

Lay Summary

What factors influence MS disability progression over time?

Parker 2025

Assessing disability progression using the WHODAS 2.0 in multiple sclerosis: Investigating clinical and socio-demographic factors in a large longitudinal cohort study (TONiC-MS)



What was the study about?

The TONiC researchers wanted to understand how disability progresses in people with multiple sclerosis (MS) over time—and what factors might influence that progression. Instead of using traditional tools that may miss important aspects of disability, they used the World Health Organization Disability Assessment Schedule (WHODAS 2.0), a questionnaire developed by the World Health Organization that looks at how health conditions affect daily life across multiple areas (like mobility, cognition, and social participation).



What did the study involve?

5,210 adults with MS from across the UK helped with this study. Everyone did the TONiC pack, including the WHODAS 2.0. We asked people to complete the pack more than once, so that we could better understand how their experiences change over time: 1,057 did the pack twice, five people filled in 6 packs over the years. Packs were sent to the participants at home about a year apart. Sufficient people at all stages of MS helped with the study to make it possible to calculate the statistical model tracking disability over time to cover up to 24 years after diagnosis. The participants' characteristics were similar to those of the UK MS population. The information from the rest of the pack investigated what might influence any changes in disability.



What was found?

- **Disability varies a lot between people.** On average, disability increased over time, but the rate and level were very different from person to person.
- **Different types of MS show different patterns.** People with progressive MS at diagnosis tended to see faster worsening early on.

- **Education and self-efficacy matter.** People with more education tended to do better, in that they were less likely to develop disability. Some of the influence of education seemed to pass through an important characteristic that we all have, called self-efficacy. Self-efficacy means belief in one's ability to take productive actions, so that people with high self-efficacy believe they can take action to improve their future situation. Higher education may help build this confidence, but interestingly, self-efficacy was even more important for people with less education. In other words, if someone didn't have many educational opportunities, they faced a higher risk of developing disability – however, if they had high self-efficacy then that disability risk tended to be less than if they had lower self-efficacy, and this difference was greater in people with lower education than in people with higher education. Self-efficacy is not fixed in people but instead can be influenced by various factors.
- **Employment also relates to disability but more research is needed.** We found that people who were working tended to have less disability. However, we don't yet know why this is the case. It might be that having a job helps slow disability by providing helpful routine, physical activity, and social contact. Or it could be that people with less disability are simply more able to stay in work. It may even be a mix of both. We're preparing another study to explore this in more detail.
- **Mental health and fatigue are key.** Depression and fatigue were strongly linked with higher disability levels and so are important areas for treatment.
- **Other health problems and smoking add to the burden.** Having additional medical conditions, or being a smoker, were linked to greater disability. The disability of smokers progressed more rapidly in the first few years after diagnosis compared to people who had never smoked or who had quit.



Why this matters?

Disability in MS doesn't follow a one-size-fits-all path. Importantly, disability in MS isn't just about the disease itself—factors like self-efficacy, depression and lifestyle also play a big role. This means that alongside medical treatments, there are a number of other factors which could be influenced to reduce the risk of MS disease progression: early support for mental health, smoking cessation, management of other health conditions, and programmes that boost self-efficacy could slow disability progression and improve life with MS.

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