwMS] know you're changing this appointment? Why are you calling and not [PwMS]?*” She obviously has no understanding of MS...every time I ring, she asks me the same questions.” Carer of Person with MS

These challenges reflect limited understanding of symptoms and the importance of carer involvement. Both clinicians and PwMS supported better integration of carers early in the disease and during unstable periods, through improved documentation, structured roles, and privacy safeguards.

Carers often have a deep understanding of the needs of PwMS. Recognising them as partners in care, with clear pathways for involvement, is essential to delivering coordinated, person-centred support.

“I think we need to be...involving carers more in the communication. I think they come along to an appointment and...what I see is a lot of people sit back, and they don't say anything until the patient doesn't say what the carer wants them to say. I don't think it's necessarily a clinician issue, I think there's a really complex relationship there that the person doesn't want to throw their loved one under a bus or tell it how it really is” MS Nurse

## 6.5 Integrated Care Framework – Voice and Representation

There is strong consensus that PwMS need greater influence in decisions affecting their care. Many feel excluded from service planning and face barriers to having their needs reflected in policy and practice. As outlined in Table 9 below, the proposed Framework focuses on strengthening the voice and representation of PwMS, alongside building self-efficacy and improving system responsiveness, to ensure services are inclusive, coordinated, and aligned with real-world needs. A logic model outlining recommended implementation steps is included in Appendix F.

**Table 9. Integrated Care Framework – Voice and Representation**

| What we learned: | What we recommend: |
|---|---|
| PwMS and carers want genuine involvement in service planning but often feel excluded, particularly in systems like NDIS, mental health and aged care where many fall through the gaps. This leads to inequity and overlooked MS-specific needs in broader policy. | • **Co-design.** Involve PwMS and carers in planning and improving services.<br>• **Advocate for policy inclusion.** Ensure the needs of PwMS are included in policy submissions such as the NSW Mental Health and Wellbeing Strategy, NDIS and Aged Care reforms. |
| Confidence in navigating care is often shaped by MS status, system familiarity, and emotional readiness. Responsive, ongoing support is key to building self-efficacy. | • **Strengthen self-efficacy.** Help PwMS feel more capable and empowered by offering practical tools, peer insights, and encouragement to speak up, take control, and plan for their future. |
| PwMS and carers can struggle to raise concerns or navigate provider changes, often due to uncertainty, power imbalances, or limited options. | • **Rights and advocacy.** Support self-advocacy and how to raise concerns or change providers. |

### Key takeaways

- PwMS want to be heard and involved in decisions but often feel excluded, particularly in large systems like NDIS, mental health, and aged care
- Self-advocacy was seen as necessary but exhausting, with many PwMS feeling they had to become the expert in their own care
- Clinicians see empowerment and self-efficacy as critical, especially early after diagnosis, and want to support PwMS to navigate care with confidence
- Carers play a vital role in communication and coordination but often face barriers to being recognised as partners in care. Clinicians acknowledged carers as critical in supporting PwMS, while also needing to balance this with privacy and the autonomy of PwMS

# Conclusion

People living with multiple sclerosis face ongoing challenges accessing timely, coordinated, and responsive care. These challenges are shaped by service fragmentation, inequity, and limited access to MS-experienced professionals.

Through this project, PwMS, carers, and health professionals described unclear pathways, poor integration between providers, and limited proactive guidance. They called for clearer team roles, stronger collaboration between neurologists, GPs, and allied health professionals, earlier and sustained access to MS-informed education, mental health care, and broader wellbeing supports, and greater recognition of the role of GPs and community-based care to make the system easier to navigate and more responsive to their needs.

The Integrated Care Framework reflects these insights, outlining practical, evidence-informed enablers across six domains to support more coordinated, equitable, and person-centred MS care.

