

# Addressing the Needs of Multiple Sclerosis Caregivers From Diagnosis Onward: The Development of a Comprehensive Online Caregiver Protocol

Rosalind C. Kalb, PhD; Deborah Miller, PhD; Jon Strum, BA; and Sara Loud, MBA, MSc

## ABSTRACT

**BACKGROUND:** Caregivers of individuals with multiple sclerosis (MS) have emotional, instrumental, wellness, and social needs beginning with their partner's diagnosis and continuing throughout the disease course. Their feelings of grief, anxiety, depression, isolation, and fatigue, as well as the limited time they have for their own self-care, impact their health and quality of life; yet caregiver needs often go unrecognized by health care providers, extended family, friends, and employers. This project creates an online caregiver resource that will benefit caregivers, enable MS clinicians to offer caregivers the support and resources they need in a timely and time-efficient way, and thereby benefit individuals with MS as well.

**METHODS:** We assembled a caregiver advisory board to help us identify caregiver needs and corresponding resources starting from diagnosis and continuing throughout the disease course. We then surveyed the larger MS caregiver community for validation and refinement of the resource list. Each of the identified resources was then vetted for quality and accuracy by the authors.

**RESULTS:** The caregiver resources are now ready to be put into a dedicated website that will allow easy access to information, support, tools, and resources as needed.

**CONCLUSIONS:** The process of creating this caregiver resource confirmed longstanding findings in the literature about the caregiving role. The resource that has been created will benefit caregivers of individuals with MS, their loved ones, and MS clinicians.

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Thirty percent of people with multiple sclerosis (MS) require care and 80% of that care is provided by informal, unpaid caregivers.<sup>1</sup> The prototypical informal caregiver in MS is male, in a spousal/partner relationship with the individual with MS, and provides more than 4 hours per day of care over the course of many years.<sup>2</sup> In our personal and clinical experience, many caregivers of individuals with advanced MS spend most of the day—and often the night—attending to their family member's needs.

Compared to caregivers of individuals with other chronic conditions, MS caregivers generally take on the caregiver role earlier in their lives and maintain it over several decades.<sup>3</sup> They often begin caregiving at a time in their lives when they expected to be focused on building a career, taking care of young children and a busy household, or attending to the needs of elderly parents. Instead, they find themselves doing all of those things while also taking care of a partner whose abilities have been impacted by confusing and unpredictable MS symptoms. Compounding the challenges is the progressive nature of MS, which means that caregivers take on responsibilities that evolve in complexity, generally requiring increasing amounts of energy and time. In the context of these responsibilities, caregivers' own health and wellness needs are often neglected.<sup>4</sup>

Research has demonstrated the profound impact of caregiving responsibilities on the lives of caregivers. They experience reductions in quality of life,<sup>5</sup> physical and emotional health, financial security, and social engagement<sup>6</sup> as well as a partnership disruption or loss of partnership accompanied by intense feelings of loss.<sup>3,7-9</sup> They also experience fatigue and depression, both of which are negatively correlated to their physical and mental health.<sup>5</sup> These stressors may, in turn, lead to various types of abuse, including physical, verbal, emotional, and sexual mistreatment of the individual with MS, as well as neglect, particularly when the caregiver engages in substance abuse.<sup>10</sup>

From Can Do Multiple Sclerosis, Avon, CO, USA (RCK); Mellen Center for Multiple Sclerosis Treatment and Research, Cleveland Clinic, Cleveland, OH, USA (DM); *RealTalk MS*, Long Beach, CA, USA (JS); and Accelerated Cure Project, Inc, Waltham, MA, USA (SL). *Correspondence:* Rosalind C. Kalb, PhD, 290 Sabino Rd, West Bath, ME 04530, USA; email: rkalb@cando-ms.org.

