



# Living with Multiple Sclerosis in 2019

The needs of people living with multiple sclerosis, their families and carers

**Key results from a quantitative research study commissioned by Multiple Sclerosis Australia**

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# Multiple Sclerosis Australia: Living with MS in 2019

Multiple Sclerosis Australia (MSA), and its member organisations, commissioned research to understand unmet demand and emerging needs of people living with multiple sclerosis (MS), their families and carers. On behalf of MS Australia, KPMG surveyed 2,261 people living with MS and 135 family members and carers across Australia, between March and May 2019. The quantitative research was informed by a baseline review and supplemented by 20 in-depth interviews. This report is a summary of the detailed research.

The key insights from this research show that there is a keen interest in services beyond medical specialists, particularly for services that support mental wellbeing and maintaining lifestyle. The research also highlighted challenges with access and affordability of services to better meet the changing needs of people living with MS, along with their families and carers.

When considering how to meet these needs, it is important to consider personalisation, as the experience of living with MS is unique to each individual.

# Our key findings in a snapshot

## Diagnosis is a highly emotional stage of the MS experience

People living with MS more recently diagnosed are seeking information about maintaining their lifestyle and emotional wellbeing; and there appears to be a generational shift in the types of information required.

## Despite the changes to the MS landscape, there are still many with unmet needs

The biggest barrier to accessing services was affordability. Not knowing how to access services was particularly common among those ineligible for the National Disability Insurance Scheme (NDIS).

## MS significantly impacts employment

An MS diagnosis has a significant impact on participating in paid employment.

The employment of carers is also impacted.

## Family members are the primary source of support

Eighty-seven per cent of people living with MS state they have someone (unpaid or informal) who is their main source of support.

## Carers need support to be the support

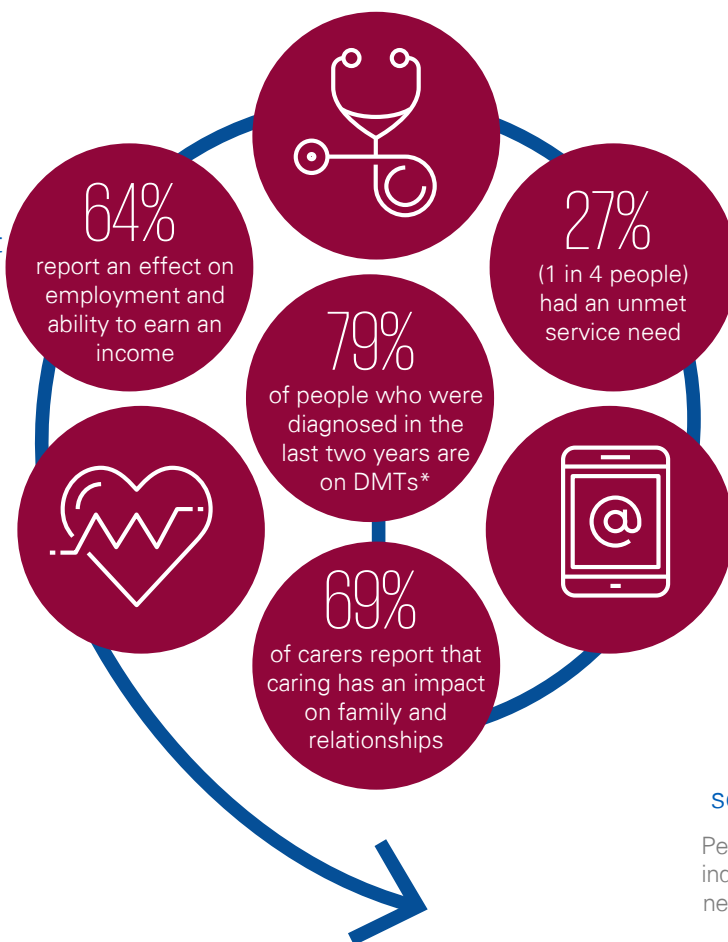
Caring impacts emotional wellbeing, family life and relationships. Tailored assistance for informal supporters is an emerging service need.

## People are using technology for information, monitoring and peer connection

Among those who self-monitor, 40% use technology and for those not yet using technology, 61% have an interest.

## There is a growing cohort living well, and likely to require fewer disability services in the future

People who were living well indicated they have reduced need for services and fewer unmet needs. This group is seeking medical, wellbeing and lifestyle, and emotional support services, and tend to rely on their informal network for support.



\*DMTs: Disease Modifying Therapies  
Statistics refer to the primary research conducted using quantitative surveys of people living with MS, their families and carers.  
Research also included a baseline review and qualitative interviews.

Read on for more details



## Diagnosis is 'ground zero'

Diagnosis is an emotional stage of the MS experience. While nearly all people (94%) seek additional medical information at this stage, significant proportions also seek information about lifestyle changes (53%) and emotional support (47%). This is a critical time to make an impact with support services.

Those aged 16-34 years are more likely to focus on lifestyle and emotional information and support. Fifty-one per cent wanted counselling at the time of diagnosis compared to 18% of those over 65 years, **potentially indicating a generational shift in requirements.**

*It felt very catastrophic. I was looking for stories and advice from people under 30 living well.*

The research found that neurologists are the key information source at diagnosis (used by 72%), but they are not always seen as helpful (17% not helpful). While used less frequently (34%), for those who did access additional support, high proportions of those in contact with MS organisation staff said they were helpful (79%) as were MS nurses (86%). **This is a potential opportunity to increase and integrate additional support services.**

*Responses were too medicalised and solutions were drug focussed.*

People are also increasingly using online information as a source at diagnosis. Forty-five per cent use websites, but only 56% found them helpful. Qualitative research indicated navigating online information can be difficult at first, as some people feel the information is too general, does not fit with their experience of MS – or did not provide them with the emotional support they were seeking.

