

May 2022 Newsletter



The Rising Cost of MS Care

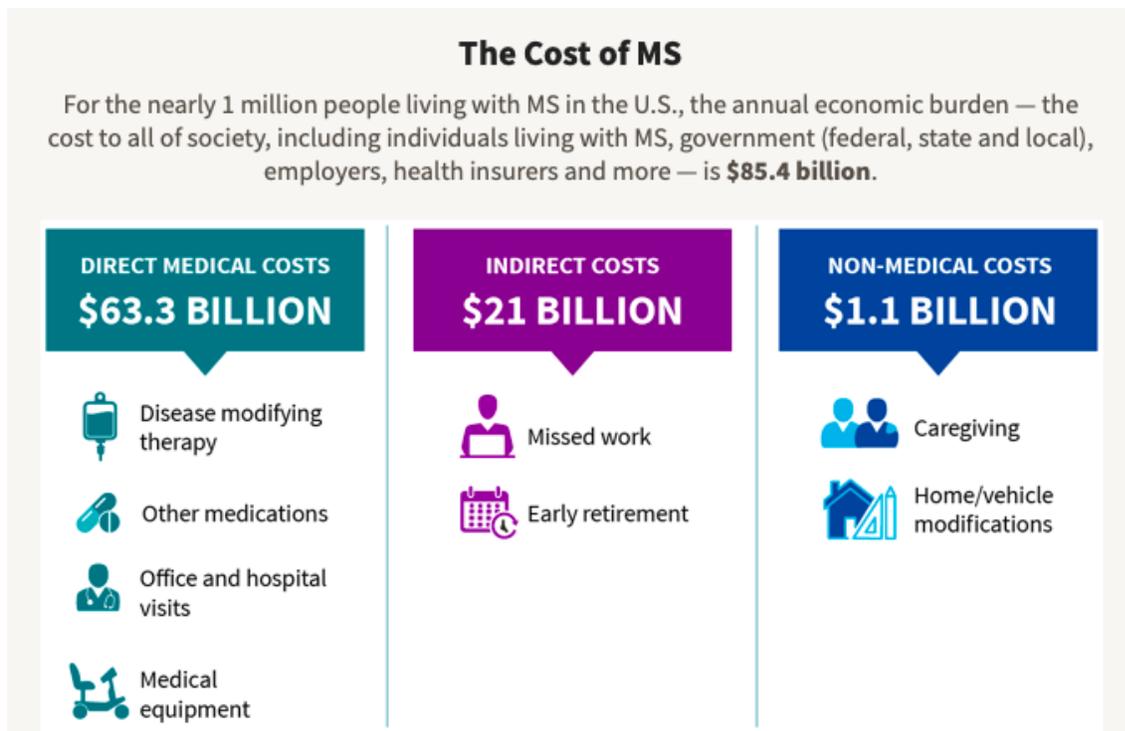
According to the [National MS Society](#) (the Society), nearly one million people are living with MS in the United States. This is more than double the previous estimate of 400,000 individuals with the disease. Chronic illnesses like MS are expensive, not just because of medical bills. The disease's debilitating effects have the potential to cause cognitive and physical decline. Mounting disability often prevents people with MS from working or limits their employment opportunities and consequently reduces their earnings. In addition, many family members need to leave their employment to be caregivers. In recent years, a number of new treatment options have become available to help slow the progression of the disease. In light of the new prevalence estimate for MS and the availability of so many new disease modifying therapies, the Society recently sponsored [research](#) to investigate the present and future cost of MS for families living with the disease. The study also sheds light on the disease's impact on the U.S. economy. As anyone living with MS can attest to, results confirm that the disease is very expensive.



For the purposes of this study, investigators divided the cost of MS into three categories: direct medical costs (for example, medications and medical appointments), indirect

medical costs (such as job loss or lost productivity at work) and non-medical costs like caregiving and expenses for necessary home or vehicle modifications. Data regarding the direct medical cost of MS was obtained from Medicare and insurance claims of 10,589 people with MS and 105,893 people without MS who were matched for age and sex. The research team calculated the direct medical cost per person for three consecutive years (2017 – 2019) and then determined average expenses for one year. Information regarding indirect and non-medical costs was obtained via a survey, which was administered to 946 study participants with MS.

Data shows the prevalence of MS increases with age. In 2019, the majority of the MS population (50%) was between 45 and 65 years old. While the prevalence of MS in people younger than 45 years was low, this age group represented the second largest group in the MS population (nearly 30%). Results confirm that the disease occurs more often in females than males, with females representing 74% of the total MS population. According to the study, the average total cost of living with MS was \$88,487 per year. The annual economic burden, or cost to all of society, including individuals living with MS, government, employers, health insurers, etc., was \$85.4 billion per year. Data trends show that, over the next two decades (by 2039), the prevalence of MS in the United States will increase to 1.1 million people, and the economic burden will soar to \$105.5 billion.



Graphic from the [National MS Society website](https://www.nationalmssociety.org/)

Researchers concluded 74% of the total economic burden of MS (\$63.3 billion) was attributed to its direct medical costs. One quarter of this figure (\$21 billion) was related to its indirect costs and the remaining one percent (\$1.1 billion) was due to its non-medical costs. Further breakdown of direct medical costs showed that disease-modifying therapies (DMTs) were the biggest expense, representing 64% of the total. The remaining direct medical costs were other prescription medications (often used as



symptomatic therapies), physician services, hospitalization and long-term care facilities. The main contributors to indirect costs were premature death (38%), lost productivity (28%) and inability to work (26%). The top non-medical costs included healthcare not covered by insurance, caregiving and necessary home or vehicle modifications.

At an individual level, results show the medical costs associated with living with MS in 2019 were \$65,612 more each year than medical costs for people without MS. The largest proportion of this cost was for medications. The actual amount spent per year varied from person to person based on many factors, including use of DMTs, individual needs and health insurance coverage. Data analysis revealed the average cost for an MS caregiver is \$4,333 per year. It's important to note that indirect and nonmedical costs were determined based on survey responses and, thus, relied on respondents' memory. Therefore, some costs may have not been accurately reported.

Living with MS and struggling with its symptoms is stressful in and of itself. Dealing with the costs of healthcare and MS treatments can add to that stress for those living with the disease. As we discussed in our [September 2020 newsletter](#), a number of financial and patient assistance programs are available to help with the cost of MS medications. In addition, the National MS Society offers a number of resources to help manage the expenses of living with MS.



National MS Society resources:



Financial and Insurance Information



Health Insurance Appeals and Exception Requests



Employment Rights / Requesting Accommodations



Ask an MS Navigator

The National MS Society study shines a spotlight on the high price tag that MS carries for the U.S. economy and the real impact these costs have on those living with the disease. A growing number of DMTs are available which generally reduce the number of relapses an individual may experience (resulting in longer disability-free periods). This, in turn, helps to reduce the indirect and non-medical cost of MS overall. However, nearly two-thirds of the direct cost of the disease is related to the cost of these medications. While there are financial assistance programs available to help, this study highlights the importance of interventions to control the rising cost of DMTs. Other programs are available to ease the cost of living with MS. The Society's recent study suggests that adding assistance to these services for things like long-term care, occupational training and employment support could serve to reduce the economic burden of MS and further improve the lives of those living with the disease.

