MS AUSTRALIA

RESEARCH
ADVOCACY
CURE

# WORLD MS DAY

# 'MY DIAGNOSIS'

## REPORT

# CONTENTS

# INTRODUCTION

## What is MS?

Multiple Sclerosis (MS) is the most common acquired neurological disease in younger adults around the world, with over 2.8 million people affected globally. More than 33,300 Australians live with MS and over 7.6 million Australians know someone or have a loved one with this potentially debilitating disease.

Symptoms vary between people and can come and go; they can include severe pain, walking difficulties, debilitating fatigue, partial blindness and thinking and memory problems. For some, MS is characterised by periods of relapse and remission, while for others it has a progressive pattern of disability. MS can rob people of quality of life, primarily driven by the impact of MS on pain, independent living, mental health and relationships.

### COMMON SYMPTOMS OF MS


## World MS Day 2024

First initiated by the MS International Federation (MSIF) and its members in 2009, World MS Day is a day to celebrate global solidarity and hope for the future.

The two-year (2024 – 2025) global World MS Day 'Diagnosis' theme and 'My MS Diagnosis' campaign will advocate for early and accurate diagnosis for everyone living with MS. The new theme and campaign will highlight global barriers to diagnosing MS, raising awareness by sharing real stories and data. The global MS community will campaign for better MS training for healthcare professionals, new research, and clinical advancements in MS diagnosis. Together we will work to build informed, caring communities and systems that support people diagnosed with MS.

MS Australia is contributing to this significant international exploration of diagnosis, its impacts, current process, and opportunities to achieve earlier MS diagnoses.

## MS Diagnosis

MS is a complex disease and diagnosis is not always straightforward. While for some, a diagnosis can be made in a few quick steps, others can wait for a long period of further testing from the time of their first symptoms until they are officially diagnosed.

By its very name, multiple sclerosis (where 'sclerosis' means scarring) suggests that there are multiple lesions or scars. To clinically diagnose MS, there needs to be evidence of not only multiple attacks at different locations in the brain and spinal cord, but also that these occurred at different times. While this might sound easy to determine, there is still no single clinical test to provide a definitive diagnosis. Therefore, a careful combination of clinical examinations, MRI scans and lumbar punctures are potentially required for a diagnosis.

To differentiate MS from other similar neurological conditions, most neurologists use what is called the McDonald criteria. This is a published medical guide for clinicians and is periodically updated in line with the latest research and understanding of the disease. Put simply, the McDonald criteria require there to be a history of two or more clinical attacks/relapses with evidence of two or more MRI lesions in different areas of the brain or spinal cord. If there has only been one clinical attack (physical symptoms), then evidence of older scars or lesions in the brain (signs of previous attacks that may have been missed) can help make the full diagnosis.

A lumbar puncture that takes a sample of the cerebrospinal fluid (CSF) can also help if there has only been one clinical attack. This method helps rule out other types of infections (virus or bacteria) that may cause an immune response. If oligoclonal bands can be detected in the CSF, indicating a current or previous immune response, a diagnosis of MS can be made.

A recent study[1] suggests that up to 18% of people with a diagnosis of MS might be incorrectly diagnosed, highlighting the challenges faced by doctors when it comes to diagnosing MS.

In addition, some genetic disorders, copper or B12 vitamin deficiency, structural abnormalities, and other demyelinating diseases can cause neurologic symptoms that can look like MS. Some of these alternative diagnoses are easy to rule out with other medical tests, while others may require a series of additional tests or a watch-and-wait approach.

# TIME TO DIAGNOSIS

The MS landscape has been comprehensively transformed over the last few years by progress in research and therapeutics. There are now 14 disease-modifying therapies (DMTs) available in Australia for people with MS, and most of these are listed on the Pharmaceutical Benefits Scheme (PBS).

Over the last 15 years, people with MS are being diagnosed earlier, and the long-term outcomes for people with MS have improved significantly, with certain disability milestones being reached almost eight years later on average. However, there is still some way to go in improving the time to diagnosis for many people living with MS.

## Australian MS Longitudinal Study

The Australian MS Longitudinal Study (AMSLS) collects real life data from people living with MS. It is a survey-based research study that has been running since 2002 and now has about 2,500 people completing research surveys each year.

The AMSLS is one of MS Australia's national collaborative research platforms and is a partnership between MS Australia and the Menzies Institute for Medical Research, University of Tasmania.

The data collected is used by policy makers and MS medical and support services to create positive change and improve the lives of people with MS.

