Re-thinking healthcare policy to reflect the disproportionate impact of MS on women

Women are twice as likely as men to be diagnosed with MS and 450,000 women in Europe are affected by the condition.\(^1\)\(^2\) CRA investigated the burden of MS on women patients and the implications on Europe’s economy and society. Our research found a significant impact for women in terms of their family life, career progression and labour market role, that is not recognised by current MS policies. Our analysis suggests a need for greater awareness initiatives to drive early diagnosis and multidisciplinary treatment approaches to facilitate timely access to care. Also, social and workplace support can increase participation in the labour force and social activities, supporting women, their families and the wider economy.

### Diagnosis, treatment and care impact

The process of obtaining an MS diagnosis is subject to delays and inefficiencies. For women with MS, the first doctor visit is often delayed due to time constraints as well as the early onset and slow progression of the disease. MS is commonly misdiagnosed and some women were told they were imagining their symptoms. The delays between symptoms, diagnosis, and care create a period of uncertainty that impacts women’s decision-making about careers, family and social relationships.

- **6 months** from symptoms to diagnosis
- **5 doctor visits** for a diagnosis
- **21%** of women with MS were initially misdiagnosed
- Common misdiagnoses:
  - chronic fatigue syndrome
  - trapped nerve
  - depression
  - brain tumour
  - epilepsy
  - chronic pain

### Family, social and daily life

MS affects the choices women make regarding their relationships and family. For example, the decision of whether to have children, as well as the timing of a pregnancy, may be influenced by MS symptoms combined with a lack of comprehensive and consistent information on how MS affects pregnancy. Additionally, the perceived “randomness” of MS symptoms has a debilitating effect on women’s daily lives. Women with MS are more likely to suffer from depression or anxiety, and they are less likely to participate in social activities.

- **41%** separated or divorced their partners
- **37%** either decided not to have children or altered their timing to do so
- **69%** of women caregivers felt their capabilities had diminished as a result of MS

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Financial and workplace impact

Women with MS are less likely to work full time and more likely to suffer from forms of presenteeism and absenteeism. Additionally, the lack of employer support and understanding from co-workers can lead to feelings of exclusion and discrimination in the workplace. MS hinders women’s ability to participate effectively in the workforce, which imposes a significant cost on the European economy every year. A conservative estimate of the cost is €1.2 billion/year; however, this does not take into account how MS impacts a woman’s career trajectory or her willingness to seek promotion.

66% reported MS affected their employment status, and 38% of those left employment altogether.

Why did they leave?
- 33% workload too high or unpredictable
- 13% lack of flexible working practices
- 10% insufficient number of breaks to rest

Policy Recommendations

Diagnosis, treatment and care
- Improve awareness of the challenges of ‘invisible symptoms’ that stop women from achieving a timely and clear diagnosis
- Establish a flexible, patient-centric approach to treatment choice
- Provide coordinated care and multidisciplinary support to ensure that patients make informed life choices and manage the impact of MS on their future

Family, social and daily life
- Extend support for the caregiving and household activities of women with MS through a budget that is separate from the general disability budget
- Implement collaborative initiatives between healthcare professionals or their representatives, patient groups, women’s organisations and other MS support structures within and across countries
- Build on existing awareness strategies, further tailoring the scope to the unique impact on women to ensure society understands challenges to avoid stigmatisation of women patients

Financial and workplace
- Encourage support from employers, particularly in providing more flexibility at work and building awareness in the workplace to avoid isolation
- Provide financial support from the government in the form of subsidised childcare to enable women’s presence in the workplace
- Support improved infrastructure in the workplace and beyond for facility access and transportation to enable mobility
About the research

Charles River Associates’ Life Sciences Practice was commissioned by Merck KGaA to investigate the economic and societal burden on women associated with MS. The conclusions set forth herein are based on independent research and publicly available material.

A three-step approach was undertaken for this research:

- A review of literature, including studies from academia (Journal of Neurology, Multiple Sclerosis Journal and Journal of Rehabilitation Medicine, among others) and from MS institutional literature such as the Atlas of MS and the MS Barometer

- A targeted interview programme with 11 representatives of local patient organisations involved in advocacy in six European markets, to elicit their perspectives on the strengths and weaknesses of the MS policy environment in their country

- A bespoke online survey of 807 women with MS from eight European countries. The survey was open from the 6 July 2017 to 31 August 2017. The survey was undertaken independently by a specialised market research partner, Lightspeed Health

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