Consultation findings highlighted the need for:

- Clearer care pathways and defined roles within the care team
- Greater coordination between neurologists, GPs, and allied health professionals
- Early and sustained access to MS-informed education, mental health, and broader wellbeing supports, including social, financial, and emotional support
- Improved recognition of GP and community-based care roles,
- Systems that support shared information, regular check-ins, and continuity of care
- Access to providers with MS-specific expertise across disciplines

Clinicians identified similar challenges, emphasising the need for sustainable shared care models, improved communication, and embedded MS capability. GPs were seen as critical to supporting care but stretched in their capacity, underscoring the importance of stronger collaboration with neurologists.

Collaboration between GPs and neurologists was a key enabler of better care experiences. PwMS in these settings reported feeling more supported and informed, had greater confidence during symptom changes, higher satisfaction with care, increased involvement in decisions, and improved sharing of allied health updates. They were also more likely to receive mental health support, discuss social and financial needs, and access regular, relevant wellbeing and lifestyle information. While important, collaboration is likely one of several contributing factors.

The Framework offers a foundation for guiding improvements in MS care. It outlines recommended enablers and priority areas across six domains, aligning clinical care with what PwMS value most. While no single approach will address all challenges, coordinated progress in these areas could support a more integrated, equitable, and person-centred system of care.

While the project engaged a wide range of stakeholders, further engagement is needed with private neurologists, people from culturally and linguistically diverse (CALD) backgrounds, and others whose experiences remain underrepresented.

Ongoing collaboration, leadership, and investment will be critical to translating this work into lasting change, with the perspectives of PwMS remaining central to design, delivery, and evaluation.

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# Logic Model: MS Specialist Care

**Problem**

Non-MS specialist health professionals often lack the opportunities for training, tools, and system support needed to confidently identify, respond to, and coordinate care for PwMS. As a result, PwMS may struggle to access timely, informed, and consistent care, particularly outside specialist settings.

**Objective**

To strengthen the capability of non–MS specialist health professionals by providing the knowledge, tools, and system support needed to deliver timely, person-centred, and coordinated care for PwMS.

| Inputs | Proposed Activites | Expected Outputs | Short Term Outcomes | Medium Term Outcomes | Long Term Outcomes | Benefits |
|---|---|---|---|---|---|---|
| Funding and project resourcing<br>Health workforce (e.g. GPs, allied health, MS Nurses, community clinicians)<br>Clinical expertise and guidance<br>Lived experience and professional input<br>Health professional associations and networks (e.g. MS Nurses Australasia Inc., AHPRA-regulated bodies)<br>Digital infrastructure for online training and resource access<br>Policy and governance support<br>Cross-sector partnerships across primary, community, and specialist care settings | Define and promote national care standards (e.g. reviews, follow-up, escalation pathways)<br>Develop tools to support post-diagnosis education and care planning<br>Promote MS-specific language and framing in clinician communication<br>Strengthen pathways to MS-specific allied health, including underserved populations<br>Create reminders and follow-up tools for key events (e.g. MRI scans)<br>Use telehealth and MS Nurse-led escalation pathways to support care continuity<br>Clarify GP-specialist communication processes and shared information tools<br>Advocate to expand public MS clinic capacity | Shared care and review protocols co-designed and distributed<br>Post-diagnosis resources developed and in use<br>MS-informed communication tools trialed in clinics<br>Referral pathways updated to better include allied health and underserved groups<br>Reminder and follow-up systems adopted<br>GP communication tools (e.g. contact resource sheet) tested<br>MS Nurse access protocols documented<br>Multidisciplinary team or care pathway models piloted and resourced<br>People understand and embed national guidelines into lifestyle eg: MS Brain Health | PwMS feel more supported following diagnosis or major care events<br>MS care is more clearly explained and personalised<br>More consistent follow-up and timely escalation of care<br>Improved communication between MS care team and GPs<br>Health professionals have better tools for guiding PwMS through care processes | PwMS experience more consistent, timely, and tailored care<br>Greater visibility and access to MS-specific supports regardless of setting<br>Improved service continuity and fewer missed care steps or delays<br>Public and private clinics apply clearer, standardised care practices<br>Improved recognition and inclusion of underserved groups including those with PPMS | MS care becomes more equitable, person-centred, and aligned with best practice<br>Gaps in care are reduced through stronger clinic capacity and national alignment<br>Interdisciplinary teams support holistic, coordinated MS management<br>PwMS report greater trust and satisfaction in specialist care pathways | PwMS experience more consistent care and improved outcomes<br>Early support and follow-up reduce risk of disengagement or deterioration<br>Services operate more efficiently with clear care protocols and shared roles<br>Greater equity in access regardless of postcode, diagnosis type, or system such as public or private<br>Carers and GPs are better supported through clearer communication from specialist teams |

