

# August 2021 Newsletter



## Understanding and Living With MS Fatigue

According to the National MS Society, 80% of people with MS experience fatigue, and over half rank it as one of their most troubling symptoms. Nearly everyone feels overtired or overworked from time to time and such instances of languor usually have an identifiable cause and a likely remedy, such as a good night's sleep. Fatigue is an unrelenting exhaustion that lasts longer, is more intense and isn't relieved by rest. It's a nearly constant state of weariness that develops over time. Fatigue can be either physical or cognitive, or both at the same time. Physical fatigue may affect an individual's energy and motivation. Limbs may feel heavy and hard to use and, as a result, individuals may feel the need to lie down immediately.

Cognitive fatigue, on the other hand, could affect one's concentration. Individuals with cognitive fatigue may have difficulty following a conversation or thinking of words or numbers. In either case, fatigue negatively impacts the functioning and quality of life of the majority of people living with MS.

MS fatigue is complex, with many layers and contributing factors. In some cases, fatigue is "secondary" to an underlying cause and may be effectively addressed by treating the source. For example, many people with MS struggle with depression. Depression itself can manifest with fatigue, so it is often difficult to distinguish it from between the two. In addition, other symptoms of depression, such as lack of motivation, are often mistaken for fatigue. [Research](#) shows a direct association between fatigue and depression, even considering the overlap between the two conditions. In instances where depression and fatigue occur concurrently, fatigue may be effectively addressed by treating the underlying depression. Investigators also



found a direct relationship between fatigue and disease severity (subjects with more disability were more likely to experience fatigue). In addition, subjects with progressive MS appeared to have higher fatigue scores (experience more fatigue) than those with RRMS. However, this difference may be attributable to the differences in disability among the types of MS. By the same token, people with MS may have [sleep disorders](#) that interfere with restful sleep. In fact, [researchers](#) at the University of Washington found the prevalence of sleep problems in people with MS is significantly higher than in the general population, particularly in women living with the disease. Exhaustion from a lack of restful sleep is considered to be a contributing, if not a causative, factor in MS fatigue. Medications used to treat MS and its symptoms have the potential to cause fatigue. For example, fatigue is a side effect of some disease modifying treatments, including interferons (Avonex, Betaseron and Rebif), Tysabri and Novantrone. Drugs taken for MS symptoms like spasticity (baclofen or diazepam) or nerve pain (gabapentin), to name a few, can also contribute to fatigue. In some cases, a medication adjustment can help with fatigue, however anyone considering such a change should first consult with their healthcare team. Sometimes, people with MS have other medical conditions, such as infections, anemia, or thyroid conditions, which can also increase fatigue.



Beneath these secondary causes is “primary” MS fatigue, called [lassitude](#), the cause of which is unknown. Lassitude has a number of specific characteristics that help distinguish it from secondary MS fatigue. Lassitude generally occurs on a daily basis. It is considered more severe than secondary MS fatigue, and is more likely to interfere with daily responsibilities. Lassitude often occurs early in the morning, even after a restful night’s sleep. This type of fatigue comes on easily and suddenly, tends to worsen as the day progresses and is often aggravated by heat and humidity. No matter what form of fatigue an individual with MS may experience, this overwhelming tiredness can affect anyone with MS, regardless of physical disability, and occur at any time in the course of the disease. Even though it is more likely in those with higher levels of disability, it is not always the case. Fatigue can also be the most prominent symptom in a person who otherwise has minimal physical limitations. People with MS may also find that fatigue worsens their other MS symptoms.

The exact cause of MS-related fatigue is still unknown. However, researchers are working to figure out this mystery. There is evidence that fatigue is related to the general activation of the immune system that occurs in MS. As discussed in our [January 2019 newsletter](#), [cytokines](#) are chemical messengers that are secreted by certain cells in the immune system.