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Despite the high levels of stress associated with the caregiver role, research has shown that people who care for individuals with MS are often reluctant to seek out or use available resources<sup>5</sup>; furthermore, they differ significantly in their readiness to acknowledge the need for support and assistance for themselves.<sup>6,7</sup>

In our combined personal and clinical experience with MS caregivers in a variety of care and support settings, several common challenges stand out: lack of time to manage their many responsibilities; guilt about taking time for themselves and their own wellness; extreme fatigue; feelings of isolation; feeling continuously “on call”; mood changes, including depression and anxiety; overreliance on substances; and worry and anxiety about the future. These challenges were highlighted in focused conversations among caregivers and clinicians at consecutive iConquer MS Leadership Summits, and workshops at 2 consecutive annual meetings of the Consortium of Multiple Sclerosis Centers that included caregivers and clinicians sharing experiences and problem-solving strategies.

In addition to common caregiving challenges, each care dyad has specific challenges. We have documented the following in patient care settings and in caregiver workshops and support groups:

- Couples often find that their relationship becomes unbalanced as one partner is able to do less and the other partner gradually takes on growing financial, household, and childcare responsibilities. They struggle to keep their partnership mutually satisfying and fulfilling, while the balance continues to shift regarding give-and-take between the partners.
- Parents looking forward to retirement may find themselves caring for an adult child with MS who has returned home. For them, caregiving challenges may be physically demanding and exhausting, impacting their own health and wellness, as well as being emotionally and socially challenging. These older parents and their adult children have to navigate a new parent-child dynamic that respects the adult status of the child with MS while also taking into account the parents' lifestyle, goals, and priorities.
- Parents of a young child or adolescent with MS need to adapt their caregiving activities as the child grows toward adulthood. Their stresses often center around the urge to protect, monitor, and oversee as much of the child's life as they can while also preparing them to become independent by learning to manage their own disease and health care and focus on their chosen education and vocation priorities.
- An adolescent child who cares for a parent with MS may experience a stressful role reversal, particularly if the parent has significant physical and cognitive impairments. The younger caregiver may also feel guilty about wanting to pursue education or work goals that would interfere with their parent's care. It is not

## PRACTICE POINTS



From diagnosis onward, caregivers of individuals with multiple sclerosis (MS) have unmet emotional, instrumental (eg, chores around the house), wellness, and social needs.

For promotion to caregivers: The protocol offers access to emotional support, practical guidance, and tools and resources that are available on demand, comprehensive, and easy to navigate.

For clinicians: The protocol is an easily accessible resource to recommend to MS caregivers.

Meeting the needs of MS caregivers helps to ensure optimal care and quality of life for individuals with MS and their families. ■

uncommon for one child in a family—particularly the last one to leave home—to become the “designated” caregiver while siblings go on with their lives.

- Adult children of a parent with MS are part of the “sandwich generation,” torn between their responsibilities to their parents and their children, leaving little time for themselves.
- Many young women diagnosed with MS are themselves providing care for multiple generations, including their own children, parents, in-laws, and even grandparents, while they struggle to manage their disease.

Each individual with MS may have 1 or more people supporting them and providing various types of care and assistance. These caregivers may be a spouse, partner, parent, or family member who provides any of the following: emotional support; financial support (eg, help with paying bills, help with insurance); instrumental care (eg, help with household chores, meal preparation, appointment scheduling, transportation, or shopping); and/or hands-on physical care and assistance. All caregivers require the attention, guidance, and support of clinicians.

## METHODS

In this collaborative project, the Care Project Team (CPT) is Sara Loud, chief executive officer of the Accelerated Cure Project for Multiple Sclerosis (whose patient-driven research initiative, iConquer MS, convened this research