Appendix B

# Logic Model: Care Navigation and Coordination

**Problem**: PwMS often lack clear pathways to navigate care, face delays in communication, and carry the burden of coordinating their own health services

**Objective**: To improve navigation and coordination of MS care across people, services, and systems by strengthening communication, shared planning, and role clarity

| Inputs | Proposed Activites | Expected Outputs | Short Term Outcomes | Medium Term Outcomes | Long Term Outcomes | Benefits |
|---|---|---|---|---|---|---|
| Funding and project resourcing<br>Health workforce (e.g. MS Nurses, Neurologists, Allied health, GPs, community organisations)<br>Co-design input from PwMS and carers<br>Digital infrastructure and IT integration capacity<br>Communication tools and health literacy resources<br>Policy and governance support<br>Workforce training and implementation capability | Co-design care planning tools with PwMS and carers<br>Create and test digital resources to support symptom updates and cross-team communication<br>Define and trial care coordinator roles and supporting workflows<br>Develop and pilot shared care planning templates and checklists<br>Build and maintain a directory of MS-trained health professionals<br>Establish processes for routine care coordinator follow-ups and symptom check-ins<br>Consult with stakeholders to define system requirements for interoperable digital communication<br>Engage PwMS to help co-design navigation resources and health literacy tools | Navigation guides and tools co-designed with PwMS<br>Health literacy tools and digital resources developed and tested<br>Refined care coordinator roles and documented workflows<br>Communication and referral protocols established across services<br>Standardised care planning templates and checklists in use<br>Role descriptions and funding models in place for MS care coordinators<br>National directory of MS-trained professionals available<br>Documented system requirements for interoperable digital communication tools<br>Recommendations developed for scaling digital tools across health settings | PwMS have improved understanding of who is in their care team and how to contact them<br>Health professionals are equipped with tools to support shared care planning<br>Care coordinators begin using defined workflows and check-in processes supporting people to navigate care systems<br>Communication across services becomes more structured through shared templates and referral protocols<br>Digital tools for symptom updates and care planning are tested and refined with user feedback | Improved coordination and continuity of care across MS services<br>Reduced reliance on PwMS to manage and communicate care information between services<br>Earlier support and more responsive care during periods of symptom change<br>Better communication and handover between GPs, neurologists, allied health, and support services<br>Care teams consistently use shared tools to guide planning and follow-up | System-wide improvements in access, equity, and navigation for PwMS<br>Reduced fragmentation and duplication across services<br>More timely, joined-up care that supports wellbeing and disease management<br>Sustainable workforce models in place, including funded MS care coordination roles<br>Digital infrastructure supports real-time, person-centred care delivery across settings | PwMS experience more coordinated, responsive, and easier-to-navigate care<br>Carers are better supported and less burdened by system navigation reducing burnout<br>Health professionals have clearer roles, better tools, and improved capacity to deliver proactive care<br>Services operate more efficiently through reduced duplication, delays, and missed follow-ups<br>The health system is better positioned to deliver integrated, equitable care for chronic conditions like MS<br>Investment in care coordination and digital tools results in improved health outcomes and system value |

Appendix C

# Logic Model: GP, Allied Health and Community Care

**Problem**

PwMS report gaps in support from GPs, allied health, and community services, including limited MS-specific knowledge, poor coordination across providers, and unclear care pathways. There is a lack of MS-informed providers across these settings, and a need for more targeted health professional education