It is important not to forget family members and carers, who were looking for information about their supporting role at this stage. Qualitative responses indicated that information is mostly received second hand via the person they care for, particularly at the diagnosis stage. **This appears to be an emerging and unmet need.**



## Despite the changes to the MS landscape, there are still many with unmet needs

Forty-one per cent of people living with MS regularly use four or more services: these often include neurologists, GPs, physiotherapists, massage therapists, MS or continence nurses. The professional support network required for those living with MS can be wide and diverse.

Interestingly, half of people surveyed stated they contact MS organisations for further information about selection of new supports and services.

**One in four (27%) people had an unmet service need that most often arose from affordability (41%) or accessibility (25%).**

The people most likely to have unmet needs are younger people who are living well. The largest critical unmet service needs at this time were physiotherapy or massage therapy.

*I used to go to an informal group of young women who all have relapsing remitting MS but are still able to work and live normally. **That was essential for my mental health** when I was diagnosed; to see that not everyone ends up in a wheelchair, unable to work.*

*I felt lost and confused, depressed ...you grow up wanting to be independent, but I realised I was going to need help.*



## MS significantly impacts employment and incomes

Two thirds (64%) of those living with MS said that the condition has affected their employment and ability to earn an income. Overall, when we look at those still of working age (under 55 years), responses indicate a 36% drop in full-time employment.

Among this group, 64% were employed full time before their symptoms started and 17% were employed part time. Currently, 28% work full time and 28% work part time.

If we look only at those diagnosed within the last two years who are of working age, responses indicate a 21% drop in full-time employment. While this is an improvement, there is evidently still a significant impact on workforce participation.

Generally, people were seeking more assistance with maintaining workforce participation and 65% of people were using employment services.

**Respondents stated that enabling ongoing workforce participation for those living well, accommodating work arrangements and fatigue management are important.**

*I was not supported by my last employer. I struggled with the tasks due to fatigue. I left and set up my own business that I can manage alongside my symptoms.*

**Carers' capacity for employment is also impacted.**

It is not just those living with MS who experience impacts on employment. The majority of those who identified as carers reported that they were employed either full time (61%) or part time (16%), before they started providing care for someone living with MS. When asked about their current employment status, only 30% of carers were employed full time and 11% part time.



## There is a growing cohort who are living well, who are likely to require fewer disability services in the future

The research confirmed there is an increasing use of Disease Modifying Therapies (DMTs).

**The majority (79%) of people who were diagnosed in the last two years are on DMTs, compared to 75% of those diagnosed three to five years ago, 66% diagnosed six to 10 years ago and 45% of people diagnosed over 20 years ago.**

Notably, people living with MS who are NDIS participants are less likely to be on DMTs.

**People who were living well indicated they have fewer (reduced) levels of service needs and fewer needs that are 'unmet'.**

This group is seeking medical services only and tends to rely on their informal network for support.

The hypothesis is that if DMTs work as expected, and are increasingly used by people who are newly diagnosed, the need for NDIS access will continue to decline. However, it may also indicate that people living with MS, their families and carers will be increasingly exposed to the economic impacts of long-term, chronic disease, along with access and affordability issues.

Further, as people increasingly turn to their informal network for support, in turn that network may need additional information and assistance.

**This support is not perceived as being readily available and accessible.**

*I am doing ok, but as MS is so individual, no one can tell me what will happen in relation to disease progression.*

*Most of the information I receive is about research into the causes... I'd like more information about the day-to-day parts of living with it.*



## People are using technology for information, monitoring and peer connection

People are increasingly using technology and accessing information online.

While the majority of people who track their symptoms don't use technology (60%), some are now turning to cognitive brain training (23%), symptom diary applications (18%) or wearable technology (16%), particularly at diagnosis. For those not yet using technology, there is strong levels of interest (61%) in using it.

**These channels have the potential to become an increasingly important connection and integration point in service delivery.**



## Family members are the primary source of support

The majority (87%) of people living with MS shared that they have someone (unpaid or informal) who is their main source of support.

For over half of people, this is a partner or spouse. Respondents in the family members and carers survey were most likely to be an immediate family member. It was reported that this person most often provided some sort of daily emotional support (69%), rather than physical assistance. **The primacy of this informal support is an emerging service need and consideration at all stages of the MS journey.**

*I just follow my wife's lead, I don't really know how to make her life easier.*



## Carers need support to be the support

Seventy-nine per cent of carers report that caring has an impact on their emotional wellbeing.

Family members and carers reported that services focused on the person living with MS. They seek direct information about how to support the person, rather than receiving information second-hand. Forty-five per cent of carers are paying for health professionals' support. This is where there is the most demand.

**Tailored assistance for informal supporters is a key emerging service need.**

*If you're still able to do all the things you used to be able to do and then they tell you, you have MS, it's hard to accept.*

*I trust my sources of info i.e. MS Society, GP & neurologist to get up to date info. With Facebook, I have to be more discerning about the validity of the information.*

*While my neuro and GP were great, what was missing was any sort of suitable online material. Special websites are needed for newly diagnosed people.*

*I didn't have very much information on who I could turn to emotionally.*



# People living with MS, their families and carers are clear about their hopes for future support services:

*Better support for newly diagnosed. It is a real shock & those first few years are incredibly rocky.*

*I would hope that the minute someone is diagnosed they were given a psychologist immediately. Not just "oh you need antidepressants". The psychologist needs to help the person.*

*Consider family members of those with MS as well when it comes to support services.*

*How do you find services, how do I afford them?*

*Advertise the services available for people ineligible for the NDIS.*



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