**TABLE 1.** Type of Support Provided by Caregivers

Type of support	Percentage
Emotional	95.5%
Assist with household activities	89.2%
Errands	88.4%
Transportation	77.5%
Paperwork/health care logistics/insurance	66.1%
Financial	59.1%
Hands-on caregiving	54.1%

effort); Deborah Miller, PhD, and Rosalind Kalb, PhD, health care consultants with Can Do Multiple Sclerosis; and Jon Strum, host of the *RealTalk MS* podcast and a former caregiver for his wife with MS until her death. The broad goal of the CPT was to develop and pilot an online tool to provide support and resources for care partners as they need to refer to them over the disease course. Specifically, the CPT’s aims are (1) to mitigate the overwhelming stress and anxiety experienced by MS caregivers by proactively connecting them to available information, support, resources, and services at the time of the MS diagnosis and throughout the disease course; (2) to increase caregiver health and well-being in ways that translate into better health outcomes for individuals with MS and also have the potential to benefit other family members; (3) to engage health care providers as sources of information to ensure that MS caregivers are familiar with where to find and how to navigate available support services before they are overwhelmed by the realities of daily life; and (4) to identify gaps in available resources to address the needs and priorities of MS caregivers. Institutional review board approval was given by the WIRB-Copernicus Group.

**Caregiver Advisory Board**

The CPT recruited an 8-member Caregiver Advisory Board (CAB): husbands of women with MS (n = 3), wife to a man with MS (n = 1), same-sex spouses to partners with MS (n = 2), adult child to parent with MS (n = 1), and parent to child (now an adult) with MS (n = 1).

Between 2020 and 2022, the CPT facilitated and recorded nine 60- to 90-minute discussions with the CAB via Zoom (Zoom Video Communications, Inc) to identify current needs and priorities, those recalled from early in their caregiver experience, and those anticipated in the days and years ahead. The recorded sessions were analyzed by CPT members for key themes, with each recording analyzed by 2 CPT members to optimize consensus.

**Survey**

The needs and priorities identified from the CAB discussions were expanded and validated through an online survey, developed by the CAB and CPT, which

**TABLE 2.** Caregiver Current Challenges and Current or Past Feelings

Challenges		Feelings	
Exhaustion	58.2%	Anxiety and/or depression	70%
Lack of time for:		Guilt/selfishness	67.3%
self-care	48.2%	Strength/resilience	45.5%
hobbies	53.6%	Loss of self/feeling invisible to others	41.8%
socializing with friends	50.9%	Pride/satisfaction	18.2%
Future/financial worries	76.4%	Resentment	50.9%
Conflict, communication, intimacy	72.7%	Irritability/impatience	76.4%
Employment	30.9%	Loneliness	51.8%
Feeling isolated	60%	Other	10%
Mood changes	42.7%	None of the above	0.9%
Other	10%		
None of the above	3.6%		

was broadly distributed to additional MS caregivers via the Accelerated Cure Project, iConquer MS, Can Do MS mailings, and *RealTalk MS* podcasts. For information on survey respondent demographics, see **TABLE S1** (available online at IJMISC.org).

The survey supplied basic information, such as the types of caregiving provided (See **TABLE 1**), as well as revealing the broad array of challenges and negative as well as positive feelings caregivers had experienced (See **TABLE 2**). There was a wide discrepancy between the support caregivers received at the time of their loved one’s diagnosis and what they would have liked to receive. Fewer than 50% of the respondents reported receiving key resources, including information about MS, emotional support, and opportunities to speak with the neurology provider; fewer than 20% received information about life or disability insurance or Social Security disability; and fewer than 10% received training for specialized tasks (eg, transfers, catheterization, skin care, or managing falls).

When asked what types of guidance or support they would like in the future, more than 50% of caregivers identified emotional support and more information about financial assistance, long-term care planning, and community resources (eg, accessible transportation, case management services, Offices of Aging and Disability Services, Meals on Wheels). Other key resources they desire include training for specialized tasks, communication strategies and conversation-starters for difficult conversations, coaching by other support partners, more information about MS, more opportunities to talk with the neurology provider, employment/career counseling, and information for children about MS.

When asked in which formats they would prefer to receive resources, 86.4% chose a web portal with materials

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they could access at any time; 70.9% opted for online support groups and/or coaching; 42.7% preferred in-person support groups and/or coaching; and 34.5% selected print materials.

