

Why advocating for your MS is so important

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For the estimated 2.8 million people¹ living with multiple sclerosis (MS) worldwide, diagnosis is life-altering and can be overwhelming. The symptoms, including loss of vision, movement and sensation, the impact on daily life, hobbies, jobs, and relationships² and the threat of progression can easily leave a person feeling out of control.

To help regain some of this control, Ellen Tutton, a mum, wife, MS advocate, patient, and influencer from the UK, explains that: "It's important for people living with MS to feel confident to ask questions early on. Getting my MS diagnosis was a long process, it was hard for me to advocate for myself when I was feeling my weakest – but I am so proud, that I did."

Unlocking empowerment: Navigating Multiple Sclerosis through shared decision-making

People living with MS can push for more collaborative conversations with their healthcare professionals from the moment they are diagnosed, using a process called shared decision-making. This is a joint approach during which healthcare professionals and people living with MS work closely together to design a disease management plan that is tailored to the specific needs of the individual³. Importantly, shared decision-making often results in better compliance (for example, in sticking to a medication or exercise regimen), reduced healthcare costs, greater experience and better relationship with their care team, and – maybe most crucially, improved quality of life^{4,5}, all of which may positively impact treatment regime outcomes.

Ellen champions the practice of making decisions together and says: "*I would tell newly diagnosed people living with MS to push for collaborative conversations from the very beginning. It's about having autonomy over our lives and the choices we have control over. My hope is that people will be vocal about their desires and understand that it's a joint conversation between you and your healthcare professional, not a one-way street.*"



People are unique, MS management should be, too

Every person living with MS is affected differently by the condition⁶, and therefore how they manage their MS should be specific to their journeys, too. As Ellen explains: *“My MS is unique to me, as such I would expect my care to also be unique to my needs and not treated with a one-size-fits-all approach.”*

People living with MS understand better than anyone the day-to-day struggles of living with the condition and how it impacts their lives. They should feel empowered to share exactly how their MS is impacting them and what it is they want in terms of managing their disease. By listening and collaborating, healthcare professionals and people living with MS can then tailor management plans unique to each individual.

Louisa, a MS patient advocate from Germany knows first-hand the impact shared decision-making has had in her MS management.

“In terms of shared decision-making throughout my personal MS journey, I would give my younger self the piece of advice to be even more open to share my lifestyle, routines, and visions (which I started to after the diagnosis) with my care team. By that, finding the best fitting treatment - for the patient, their lifestyle, and their MS - is way easier. Because, in the end, the aim of shared decision-making is to find an MS treatment which fits a patient's lifestyle and preferences and simultaneously treats MS”, confirms Louisa

Exploring the impact of location on your MS diagnosis journey

As every MS experience is unique, Adaaajo, a Japanese fashion influencer living with MS, had a different diagnosis experience from Ellen. A key factor contributing to this divergence was geographical. Japan, Adaaajo's home, classifies MS as a rare disease, meaning that it affects a significantly smaller proportion of the local population compared to many Western countries like Germany and the UK. In Japan, MS is prevalent in 14 in every 100,000 people, whereas in the UK and Germany the figures are much higher at 199 and 300 in every 100,000 people, respectively^{7,1}. This can impact the diagnostic experience significantly, especially if you live without an MS experienced neurologist close by.

“MS is considered a rare disease in Japan and as somebody affected by the disease, I think that this might impact the

awareness for MS and might lead to differences in the process of diagnosis and treatment. I am fortunate that I found the right doctor who supported me in being able to keep my lifestyle as much as possible. For me as well as many other MS patients, I believe that building a trusting relationship with their doctor and care team is very important – maybe even more so in regions where MS is not as common. And I hope for anybody with MS – whether they are in a country where MS is a rare disease or not – that they feel empowered to speak up for themselves so they can keep choosing a life that suits them!", said Adaaajo

The diagnosis process for MS can take time and involve various invasive tests such as magnetic resonance imaging (MRIs) and lumbar punctures. Evidence shows that an early diagnosis and an early start of the most appropriate treatment for each MS patient can result in an overall delay in MS progression¹. For Adaaajo in Japan, reaching the right doctors to receive the right treatment may take longer due to it being a rare disease. In this case, shared decision-making, as in advocating strongly for themselves and collaborating openly with their care team – beginning at the earliest stages is particularly important to achieve the best outcomes.



Supporting shared decision-making in MS – tools to encourage conversations

Receiving the right support and information on how to reclaim ownership of their life at the earliest stages after diagnosis is critical in taking an active role in making decisions on treatment choices. As the experts on living with the disease, it's important that people living with MS are involved in creating resources developed to help others as they navigate their diagnosis and to teach them about the value of shared decision-making.



Dr Alice Laroni, MD

Dr. Alice Laroni, MD is an Italian neurologist and MS specialist who regularly advocates the importance of taking patient perspectives into account and why co-created guides and tools are essential to support shared decision-making in practice.

"As a neurologist, I recognize that for a person living with MS, the encounter with the healthcare professional (HCP) can be a challenge: time constraints, emotions, and a plethora of complex information contribute to hindering an open dialogue. Even for the neurologist, finding time for active listening can be difficult amid the myriad bureaucratic tasks. The co-creation of resources, such as MyMS Workbook and MyMS Checklist, has been a key moment for the advancement of shared decision-making in MS. Thanks to these resources, the neurological visit can center around the person living with MS, their priorities, and their needs", said Dr Laroni, MD

Dr. Laroni was a member of the shared decision-making steering committee along with diverse actors of the MS community, including people living with MS and their care partners who co-created a set of tools with Novartis for **"Making MS Decisions Together"** on <https://www.novartis.com/diseases/multiplesclerosis/ms-tools>.

Shared decision-making in MS: Consider what matters to you

To help people living with MS take an active role in shaping their future around what matters most to them and advocating for this from the earliest stage of diagnosis, Novartis launched the **My Love Stories** program. My Love Stories shares the experiences of multiple different people living with MS, including Ellen and Louisa, with the aim to empower others to actively participate in their decision-making and disease management choices. Discover Ellen and Louisa's My Love Stories [here](#).

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