**Objective**

To improve access, communication, and coordination between GPs, allied health, community services, and MS Specialist Care by strengthening resources, training, and shared processes.

| Inputs | Proposed Activites | Expected Outputs | Short Term Outcomes | Medium Term Outcomes | Long Term Outcomes | Benefits |
|---|---|---|---|---|---|---|
| Funding and project resourcing<br>Health workforce (e.g. GPs, allied health, MS Nurses, community providers)<br>Policy engagement channels (e.g. Primary Health Networks, peak bodies)<br>Digital infrastructure and directories<br>MS-informed training and education content<br>Lived experience from PwMS and carers<br>Service mapping and care pathway tools | Co-design information sheets and resource handouts for non-specialist providers<br>Develop care summary templates and referral prompts<br>Training providers in trauma-informed care and supportive communication<br>Build a national MS-trained provider directory<br>Develop a digital learning hub with MS health professional training in partnership with professional bodies<br>Embed wellbeing prompts into routine reviews<br>Develop shared care protocols and standardised referral tools<br>Create resources to educate on team roles | MS info sheets and tools distributed across care settings<br>Standardised care planning and referral templates developed<br>Training delivered in trauma-informed care and MS support<br>MS-trained provider directory created and maintained<br>Digital learning hub launched and populated with MS-specific content<br>Wellbeing review prompts embedded in routine assessments<br>Shared protocols for GPs and neurologists adopted<br>Improved resources to support patient-provider communication<br>Care team mapping tools available to PwMS and carers | Non-MS specialist health professionals have better understanding of MS and available supports<br>PwMS are more confident accessing support from GPs and allied health<br>Care team communication becomes more structured and consistent<br>More GPs and community providers use MS-informed tools<br>Reviews begin to include social and financial wellbeing factors | PwMS receive more coordinated, MS-relevant care across community services<br>Communication and care handover improves between non-specialist and specialist providers<br>GPs and allied health professionals feel more equipped to support MS care<br>Wellbeing needs are identified earlier in routine care<br>Referrals between services become more timely and appropriate | PwMS experience more coordinated, confident, and holistic care<br>Fewer people fall through gaps due to poor communication or lack of referrals<br>Health professionals across sectors operate from a shared understanding of MS care<br>Non-specialist services actively contribute to long-term wellbeing of PwMS<br>System-level consistency in MS-relevant pathways and education is embedded | Improved quality of life and care confidence for PwMS<br>Greater system efficiency through clearer communication and role clarity<br>Equity strengthened through better access to MS-informed care regardless of location<br>Reduced burden on specialist services through early, appropriate community support<br>GPs and allied health professionals feel empowered and included in MS care delivery |

Appendix D

# Logic Model: Wellbeing Supports

**Problem**

PwMS often lack timely, coordinated support to manage emotional, financial, and social challenges that affect their health and wellbeing.

**Objective**

To improve access to mental health, financial, and social wellbeing supports for PwMS by integrating services, strengthening peer and professional pathways, and embedding early triggers for support.

