

# MS experts call for increased focus on progressive MS rehabilitation research

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Demyelination by MS. The CD68 colored tissue shows several macrophages in the area of the lesion. Original scale 1:100. Credit: [CC BY-SA 3.0](https://creativecommons.org/licenses/by-sa/3.0/) Marvin 101/Wikipedia

An international team of multiple sclerosis (MS) experts has identified four under-researched areas that are critical to advancing symptom management for progressive MS, recommending interdisciplinary

collaboration among scientists, clinicians, industry leaders, and those with progressive MS. Their call to action was published in *Multiple Sclerosis Journal* on March 15, 2021, in the article "Prioritizing progressive MS rehabilitation research: A call from the International Progressive MS Alliance." The Alliance was represented by authors from Canada, the United States, the UK, Australia, Denmark, Belgium, Germany, and Switzerland.

Recent advances in MS research have resulted in a variety of disease-modifying therapies that can significantly improve [quality of life](#) for people with certain phenotypes of the disease. For example, those with relapsing-remitting MS have access to more than 20 therapies. However, these phenotypes represent only some in the MS community.

A major barrier to the development of [rehabilitation](#) therapies for progressive MS is the fact that the vast majority of studies conducted to explore rehabilitative therapies involve people with relapsing-remitting MS, not progressive MS. In addition, trials are often designed based on strategies used for pharmaceutical trials, which are not necessarily conducive to clinical rehabilitation trials. Unfortunately, this lack of clinical data to inform therapies for progressive MS leaves this population with few options to manage potentially debilitating symptoms that can lead to challenges such as loss of a job, personal and family stress, and financial strain.

In this article, experts from research, medicine, and industry highlight four major symptoms affecting people with progressive MS that should be the focus of new research: fatigue, mobility and upper extremity impairment, pain, and cognitive impairment. They contend that rehabilitative therapies show great promise for managing these symptoms and for improving physical and cognitive function as well as quality of life, and that directing research efforts toward rehabilitation is critical to developing effective therapies.

"There is a strong need to study the effect of early preventive interventions and to evaluate management of existing symptoms," says co-author John DeLuca, Ph.D., Senior Vice President for Research and Training at Kessler Foundation. "Effective [symptom](#) management and rehabilitation remain far behind in progressive MS. We have little empirical rehabilitation data, and our understanding of mechanisms underlying symptoms and treatment responses is incomplete." Dr. DeLuca emphasizes, "We have ample evidence from research in other clinical areas that rehabilitation can improve quality of life and find support from diverse payers and stakeholders. Our aim is to bring attention to the pressing need to develop rehabilitation treatment interventions for the progressive MS community."

**More information:** Kathleen M Zackowski et al, Prioritizing progressive MS rehabilitation research: A call from the International Progressive MS Alliance, *Multiple Sclerosis Journal* (2021). [DOI: 10.1177/1352458521999970](#)

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