## Time to Diagnosis Data

In April 2024, The Menzies Institute reviewed the data from the AMSLS to look at trends in MS diagnosis over the last 25 years[2]. The report found that since the introduction of the first DMT for MS treatment in 1996:

- The average time to diagnosis has reduced from five years and almost four months (median two years) in 1997-2000 to three years and almost 11 months in 2017-21 (median one year).
- There remain people who are not diagnosed as having MS for many years. This reflects the complexity of MS, with some people taking many years to manifest.
- The fall in the median time to diagnosis from two years to one year is very significant.
- Those with a longer time to diagnosis are likely to be older at diagnosis and more likely to be deceased (and no longer part of the study).

This research highlights that individuals diagnosed with MS continue to undergo prolonged and intricate diagnostic processes. It underscores the pressing need for interventions aimed at shortening these timelines and enhancing the precision of diagnoses.

# LIVED EXPERIENCE DIAGNOSIS STORIES

In 2023, MS Australia established a Lived Experience Expert Panel to provide expert advice to inform our advocacy work. The panel is made up of people who either live with MS or are a carer for someone living with MS.

For World MS Day 2024, LEEP members have shared their lived experience of gaining a MS diagnosis. These stories represent the complexity and diversity of the MS diagnosis journey and the need for self-advocacy, strong support networks and caring and engaged health professionals.

## SIENNA SULLIVAN

My journey with MS began when I was just six years old. It started with strange visual disturbances – flashing lights and dots that clouded my world. What followed was a whirlwind of doctor's appointments and neurological tests, but at nine, the doctors concluded it was psychological.

For four years, until I was nine years old, I underwent behavioural therapy, being told it was all in my head. Despite the support of my paediatrician, the trauma of being dismissed by medical professionals made me keep my struggles to myself, fearing I wouldn't be believed.

At thirteen, I lost all feeling in my right hand, a stark reminder that something was seriously wrong. Yet, once again, a neurologist told me it was psychological. For years, I was unable to write or use my hand as I wasn't receiving the right treatment.

Then, at fourteen, numbness crept from my head to my toes. This was the moment I knew it was not in my head. Another trip to the neurologist yielded little hope until an MRI uncovered the truth – multiple lesions on my brain and spine, finally explaining my symptoms.

The whole diagnosis process was not easy for me, as I was young, and many doctors didn't believe me. It took eight long years to receive a diagnosis, and throughout my journey, my mum and family were my biggest support system. They never stopped fighting for me, pushing for better care and accommodations. But I also learned the importance of self-advocacy – of trusting myself and knowing my body.

Finding medical professionals – such as a neurologist I could trust and be comfortable with, and MS nurses who I can share my concerns with – has been critical. MS has impacted every aspect of my life – friendships, education, even my ability to work.

The lack of awareness and support for young people with MS is staggering, and I'm determined to change that. No one should face the hurdles I did, especially in school. The education system has very poor special considerations for children with disabilities, and I believe there is much that needs to be changed.

Luckily for me, I had parents and a school who fought for me to get better considerations, which were still not good enough. However, for other children with MS, I know they do not have these supports, making them unable to complete school. For me, helping others with MS through school is very important as I know the struggles I faced, which nearly led me to drop out.

Now, I strive to be a voice for others with MS, ensuring they receive the understanding and assistance they deserve. It's a journey filled with challenges, but with the love of my family and the support of the MS community, I know we can make a difference.

## LAURA BIRCHALL

"At 28 years of age, my diagnosis journey went about as smoothly as possible. Between my GP and neurologist, it took less than two months from reporting my symptoms to completing testing, confirming the diagnosis and starting treatment with a DMT. The most challenging part of my diagnosis was the immediate aftermath of reconciling what it means to have MS."

## AMANDA KENNEDY

I was just 31 when MS made its abrupt entrance into my life. My first symptom was a hot sensation around my right knee followed by an altered sensation in the back of my right thigh. Then came the pins and needles from my waist down.

When these symptoms had not improved a week later, I saw a GP who immediately suspected I might have MS. He gave me a referral and sent me to the Emergency Department, with the intention of seeing a neurologist straight away.

The doctors in the Emergency Department brushed off my symptoms, disbelieving that MS could be the culprit. MRI? Not unless it was a life-or-death situation, they said. Apparently, I didn't qualify. So, I endured six long weeks of uncertainty before finally getting a brain MRI as an outpatient.

The results were telling—multiple lesions decorating my brain, a silent language of MS that no one bothered to translate for me. However, no one contacted me with the results or followed up.

