



**MARCIA FINLAYSON,
PHD, OT REG (ONT), OTR**

Queen's University
Kingston, Ontario, Canada

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Readers of the *International Journal of Multiple Sclerosis Care* understand that multiple sclerosis (MS) affects more than just the person with the disease. It also affects family, friends, coworkers, and other members of their social network. Whatever term we use for these individuals—caregivers, care partners, or carers—their care. In the context of MS, the duration of caregiving is often lengthy, sometimes 40 years or more.¹ And, as a result, they offer different types of social support (eg, emotional, instrumental, informational, appraisal)² to enable persons with MS to manage their disease and its impact on everyday life. These various forms of support can be episodic, occasional, or regular and frequent.³

Nevertheless, during the past 20 years, there have been relatively few articles about MS caregiving in the scientific literature.⁴ This scarcity of research has occurred despite the longstanding acknowledgment that comprehensive MS care includes education and assistance to caregivers.⁵ This special issue recognizes the importance of adding to our collective knowledge about MS caregiving, and hopefully will inspire more researchers and clinicians to contribute to this area of inquiry.

The existing MS caregiver literature has several notable gaps, as described by Kenneth Pakenham, PhD, an internationally recognized researcher in MS caregiving, who was interviewed for this issue (see page 278). Current MS caregiving literature has a predominant focus on examining heterosexual spousal caregivers and psychological burden. This focus has resulted in little attention being paid to other types of caregivers (eg, same-sex partners, siblings, parents, children), understanding caregiving as a dyadic and interactive experience, or identifying effective strategies to support caregivers, whoever they may be. Although this issue does not address all these gaps, an article by Holden et al about parent caregivers highlights one of these unique carer groups. Douglas et al, Hoseinpour et al, and Kalb et al each offer an article about promising interventions. Caregiver resilience is addressed in an article by Cardwell et al, and this and the continuing education article about symptom management by care partners, also by Cardwell et al, have the potential to guide additional intervention development.

We have much to learn about caregiving, caregivers, and how the relationships between caregivers and persons with MS evolve over time and influence how, when, and why support is offered and accepted. I hope this issue generates curiosity and commitment to advance our knowledge.

—**Marcia Finlayson, PhD, OT Reg (Ont), OTR**
Guest Editor

REFERENCES

1. Finlayson M, Cho C. A descriptive profile of caregivers of older adults with MS and the assistance they provide. *Disabil Rehabil*. 2008;30(24):1848-1857. doi:10.1080/09638280701707324
2. Cohen S. Social relationships and health. *Am Psychol*. 2004;59(8):676-684. doi:10.1037/0003-066X.59.8.676
3. Schulz R, Tompkins CA. Informal caregivers in the United States: prevalence, caregiver characteristics, and ability to provide care. In: Olson S, Committee on the Role of Human Factors in Home Health Care National Research Council, eds. *The Role of Human Factors in Home Health Care*. National Academies Press; 2010. Accessed October 10, 2023. <https://www.ncbi.nlm.nih.gov/books/NBK210048/>
4. Rajachandrakumar R, Finlayson M. Multiple sclerosis caregiving: a systematic scoping review to map current state of knowledge. *Health Soc Care Community*. 2022;30(4):e874-e897. doi:10.1111/hsc.13687
5. Consortium of Multiple Sclerosis Centers. Comprehensive care in multiple sclerosis. 2010. Accessed October 10, 2023. https://cdn.ymaws.com/www.ms-care.org/resource/collection/4CB3E940-0D5C-4ADD-9C48-8FA7AAAC2DB9/CMSC_WhitePaper_Comprehensive_Care_in_MS.pdf