

The Silent Epidemic: Confronting the Invisible Communication Crisis in Multiple Sclerosis

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Multiple Sclerosis (MS), a chronic inflammatory disease affecting the brain and spinal cord, is a growing public health challenge, impacting approximately 40,000 people in Australia. While its physical manifestations receive necessary attention, MS inflicts profound damage through a number of "invisible problems" that erode an individual's quality of life (QoL). These non-motor symptoms—including cognitive impairment, fatigue, and depression—are highly prevalent and demand recognition.

The traditional reliance on physical measures, such as the Expanded Disability Status Scale (EDSS), risks masking the true burden of the disease. Research analysing individuals with "benign MS," defined by minimal physical disability (EDSS score of ≤ 3) after ten years, strongly challenges the term's validity. Data shows that cognitive impairment affects 38% of persons with benign MS. Furthermore, clinical fatigue (78%) and depression (55%) are common in this subgroup, with rates showing no significant difference when compared to people with non-benign MS.¹ This evidence underscores that even a physically mild course of MS can be mentally and emotionally debilitating.

Among these invisible challenges, communication difficulties pose a critical threat to daily function and health-related quality of life (HRQoL).² A significant majority of persons with MS (PwMS) experience these difficulties. One international survey highlighted the scale of the crisis, reporting that 75% of participants self-reported a language impairment. Specific deficits are widespread: 66% reported difficulty with word retrieval, 54% with expressive language, and 41% with difficulty understanding spoken discourse. This self-reported language impairment is directly associated with lower HRQoL.³

These difficulties are not trivial; client narratives capture the profound personal frustration, describing the struggle as "mostly forgetting the name of things" or knowing "what it is but can't get it out". Such struggles are often rooted in broader cognitive decline. People with MS who experience cognitive impairment (CI) are 4.7 times more likely to have word-finding difficulties compared to those without CI.⁴ Given this high prevalence, the role of the speech pathologist is vital. Yet, the evidence base supporting speech and language interventions remains severely limited. A systematic review found only ten studies addressing communication interventions over the last two decades, with just three articles focusing on language.⁵

To ensure PwMS receive the best evidence-based care possible, the research agenda must shift. Future intervention trials must be high-intensity and focus on high-level language problems with practical application. These trials should be guided by principles of experience-dependent plasticity, emphasizing targeted activities, repetitive practice, and meaningful interventions. While new tools like the psychometrically robust Speech Pathology-specific questionnaire for persons with Multiple Sclerosis (SMS) and the Communication and Language Assessment Questionnaire for persons with Multiple Sclerosis (CLAMS)^{6, 7} are emerging to help measure self-perceived function, we must urgently invest in robust intervention research. Until that evidence is secured, a significant element of MS care will remain shrouded by a research deficit, leaving persons with Multiple Sclerosis to battle the silent epidemic of communication disorders largely unsupported.

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