It took three more months, and a return visit to my GP with a resurgence of pins and needles, before anyone bothered to inform me of the diagnosis. A spine MRI and a blood test followed, each adding weight to the confirmation of what I already knew in my gut.

Based upon the results of the two MRIs I was referred to a neurologist who finally provided my diagnosis – four months after the onset of my first symptoms.

Promises of lumbar punctures and treatment before Christmas fell by the wayside, replaced by a frustrating four-month wait until late February. Meanwhile, another relapse wreaked havoc, rendering my right side numb and an inability to control the movement of my left eye and severe double vision.

Getting continued access to treatment has also been challenging.

The prescribed monthly infusion tied me to the hospital, demanding precious hours I couldn't spare. With a full-time job, the rigidity of appointment times during work hours made it very difficult to attend treatment appointments. So, I made the decision to change my treatment to a monthly injection I can administer myself at home to keep my work life intact.

Before my diagnosis, MS was just a distant concept, a few pages in a childhood readathon. Wheelchairs and uncertainty—those were the images it conjured. But now, I see it differently. I have no family history of MS, and before MS, I didn't think that I knew anyone who had it. Since my diagnosis, I've discovered that MS isn't always visible. I did in fact know people with MS, however, they had kept it hidden out of fear of being judged in the workplace.

While my journey with MS has been fraught with challenges, it's also been a lesson in resilience and the power of adaptation.

## JESSICA WORSLEY

Following a challenging IVF journey and the traumatic birth of my daughter in May 2018 at 27 years old, I was eager to embrace newborn life. Instead, I found myself unwittingly navigating MS symptoms while being dismissed by multiple GPs. Over six months, I experienced severe fatigue, dizziness, balance issues, weakness, and numbness in my hand. Despite expressing my concerns, five GPs brushed them off with comments like "You're a new mum, you're supposed to feel awful," "this is your new normal," and "your numbness is from holding your baby, try using your other arm."

When I raised concerns about breastfeeding issues, I was told that my prolactin levels were unusual, and there might be a benign tumour on my pituitary gland. However, I was advised to wait a few months. Uncomfortable with this suggestion, I insisted on an MRI after a fall in the shower (which I now attribute to heat sensitivity). The first clinic declined, but at another clinic (with

## JULIE LONSDALE-LIGHT

"The diagnosis process took approximately six weeks in total. But because I was living in a small regional town, I experienced some difficulty in travelling long distances to see a neurologist and attend all my appointments."

GP number six), I finally got an MRI the next day. It was a long and terrifying experience, watching a group of people discussing my case without any information given to me.

Later that day, a GP from the clinic called to inform me that lesions suggesting MS had been found on the MRI and urged me to come in the next day to discuss further. The GP immediately contacted my neurologist and arranged for an urgent appointment, though it took almost four weeks to be seen. The suspicion of MS was high, but it required a battery of blood tests and a traumatic lumbar puncture, which took multiple failed attempts until it was successfully done under CT/X-ray guidance (a practice I wish was standard).

Eight months after my daughter's birth and the onset of symptoms, I finally received an official diagnosis and began treatment in the ninth month. It was a frightening and isolating time as a new mother and a young woman newly diagnosed with MS. Joining the MS Society and volunteering on the people living with MS committee provided a lifeline, and the MS nurses became my sanctuary. This experience motivated me to share my journey publicly on social media and podcasts to raise awareness and advocate for others.

Redirecting my career back to university to gain a degree in disability and inclusion, I now oversee a successful Newly Diagnosed Peer support program at the MS Society SA & NT, providing reassurance, validation, and connection to others. I also mentor clients as part of my role. Early intervention and lived experience support in the first year, I believe, can significantly impact the mental well-being and outcomes for people diagnosed with MS.

## HANNAH WOOLFORD

"After the MRI, I was brought back to my little cubicle and was having further observations. The emergency doctor came in. I can till hear his voice saying, "You've got Multiple Sclerosis". I was 23 years old. My response – immediate tears. I had what felt like 50 million questions and concerns floating around in my head."

## SARAH FLAIM

*"At least it's not a brain tumour..."*

I vividly recall Christmas Eve 2013. Three excited kids. Check. Three stockings beside beds. Check. One tingly left arm. Whoa, what's that about!? One sleepless night due to frantic worrying about early onset cardiac disease. One trip to the emergency room. One cursory work-up by an under-enthused EMT registrar who diagnosed 'stress'. And finally, one very delayed Christmas dinner, comforted by the notion there was no imminent chance of a heart attack. Whew, I thought, I've dodged a bullet. Oh my, how wrong I was.