| Inputs | Proposed Activites | Expected Outputs | Short Term Outcomes | Medium Term Outcomes | Long Term Outcomes | Benefits |
|---|---|---|---|---|---|---|
| Funding and project resourcing<br>Health workforce (e.g. MS Nurses, mental health professionals, social workers, GPs, community organisations)<br>Lived experience from PwMS, carers, and peer leaders<br>Digital infrastructure and screening tools<br>Mental health and wellbeing resource frameworks<br>Policy engagement channels (e.g. NSW Health, strategy consultations) and governance support<br>Cross-sector partnerships (e.g. health, mental health, disability, community services)<br>Workforce training and implementation capability | Co-design tools to support NDIS applications and low-cost service access<br>Develop and promote financial navigation guides to help PwMS and clinics understand available supports<br>Create and pilot social screening questions for inclusion in MS health reviews<br>Establish protocols for wellbeing "triggers for support" during major life changes (e.g. pregnancy, job loss)<br>Deliver peer-led resilience programs<br>Implement brief digital or in-clinic wellbeing check-ins<br>Coordinate funding models and referral processes across services to enable connected care delivery<br>Share mental health messages via trusted MS channels | NDIS and low-cost support resource kits available online and in clinics<br>Financial navigation tools for clinics and PwMS<br>Social screening tools integrated into routine MS reviews<br>Guidelines for identifying and responding to wellbeing triggers in care settings<br>Peer-led wellbeing and resilience programs delivered and evaluated<br>Mental health referral protocols established and shared<br>Brief check-in tools implemented in clinical and digital settings<br>Service agreements or frameworks piloted to enable shared or connected funding pathways | PwMS feel better supported to access mental health, social, and financial resources<br>Services become more responsive to social and emotional needs, including during key life changes<br>Increased identification of people at risk of stress, isolation, or poor mental health<br>Peer and professional mental health pathways are more visible and accessible<br>MS health professionals are more confident in responding to mental health, social and financial needs | PwMS are more likely to receive timely support in periods of instability or transition<br>Routine care includes consideration of social determinants (e.g. housing, transport, relationships)<br>More people engage with and benefit from mental health and peer support services<br>Greater service coordination between MS, health, mental health, and disability sectors<br>Reduced delays in referrals and service access due to improved navigation tools to social, mental health and financial supports | MS care is more holistic, person-centred, and responsive to emotional, financial, and social wellbeing<br>Fewer PwMS fall through the gaps during major life events or funding transitions<br>Integrated service models reduce fragmentation and improve continuity of support<br>PwMS experience improved quality of life, mental health outcomes, and confidence in the system | PwMS experience improved mental health, stability, and overall quality of life<br>Early intervention reduces escalation of health and psychosocial issues<br>Carers are better supported and less likely to experience burnout<br>Services respond more effectively to the full spectrum of wellbeing needs, not just clinical care<br>System-level efficiency improves through reduced fragmentation and more coordinated funding<br>Equity is strengthened through access to mental health and social supports regardless of NDIS eligibility |

Appendix E

# Logic Model: Education and Self-Management

**Problem**

PwMS often lack timely, accessible, and consistent information to understand their condition, navigate services, and feel informed to actively participate in decisions about their care.

**Objective**

To strengthen education and self-management by ensuring PwMS and their carers have access to clear, consistent, and supportive tools that build understanding, confidence, and active involvement in MS care.

| Inputs | Proposed Activites | Expected Outputs | Short Term Outcomes | Medium Term Outcomes | Long Term Outcomes | Benefits |
|---|---|---|---|---|---|---|
| Funding and project resourcing<br>Health workforce including MS Nurses, neurologists, allied health professionals, and peer support leaders<br>Digital tools for education and symptom tracking<br>Lived experience from PwMS and carers<br>MS-specific educational resources and guidelines<br>Policy and governance channels such as ACI and health literacy networks<br>Consumer rights and safety frameworks<br>Training and communication design capability | Co-design and deliver early education tools<br>Develop care guides that explain roles, care steps, and contact points<br>Create plain language materials and visual tools for use across care settings<br>Expand peer mentoring and lived experience education programs<br>Strengthen education on rights, self-advocacy, and changing providers<br>Develop consistent, trusted information resources across platforms<br>Test simple tools that explain care decisions and show how people can give feedback or raise concerns | MS education tools delivered in early care pathways<br>Care guides and role explanation resources co-designed and tested<br>Plain language and visual materials in use across services<br>Peer support and mentoring programs expanded<br>Self-monitoring tools integrated into MS check-ins<br>Team awareness resources used in clinical and community settings<br>Resources and training on rights and advocacy available<br>Standardised, consistent resources accessible via trusted channels | PwMS feel more confident in understanding their condition and care<br>Care decisions and service options are easier to navigate<br>People are better equipped to track and reflect on their symptoms<br>Care teams are more transparent and responsive in communication<br>Carers feel more included and informed<br>People know where to seek trusted, evidence based information | PwMS and carers engage more actively in shared care decisions<br>MS education is delivered more consistently across care settings<br>Use of trusted, evidence based resources reduces misinformation<br>Increased self-efficacy leads to earlier help-seeking and reduced distress<br>People are health professionals are more aware of their role in supporting informed care | PwMS are more empowered to manage their condition<br>Improved trust and communication across care teams<br>Fewer complaints or disengagement from services due to poor information<br>MS care is more person-centred and inclusive of individual goals and preferences<br>Better system-wide integration of education and self-management support<br>PwMS have increased health literacy | PwMS have greater confidence, agency, and health literacy<br>Early support reduces confusion, distress, and disengagement<br>Services become more transparent, equitable, and aligned with person-centred principles<br>Carers and family members are better informed and supported<br>Equity in access to clear information improves outcomes regardless of background or location |