[Researchers](#) in Germany found pro-inflammatory cytokines are significantly higher in MS subjects with fatigue, compared to MS subjects not experiencing fatigue. This suggests that fatigue is at least partially mediated through activation of these cytokines. Another [study](#) showed that the levels of the hormone [dehydroepiandrosterone](#) (DHEA) are lower in MS subjects with sustained fatigue when compared to those without fatigue, suggesting the endocrine system may play a role. The fact that many people with MS report increased energy while taking [corticosteroids](#) as treatment for their neurologic symptoms further supports a possible hormonal influence. However, it’s important to note that, because of the

chronic nature of fatigue and risks of long-term steroid use, steroids are not recommended as treatment for fatigue. Other studies suggest that MS fatigue stems from damage to the central nervous system caused by demyelination. Specifically, one [study](#) suggests that a reduced transmission of electrical signals in the brain could play a role and another [study](#) points to nerve loss as a contributing factor.



In some cases, drugs may be used in treating fatigue. However, medication is not a solution to fatigue on its own. Because different factors can cause or add to MS-related fatigue (such as depression or sleep disorders), anti-fatigue medications should be used in conjunction with treatment for these factors (when applicable). It's also important for people with MS to see their physician regularly to ensure their disease is under the best control possible. [Modafinil](#) (Provigil) is a medication used to increase wakefulness in individuals with the sleep disorder, [narcolepsy](#). It is used off-label in MS to treat fatigue and sleepiness. [Studies](#) suggest that low dose modafinil (200 mg daily) significantly improves both, and is well tolerated in people with MS. [Armodafinil](#) (Nuvigil) is a medication that is similar to modafinil and is also prescribed for the treatment of MS fatigue. [Amantadine](#) (Symmetrel) is an antiviral medication used in Parkinson's disease. It has also been used in the treatment of MS fatigue since the 1980s, although its [benefit](#) in this regard is not well documented. [Methylphenidate](#) (Ritalin) is a central nervous system stimulant used for treatment of attention deficit disorders. In some cases, it is also helpful in reducing MS fatigue. [Studies](#) are underway to confirm this benefit. [Dextroamphetamine](#) (Dexedrine) is also a stimulant medication. Its effects on MS fatigue are similar to those of methylphenidate. A [recent study](#) suggests that aspirin may lessen fatigue in people with MS (among other benefits). While aspirin usage is relatively common in the general population, its use by people with MS also has the potential for negative effects on specific components of MS disease process (for example, further decreasing [mitochondrial function](#), which is a cause of nerve degeneration MS). Further studies are needed to confirm the potential benefits, as well as the risks, of aspirin treatment for people with MS.

A number of alternative therapies may provide some benefit for MS-related fatigue. Some people with MS find that caffeine (in moderation) can be helpful in managing fatigue. Unfortunately, caffeine is an irritant to the bladder, and can exacerbate urgency and frequency. Individuals with MS should speak with their healthcare team about their caffeine intake to be sure they are not exceeding levels that are appropriate for them. [Acetyl-L-](#)



[carnitine](#) (ALCAR) is a dietary supplement that appears to reduce MS-related fatigue, however research to support this benefit is mixed. A [small study](#) of 36 subjects, done in 2004, suggests ALCAR is well tolerated and more effective than amantadine for the treatment of MS-related fatigue. Other [studies](#) claim there is insufficient evidence to support this benefit. As discussed in our [February 2019 newsletter](#), some herbs are used to help relieve fatigue. These include ginkgo biloba, valerian, St. John's wort, as well as Siberian and Asian ginseng. As we mentioned last month, many of these herbs have problematic side effects that should be carefully considered before use. Some people with MS turn to [Tai chi](#) and yoga for relief of their MS fatigue. A [recent review](#) of studies conducted on Tai chi practice and MS concluded

the evidence to support a benefit with regard to improving fatigue is inconclusive. However, researchers found Tai chi significantly improves quality of life and functional balance in people with MS.