Over the next months the sensory symptoms didn't abate and were compounded by neuromuscular pain and a relentless accompanying fatigue. Desperate for some indicator of what was causing these symptoms, I engaged with several medical specialists and was launched into an abyss of medical prodding and probing, investigations and interrogations. As I began that free fall into what would become a seemingly endless onslaught of specialist appointments, each resulting in ever increasing emotional turmoil and generating far more questions than answers, I had no idea that it would take an epic 12 months to land on the solid ground of a definite diagnosis.

Blood tests, MRIs, a lumbar puncture, and nerve conduction tests—all yielded bafflingly inconclusive results. An increasingly varied suite of theoretical potential diagnoses – spanning the gamut from a brain tumour to schizophrenia, lupus to syphilis – were all explored and systematically ruled out. Months went by and I remained in a sort of medical purgatory – euphemistically referred to by my doctors as 'it could be nothing'. Because even though MS remained defiantly on the list of not-yet-excluded hypotheses, one demyelination attack does not equate definitionally to the multiple that MS draws its name from.

And yet, although I was 'clearly not fine', I was also 'not visibly unwell' either. Things settled down for a few months until another relapse and then after yet another MRI (I was half-expecting the kitchen cutlery to start sticking to me). After delving into yet more diagnostic rabbit holes, I was finally, at the age of 34, proclaimed to have MS.

And with the diagnosis came relief – an end to the disquieting uncertainty of 'what is wrong with me?' – and the promise of disease-modifying therapies to stall neurodegeneration.

Fast-forward ten years to now, and I'm living comfortably without major disabilities, under the care of a neurologist I trust. It was without a doubt a rocky road to diagnosis, but I consider myself fortunate that it was caught relatively early, and I've experienced no major relapses. My hope is that with the improvements over the years in technology and training, others may experience a much less fraught diagnosis journey.

# IMPROVING MS DIAGNOSIS

Great progress has been made in MS over the past 25 years. In this timeframe we have delivered many specific MS therapies where there were none available previously. MS occurs because the immune system mistakenly attacks the brain and spinal cord, and MS therapies suppress the immune attack.

Despite the incredible progress made, MS remains a serious burden on people's quality of life and on the economy. The great unmet need in MS is to prevent, halt and reverse neurological damage and disability. Experts believe a large proportion of MS could be preventable. Even being able to halt MS at an earlier stage has enormous potential to significantly reduce the burden of this disease.

Working with Australian researchers, MS Australia has initiatives in place to tackle the reversal of neurological damage and disability. Our urgent unmet need now is to prevent or detect MS earlier and to stop irreversible damage to the brain and spinal cord before it begins.

## Using an MS Biobank to Stop MS Earlier

At present, MS can often be delayed or significantly halted from the time it is first seen in the clinic. This is usually soon after the onset of clinical symptoms, such as vision problems, loss of feeling, pain or weakness of the limbs.

Given the powerful therapies now available, earlier detection of MS would give us the power to shut down the attack on the brain much earlier. This could help preserve precious brain tissue, halt or delay disease, and potentially reclaim many years of function for people with MS.

Earlier detection of MS requires the development of reliable markers of early disease, an effort that is reliant upon MS biobanks.

## The 'pre-MS' period

We have known for many years that the disease process in MS likely begins many years before the onset of typical clinical symptoms at around age 20-40.

But over the last decade, large studies have shown a trend of declining health in the years before MS diagnosis. A newer concept of an 'MS prodrome' has emerged, with early signs and symptoms that occur years before typical MS clinical symptoms appear[3].

Better understanding and better detection of this 'pre-MS' phase could profoundly improve our ability to recognise and diagnose MS earlier; allowing us to prevent MS or halt/delay symptoms and disability

## Finding biomarkers of 'pre-MS'

Given the genetic susceptibility to MS, insights into the 'pre-MS' period have come from studies of healthy close relatives of people with MS.

Brain imaging of these relatives (including many twins) showed that 14 per cent had brain abnormalities fitting MS criteria; and many of these went on to develop MS later. This suggests there are early changes in the brain before MS clinical symptoms appear[4]. However, regular brain imaging may prove impractical and too costly for screening large numbers of healthy people.

We do not have a blood test to detect early MS, however, international MS biobanks have identified promising candidates. One of these is a breakdown product of damaged nerves that can be detected in the blood. Levels of this 'neurofilament light chain' are raised in the blood from around six years before MS onset[5]. Further work is required to understand the potential of this, and several other candidates, as blood markers for the "pre-MS" phase. MS biobanks are critical to this work.

