

MS MindSet Survey

Uncovering the Unpredictability of MS

Multiple sclerosis (MS) is a chronic disease of the central nervous system (CNS) in which the immune system abnormally attacks the insulation and support around the nerve cells (myelin sheath) in the brain, spinal cord and optic nerves, causing inflammation and can lead to irreversible disability.

The most common form of MS, relapsing MS, most often diagnosed in people in the prime of their lives (20s-40s), affects every person differently. The symptoms of MS – either periodic relapses, when symptoms worsen, or chronic problems such as difficulty walking, fatigue, bladder issues and vision problems – can happen at any time.^{1,2}

To learn more about the experiences people living with MS and their support partners face each day, Roche conducted one of the largest international research studies of its kind. The “MS MindSet Survey” gathered data from 3,478 participants to identify common barriers that stop people from feeling in control of their lives with MS, and how the unpredictability of its symptoms affect them on a day-to-day basis.

The Social Impact of Unpredictability

Unpredictability can significantly impact the mindset and day-to-day lives of people with MS and support partners, especially when it comes to making social commitments. The survey found that:

For people with MS



Missed out on activities, such as weddings, birthdays and holidays, due to MS symptoms or flare-ups



Avoid making long-term plans because they cannot predict how they'll feel



Limit social commitments due to the unpredictability of MS

For support partners



Missed out on activities, such as weddings, birthdays and holidays, due to the MS symptoms of their loved one



Say MS has impacted their relationship with their loved one who has the disease



Say they were unprepared for the amount of work caring for someone with MS entails



Almost a third (32%) limit their own social commitments because they don't know how their loved one will feel

Daily Experiences And Support Needs

MS symptoms and flare-ups often strike unexpectedly, making day-to-day tasks more difficult to manage for both people with MS and support partners. The survey found that:

For people with MS



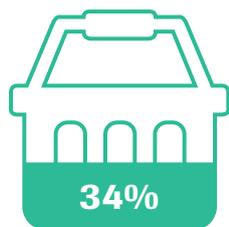
Say they wish they had help with chores and activities inside the house, such as cleaning and cooking when they're not feeling well

For support partners



Say they wish they had help with chores and activities inside the house, such as cleaning and cooking when the person they care for is not feeling well

The daily chores that people with MS want help with most include:



Food shopping



Cooking



Cleaning the house

Survey Methodology

KRC Research conducted the Roche MS MindSet Survey via an online survey of a total of 1,727 people living with MS and 1,751 support partners of someone with MS. The survey fielded from July 8-July 25, 2016 in the US; and from January 26-February 16, 2017 in Canada, France, Germany, Italy, Spain and the UK.

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1: Multiple Sclerosis International Federation. About MS: What is MS? Available at: <https://www.msif.org/about-ms/what-is-ms/>

2: National Multiple Sclerosis Society. MS Symptoms. Available at: <http://www.nationalmssociety.org/Symptoms-Diagnosis/MS-Symptoms>