

Long-Term Care & Multiple Sclerosis



Part of my duties as a financial advisor is to provide a comprehensive strategy for clients preparing to transition into retirement. I create a financial plan that not only considers investment recommendations, but also how our clients can afford healthcare during retirement. The fact that I live with multiple sclerosis makes me particularly empathetic towards the challenges associated with the accessibility of healthcare. Since my diagnosis in 2012, I have been denied health insurance, life insurance, and fully understand that I am not qualified to purchase long-term care insurance due to my MS.

The traditional conversation regarding “healthcare” is not broad enough to include the rising cost of custodial care. How does an MS patient manage to pay for traditional medical care and assistance conducting ordinary daily activities around the home? Furthermore, how can someone living with a pre-existing condition like multiple sclerosis gain access to insurance that helps pay for fundamental functional abilities like bathing, eating, and getting in and out of a bed or chair?

Long-term care is a problem in desperate need of a solution, especially if you live with MS. “Long-term care” frequently encompasses a broad range of services designed to assist people with medical, personal, or social needs who cannot independently support themselves. The demand for long-term care is quickly rising and maintaining a comfortable level of independence can be very expensive.

The most common solution proposed is to purchase some form of private long-term care insurance. But with long-term care premiums often experiencing **double-digit increases**, elder care has become a financial burden that weighs particularly heavy on MS patients. If

living with a pre-existing condition wasn't hard enough, MS can actually prohibit you from qualifying for long-term care insurance protection.

With private long-term care plans failing to address the problem, MS patients may have to turn to public benefits in order to acquire assistance with basic activities of daily living. Unfortunately, traditional [Medicare](#) (Part A and Part B) does not cover long-term care. Over the past year, Congress has demonstrated an increased interest in implementing legislation that would allow for Medicare Advantage plans to begin offering supplemental benefits that include non-medical services. Despite the positive congressional momentum on the issue, there are plenty of complications for Medicare Advantage plans offering long-term care benefits. Furthermore, MS patients may require long-term care assistance long before the age of 65 and being able to afford a Medicare Advantage plans while on SSDI may be financially challenging.

As is typically the case, the odds are stacked against those living with MS. The search to access long-term care coverage is frustrating and often there are no simple solutions. This is why MS activists in the state of Washington led the charge to enact the nation's first public state-operated long-term care insurance program. Starting in 2021, the [Long-Term Care Trust Act](#) will pay benefits of up to a maximum of \$36,500 for those who need assistance with three or more daily activities. The program is not universal and will only be available to Washington residents 18 years or older who have paid into the Trust Program for a specified amount of time. This innovative program, the first of its kind in the nation, will hopefully help pave the way for subsequent states to address the problem of providing affordable long-term care to those who need it most.

The need for long-term care is becoming a serious issue in the MS community. With over 1,000,000 Americans living with MS and continued advancements made in disease modifying therapies, we need a solution. The new program in Washington is a perfect example of the importance of advocacy and what is possible when those living with MS refuse to give up and instead fight back. The issue of long-term care will not be resolved overnight.

Continuous advocacy at both the state and national levels will be necessary to ensure that the voices of those living with MS are heard and the problems associated with accessing affordable long-term care are finally resolved. As an MS activist, I have seen first-hand the impact of sharing your story. [Please consider joining me as an MS activist!](#)