## Stopping MS Before It Starts

A recent study has provided the strongest evidence yet that infection with the Epstein-Barr virus (EBV, the causative agent of glandular fever) is essential for the development of MS[6] . EBV infection increased the risk of developing MS by 32-fold in a large US military cohort measured over many years. Signs of nerve damage in the blood only ever appeared after EBV infection.

We are closer than ever to preventing EBV infection, with two new-generation EBV vaccines currently in international clinical trials. In future, biobanking will be essential to monitor any rollout of EBV vaccines, and their impact on rates of glandular fever and MS.

A biobank would also allow us to monitor the other important environmental risk factors for MS, including low vitamin D and sunlight exposure, smoking and obesity, and the effect of public health initiatives towards preventing MS.

## The National MS Biobank

A national collaborative research platform is needed to develop markers to detect MS earlier, and to identify people at high risk of developing MS so we can prevent it. For this work we need very detailed insights into people's MS, or their risk factors for MS. This will include blood and other biological sample markers and genetics. Together with clinical data and brain imaging, this rich data source will allow us to screen and group people according to risk or stage of MS.

Such a resource is essential if we are to find patterns to detect MS earlier, and ultimately a large proportion of new cases of MS could potentially be prevented.

## MS Nurses

MS nurses are an integral part of the multidisciplinary healthcare team of specialist healthcare professionals providing support, education, advice, and care for people with MS and their family and carers.

Access to MS nurse care brings health benefits for people with MS. These include lower disability level, slower self-reported disease progression, less severe symptoms, lower levels of depression and anxiety, and a higher quality of life. Access to an MS nurse can significantly improve the diagnosis journey for people living with MS.

The MS Nurse Care in Australia Report[7] by MS Australia, in collaboration with the Menzies Institute for Medical Research and MS nurses Australasia found that one-third of Australians living with MS (equivalent to 8,000 people) do not have access to life-changing MS nurse care and have consistently worse health outcomes. MS nurse care reduces the need for other, more costly health professionals, such as GPs and neurologists and prevents emergency department presentations and potentially, hospital admissions.

If every Australian with MS had access to MS nurse care as part of their ongoing MS management plan this would result in substantial cost savings for MS healthcare in Australia. It would significantly delay disease progression and contribute to an increased quality of life. There are further savings from a reduced reliance on National Disability Insurance Scheme (NDIS) supports and other health, disability and aged care programs and supports. The increasing numbers of Australians living with MS will significantly impact on the Australian health system. An immediate increase in MS nurses is crucial if this growing need is to be met.

## Education and Awareness

MS diagnosis can be further improved by better education for health professionals, so they understand neurological conditions and how to support their patients through the diagnosis journey.

# FUNDING THE FUTURE

World MS Day 2024 presents a unique opportunity for the global MS community to come together to discuss MS diagnosis and seek solutions. Collaborating on research that will assist in the early detection of MS will improve outcomes for people living with MS all over the world.

This is also an opportunity for the Australian government to partner with the MS research community and co-fund the initiatives outlined above. Early and improved diagnosis of MS will improve outcomes for people living with MS, significantly reduce the disability burden of MS and reduce the economic impact for the Australian health, disability and aged care sectors.

Together we can change the future.

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

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

Fund, coordinate, educate and advocate for MS research as part of the worldwide effort to solve MS

Provide the latest evidence-based information and resources

Help meet the needs of people affected by MS

# APPENDIX A:

## Report on time to diagnosis for MS Australia using data from the Australian MS Longitudinal Study

UNIVERSITY of TASMANIA
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AUSTRALIA
AUSTRALIAN MS LONGITUDINAL STUDY

# Report on time to diagnosis for MS Australia using data from the Australian MS Longitudinal Study

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## Time to diagnosis and year of diagnosis in the whole Australian MS Longitudinal Study cohort

People living with multiple sclerosis (MS) and enrolled in the Australian MS Longitudinal cohort (n=4810) had been diagnosed with MS from 1947-2021. Average year of diagnosis of the cohort was 2001, with a mean time from first symptoms to diagnosis of 4.9 years (median 2 years), with a wide range (up to 52 years) (Table 1).

*Table 1: Year of diagnosis and time to diagnosis, AMSLS participants (n=4810)*

| | Range | Mean | Median |
|---|---|---|---|
| **Year MS Diagnosed** | 1947 to 2021 | 2001 | 2002 |
| **Time to diagnosis (years)** | 0 to 52 | 4.9 | 2 |

There is no clear linear association between time from first symptom to diagnosis (r=-0.005, p=0.61), but there may be a non-linear association (see Figure 1).