Appendix F

# Logic Model: Voice and Representation

| | |
|---|---|
| **Problem** | PwMS are often not adequately supported to participate in care decisions, influence service design, or access fair and responsive systems. |
| **Objective** | To strengthen the role of PwMS in shaping services and systems by embedding co-design, enabling self-advocacy, and improving policy and funding alignment |

| Inputs | Proposed Activites | Expected Outputs | Short Term Outcomes | Medium Term Outcomes | Long Term Outcomes | Benefits |
|---|---|---|---|---|---|---|
| Funding and project resourcing<br>Lived experience from PwMS and carers<br>Health workforce (e.g. MS Nurses, Neurologists, Allied health, GPs, community organisations)<br>Peer education networks and community organisations<br>Policy engagement channels (e.g. NSW Health, strategy consultations)<br>Health literacy and self-advocacy resource frameworks | Advocate for system-wide funding solutions to close support gaps for PwMS not covered by the NDIS<br>Facilitate co-design sessions with PwMS and carers to shape services and policies<br>Co-design self-advocacy tools<br>Deliver peer-led education sessions to build health confidence and self-efficacy<br>Engage with health and disability sectors to embed MS-informed perspectives in policy and planning<br>Draft a nationally consistent MS care plan with clear expectations around care steps, timing, and regular review | Summary reports from co-design sessions with consumers, outlining priorities for service and system improvement<br>Co-designed self-advocacy tools and resources<br>Peer-led education session package<br>Draft national MS care plan, developed in partnership with clinicians and PwMS<br>MS-informed submissions and guidance provided to health and disability policy forums and government stakeholders<br>Advocacy toolkit for use by MS organisations, incorporating core messages and adaptable templates for engagement | PwMS feel more confident to speak up and participate in care discussions<br>Health professionals and policymakers are more aware of lived experience priorities and practical policy options<br>MS organisations have access to ready-made advocacy tools and messaging to support local and system-wide efforts<br>Peer-led education sessions build initial confidence and community connection among participants<br>Policy forums and service partners begin to consider MS-informed recommendations in their planning<br>Co-designed self-advocacy tools are used in clinical and community settings | MS-informed perspectives are embedded in ongoing policy and funding reviews<br>The draft national MS care plan informs consistent, person-centred care approaches across services<br>More PwMS actively use self-advocacy resources to support engagement in care<br>Peer-led education becomes a sustained and valued part of community-based MS support | PwMS are routinely included in care design, service planning, and policy decisions<br>Structural advocacy mechanisms and lived experience leadership are embedded in health and disability systems<br>Gaps in support for people not eligible for the NDIS are reduced through alternative, sustainable funding models<br>A nationally consistent MS care plan supports more equitable, coordinated, and responsive care across the country<br>MS advocacy becomes more strategic, aligned, and impactful across organisations and regions | PwMS experience greater agency, dignity, and control in decisions about their care<br>Health and disability systems are more equitable, transparent, and person-centred, with services shaped by lived experience<br>MS advocacy efforts are better coordinated and more effective, leading to stronger policy influence and resource allocation<br>Support is more accessible<br>Improved quality of life for PwMS through timely, flexible, and coordinated care<br>Stronger partnerships across sectors, enabling sustainable solutions that bridge health, disability, and community needs |

## Tables

## Figures

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