### **Environmental Scan**

The CPT and CAB conducted an environmental scan of caregiver resources. Utilizing the critical needs identified by the CAB and confirmed by the survey, small teams focused on key areas (ie, MS information, navigating the health care system, employment and financial concerns, long-term care, resources for families, relationship challenges, logistics of daily caregiving, self-care), and searched online for organizations, services, and resources committed to meeting care partner needs. The CAB shared that the frustration and time-drain they experienced as they searched for credible online resources highlighted the need for the Caregiver Protocol. Caregivers do not have time for frustrating searches, even if they eventually do yield helpful results. The CAB also shared their concerns about identifying the most current and credible resources. To address that challenge, the CPT vetted each of the identified resources to ensure their accuracy, credibility, and value. Together, CPT and CAB members created a compendium of resources organized into sections related to specific needs (see [APPENDIX](#)). This compendium will be developed into the Caregiver Protocol website in the next phase of this project.

### **DISCUSSION**

Survey results confirmed our clinical experience and decades of caregiver literature: The people who support and care for individuals with MS in a myriad of ways have significant unmet needs of their own. Labeled our “invisible patients”<sup>12</sup> 15 years ago, they continue to be and feel invisible. The survey also highlighted our shared mandate to address the needs of caregivers from the time of initial diagnosis and to ensure that they remain visible to us throughout the disease course.

The challenges to addressing caregiver needs are complex. At the time of diagnosis, caregivers may be overwhelmed with feelings they find difficult to express or are ashamed to admit in the face of their family member’s challenges. They may not immediately recognize that they need support and resources, let alone what types of support they need; it’s only in retrospect that they recognize what they wish they had known. MS caregivers differ in their readiness to seek out help and support, which suggests that the resources need to be readily available when the time is right.<sup>6</sup> Current resources are challenging to find and busy care providers do not have time to conduct exhaustive online searches, thus, a centralized caregiver resource is essential.

Perhaps one of the most important issues in caregiving is that MS caregivers often do not have the knowledge or skills to manage some of the care that health care

professionals expect them to handle. Catheterization, bowel management, skin care, significant cognitive impairment, and transfers, among others, pose challenges for even the most dedicated partners. Failure to provide adequate training and support may contribute to premature long-term care placement.<sup>13</sup> Training resources in these areas will need to be developed by health care providers prior to inclusion in the protocol.

### **CONCLUSIONS**

The goal of the Caregiver Protocol is to package resources so they can be easily and quickly shared with caregivers when their family member is first diagnosed with MS and also shared periodically throughout the disease course. Caregivers should have access to online resources whenever they feel ready for them or when a resource about a specific topic is needed. In addition, for this protocol to be an effective tool, it must meet the needs of busy clinicians as well.

The next step of the project is the creation of the Caregiver Protocol website prototype, due to be completed by the end of 2023. Once the website has been finalized, it will be piloted at 2 comprehensive MS care centers. Input from providers, caregivers, and individuals with MS will give us the information and guidance required to enhance the resources, website functionality, and ability to share the protocol.

This project has several limitations. Members of the CAB have diverse caregiver experiences, but do not represent the complete profile of caregivers across the MS population. Respondents to the online survey were self-selected and women were overrepresented, even though men are known to make up the greater percentage of MS caregivers. The majority of the respondents were White spouses or partners, which means that information is lacking about caregivers who are siblings, parents, or children, or those with different racial and/or cultural backgrounds. Furthermore, the respondents were predominantly suburban, so the needs of urban or rural caregivers may not be adequately represented. The CPT is also aware that a caregiver resource ultimately needs to be accessible to people for whom English isn’t their primary language. The Caregiver Protocol effort is an important, systematic first step, but upon completion, the website will actively solicit feedback and suggestions from its users, which will provide the input necessary for growth.

As providers, we are keenly aware of the many challenges our patients with MS face. In order for these individuals to thrive, we also need to meet the needs of their caregivers. When caregivers are depressed, anxious, resentful, or are abusing substances or are otherwise in poor health, our patients cannot feel their best, physically, emotionally, or socially, and the family system suffers. By mitigating some of the very real challenges faced by family caregivers, we can improve caregiver well-being while ultimately improving patient outcomes. ■

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