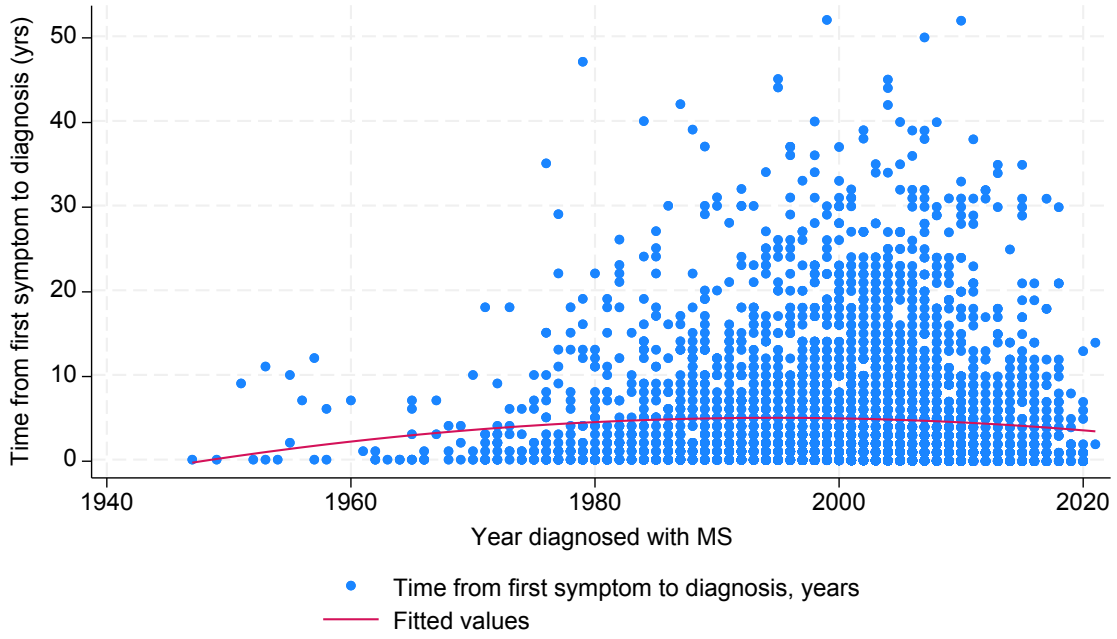


*Figure 1: Time from first symptom to diagnosis, by year of diagnosis*

**Interpretation:** Time to diagnosis is not linear, with no clear trend over time (Figure 1). Outliers significantly influence mean time to diagnosis.

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## Time to diagnosis in the AMSLS cohort – considering important flexion points

Table 2 shows time to diagnosis by different time periods, with the following important dates:

- 1996: first disease modifying therapy was approved for use
- 2001: McDonald criteria for diagnosis of MS using MR images version 1
- 2010: McDonald criteria version 2
- 2017: McDonald criteria version 3

These cut points are reflected in Table 2 and Figure 2.

*Table 2: Time to diagnosis (years), by time period diagnosed*

| | Range | Mean | Median | Frequency (%) |
|---|---|---|---|---|
| **<1996** | 0 to 47 | 4.9 | 2 | 1162 (24%) |
| **1997-2000** | 0 to 52 | 5.3 | 2 | 860 (18%) |
| **2001-2009** | 0 to 50 | 4.9 | 2 | 2003 (41%) |
| **2010-2016** | 0 to 52 | 4.3 | 1 | 675 (14%) |
| **2017-21** | 0 to 31 | 3.9 | 1 | 110 (2.3%) |
| **Total** | 0 to 52 | 4.9 | 2 | 4810 (100%) |

