

Insights Into MS

Patient Views on Disease Progression

Patient perspectives on diagnosis



- At diagnosis, patients can be overwhelmed by an abundance of information and different treatment options, leading to anxiety and decreased motivation to engage in care plans^{1,2}
- In addition to managing MS symptoms and treatments, patients must deal with practical challenges such as school, work, or family commitments¹
- The concerns and priorities vary from patient to patient throughout the disease spectrum¹

“ I remember being terrified and also in deep denial... I can still remember how it felt like the end. We now knew that I really did have MS, but we did not know what was coming next.¹ ”

– Jeri, on being diagnosed with MS at age 38



Patient priorities in disease management



- In a survey, patients with MS said they wished they had known more about MS when they were diagnosed, including its impact on mental health, physical health, and lifestyle, as well as questions they should ask their doctor³
- As priorities can differ between patients and for the same patient over time, conversations that focus on strategies to promote a healthy lifestyle⁴ and understanding assistive devices for MS⁵ can help patients manage daily challenges
- Invisible symptoms, such as fatigue, cognitive impairment, and mood symptoms, need to be managed even when there are no clear signs of physical disability or disease progression^{5,6}

“ The MS books are glossy. [They] tell us a lot about MS, but not about how to live with MS. It's frustrating; we need something more, some better information.¹ ”

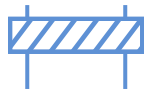
– Kit, diagnosed with MS at age 55, on the importance of educational materials that meet patient needs

Education, assistive devices, and technology may all be tools that can help patients manage their disease progression.



Visit our website at www.mshcpeducation.com to learn more and hear leading clinical expert opinions on this topic.

Overcoming treatment barriers



- There are multiple issues that should be considered on a patient-by-patient basis as they can impact compliance and adherence to treatment plans⁶
- Lack of understanding of disease progression and the importance of early intervention, medication side effects, psychosocial factors, and financial restrictions all pose potential barriers to initiating and maintaining treatment that can delay disease progression^{6,7}
- Patients with MS are vulnerable to social isolation; therefore, advocacy and support groups as well as social media platforms can be a resource for patients to share their experiences and to support each other in their journey¹²



Optimizing patient communication



- Facilitate conversations to understand how MS uniquely impacts each patient, and consider the patient's level of understanding of MS¹
- Communication can be most effective when it comes from a multidisciplinary team of specialists that can manage different disease aspects, and should include a professional with expertise in MS⁶
- There may be hesitation to initiate conversations about transitioning to secondary progressive MS and new concerns associated with uncertainty about this stage; however, it is important to routinely discuss the possibility of disease progression and encourage patients to assess their own condition over time⁸



MS, multiple sclerosis.

References

1. Burtchell J, Fetty K, Miller K, Minden K, Kantor D. Two sides to every story: perspectives from four patients and a healthcare professional on multiple sclerosis disease progression. *Neurol Ther*. 2019;8:185-205.
2. Rieckmann P, Centonze D, Elovaara I. Unmet needs, burden of treatment, and patient engagement in multiple sclerosis: a combined perspective from the MS in the 21st Century Steering Group. *Mult Scler Relat Disord*. 2018;19:153-160. doi:10.1016/j.msard.2017.11.013
3. MultipleSclerosis.net. MS in America 2016: being diagnosed with multiple sclerosis. Accessed March 17, 2021. <https://multiplesclerosis.net/living-with-ms/ms-in-america-2016-being-diagnosed-with-multiple-sclerosis>
4. Vermersch P, Shanahan J, Langdon D, et al. Knowledge is power, but is ignorance bliss? Optimising conversations about disease progression in multiple sclerosis. *Neurol Ther*. 2019;9(1):1-10. doi:10.1007/s40120-019-00170-7
5. Filippi M, Bar-Or A, Piehl F, et al. Multiple sclerosis. *Nat Rev Dis Primers*. 2018;4:43. doi.org/10.1038/s41572-018-0041-4
6. Giovannoni G, Butzkueven H, Dhib-Jalbut S, et al. Brain health: time matters in multiple sclerosis. *Mult Scler Relat Dis*. 2016;9(suppl 1):S5-S48.
7. Costello K, Halper J, Kalb R, et al. The use of disease-modifying therapies in multiple sclerosis: principles and current evidence. *Multiple Sclerosis Coalition*. 2020. https://ms-coalition.org/wp-content/uploads/2019/06/MS_CDMTPaper_062019.pdf
8. Davies F, Edwards A, Brain K, et al. "You are just left to get on with it": patient and carer experiences of the transition to secondary progressive multiple sclerosis. *BMJ Open*. 2015;5:e007674.