While proper treatment can help control fatigue, changes in lifestyle can also prove beneficial. Strategies to conserve energy are often helpful. An analogy can be made for people with MS between bank accounts and energy levels. Both benefit from the same rule of thumb – less money, or energy, used now means more will be available later on. In other words, doing too much early in the day can burn through all energy stores and leave an individual feeling tapped out. Energy rationing is especially important for people with MS, who tend to start the day with lower energy levels than the average person. For some, a brief rest is very helpful to recharge and scheduling breaks (alternated with periods of activity) is useful to avoid becoming too tired too quickly. If a task is too much to handle at one time, it may be helpful to divide it into smaller parts or ask for help if this isn't possible. Planning one's activities can also help, for example to avoid going up and down the stairs more often than necessary. Listing activities in their order of importance can be useful to see what needs to be done first and what can wait until another day, should all energy be used up before reaching the end of the list. Those with limited energy often need to accept the fact that not everything will necessarily be completed when and how one prefers them to be done.

Efficiency while performing household duties is also useful in battling fatigue. Whenever possible (when cooking or cleaning, for example), arrange supplies in advance to minimize the amount of time spent standing. With respect to meals, selecting menus in advance with easy recipes can help preserve stamina. Having food delivered (rather than shopping) is the most time and energy efficient option. If that's not an option, make a list of all necessary ingredients for the week's meals before shopping for food. Being familiar with a local store and the aisles where individual items are located can assist with saving time and energy as well. Whenever possible, prepare double portions of a meal and freeze leftovers for another day. This provides extra meals that require little time to prepare.

It's important for people with MS to recognize and avoid environmental factors that may cause fatigue. For example, many find it helpful to avoid extremes in heat (long, hot showers or baths, for example) because it drains their energy. On a hot summer day, it may be useful to cool down with a fan or spray bottle or stay in air-conditioning when possible. As mentioned in our [May 2018 newsletter](#), the Multiple Sclerosis Association of America's [Cooling Distribution Program](#) offers cooling vests, smaller products to wear under clothing and other accessories to help people with MS keep cool.



Other basic principles of healthy living can also be helpful in managing MS fatigue. Eating a well-balanced, healthy diet can help boost energy levels. Decreased physical activity can lead to tiredness and lack of energy. Regular, moderate exercise can decrease these feelings, as well as improve strength and foster a more positive attitude. Any person with MS who is considering a new exercise program should consult with a physician

before starting, and throughout, their regimen. An exercise program needs to fit the capabilities and limitations of the individual and it may need to be adjusted as changes in MS symptoms occur. Periods of exercise should be carefully timed to avoid the hotter periods of the day. Many people with MS find exercising in water to provide exceptional benefits as it is not only cool, but water helps them move in ways they may not be able to on land. Finally, managing stress can play an important role in combating fatigue. This can be done in a variety of ways. Adjusting expectations and limiting daily to-do lists will likely bring a sense of accomplishment that can go a long way toward reducing stress. Educating family and friends about MS fatigue may also help. Given that fatigue is an “invisible symptom” of MS, they might not understand it and may be more helpful if they appreciate its full impact. Some people with MS find [support groups](#) to be a source of comfort and camaraderie, as well. Others rely on [relaxation techniques](#) to help reduce stress.

Fatigue management has many dimensions and often requires a team effort between family, caregivers, healthcare providers, and many other members. Physicians and other healthcare providers can prescribe and monitor medications, as well as provide education and help develop strategies. Family and caregivers can help provide for physical needs, or with moral support. Perhaps more than with any other symptom of MS, the key player in coping with fatigue is the person with MS. He or she has the ultimate responsibility for implementing any suggested game plan and making adjustments based on its effectiveness. Managing fatigue involves both trying to keep energy levels up and using energy efficiently. Finding the right balance may be a learning process that requires trial and error. As an individual with MS goes through this process, it’s important for them to have a support system (team) to lift them up when they may falter. Through this team effort, it’s possible for individuals with MS to function, participate in extracurricular activities and have the best quality of life possible.