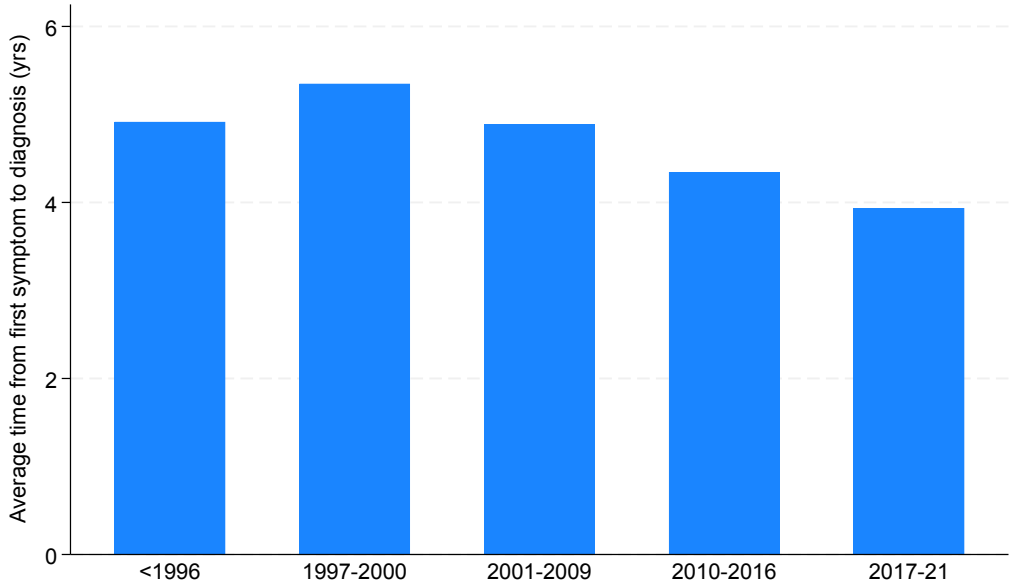


*Figure 2: Average time from first symptom to diagnosis (years) by year of diagnosis*

**Interpretation:** Average time to diagnosis has reduced since DMTs were introduced in 1996, from average 5 years (median 2 years) in 1997-2000 to 3.9 years in 2017-21 (median 1 year) but there remain people who are not diagnosed as having MS for many years. This reflects the heterogeneity of MS, with some people taking many years to manifest. The fall in the median time to diagnosis from 2 years to 1 year is very significant.

Table 3 shows time to diagnosis by different time periods, with the following important dates:

- 1983: Poser criteria
- 1989: Updated Poser criteria
- 2001: McDonald criteria for diagnosis of MS using MR images version 1
- 2005: McDonald criteria update
- 2010: McDonald criteria version 2
- 2017: McDonald criteria version 3

These cut points are reflected in Table 3 and Figure 3.

*Table 3: Time to diagnosis (years), by time period diagnosed*

| | Range | Mean | Median | Frequency (%) |
|---|---|---|---|---|
| **<1983** | 0 to 47 | 4.0 | 1 | 270 (5.6%) |
| **1983-1988** | 0 to 42 | 5.2 | 2 | 259 (5.4%) |
| **1989-2000** | 0 to 52 | 5.3 | 2 | 1493 (31%) |
| **2001-2004** | 0 to 45 | 5.0 | 2 | 936 (19.5%) |
| **2005-2009** | 0 to 50 | 4.8 | 2 | 1067 (22.2%) |
| **2010-2016** | 0 to 52 | 4.3 | 1 | 675 (14%) |
| **2017-21** | 0 to 31 | 3.9 | 1 | 110 (2.3%) |
| **Total** | 0 to 52 | 4.9 | 2 | 4810 (100%) |

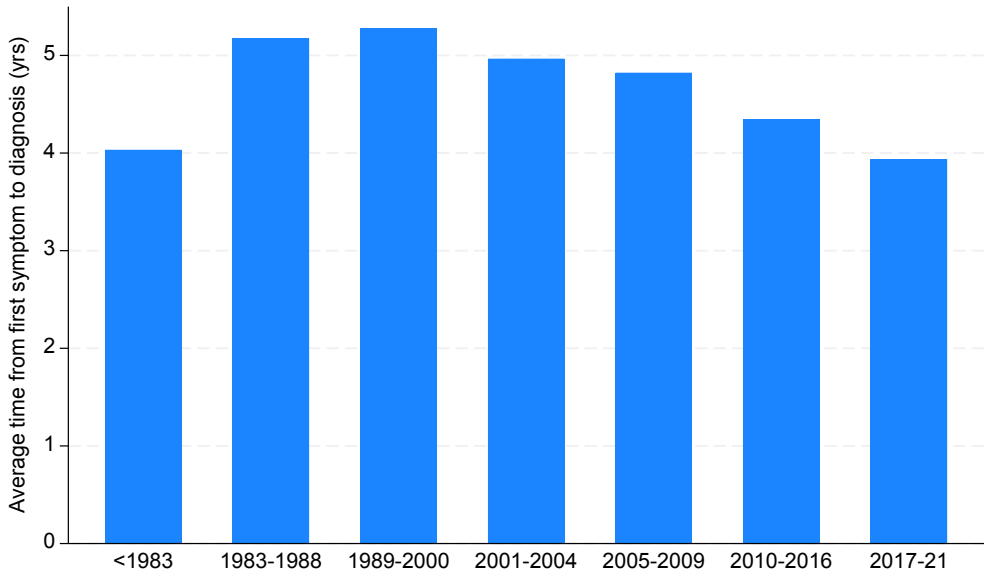


*Figure 3: Average time from first symptom to diagnosis (years) by year of diagnosis*

**Interpretation:** Average time to diagnosis has reduced since 1983-2000, from 5 years (median 2 years) in 1983-2000 to 3.9 years in 2017-21 (median 1 year). There remain people who are not diagnosed as having MS for many years. Time to diagnosis prior to 1983 is likely a cohort effect. Those with longer time to diagnosis are likely to be older at diagnosis (see Table 4) and more likely to be deceased.

## What about the shorter time to diagnosis in people diagnosed prior to 1996

People who were younger at the time of diagnosis were more likely to have a shorter time between when they first experienced symptoms and when they were diagnose with MS (Figure 3).

People in AMSLS diagnosed prior to 1996 were diagnosed at a younger age (Table 3), so this effect of shorter time to diagnosis could be a real effect, or it could be a cohort effect (year of diagnosis), or a combination of both. This could also be due to other effects eg survivor bias, as AMSLS began recruitment in 2002, people living with MS had to be alive and in good enough health to enrol in AMSLS after 2002.

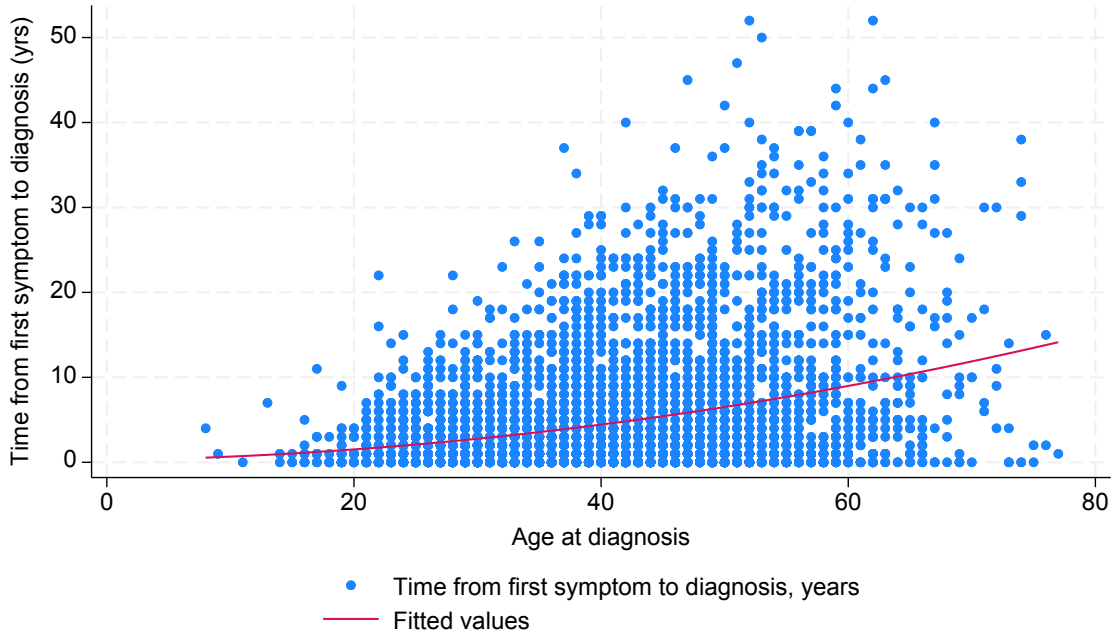


*Figure 4: Time from first symptom to MS diagnosis, by age at diagnosis*

*Table 4: Age at diagnosis, by time period diagnosed (n=4790)*

| | Range | Mean | Median | n |
|---|---|---|---|---|
| **<1996** | 8 to 71 | 36.7 | 36 | 1157 |
| **1997-2000** | 11 to 75 | 41.1 | 41 | 854 |
| **2001-2009** | 13 to 77 | 41.8 | 42 | 1995 |
| **2010-2016** | 19 to 74 | 44.0 | 43 | 674 |
| **2017-21** | 21 to 72 | 42.3 | 40.5 | 110 |
| **Total** | 8 to 77 | 40.8 | 40 | 4790 |

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