

with treatment, improvement is often gradual and some symptoms may take months to completely resolve.

The type of steroids used to treat MS relapses are called glucocorticoids. They belong to a larger class of steroids called corticosteroids. These medications are designed to mimic cortisol, a hormone produced by the adrenal glands, which has anti-inflammatory effects. Several



different corticosteroids are used to treat MS relapses. Some can be taken orally, while others are administered via an injection or intravenous (IV) infusion at a clinic or hospital. These drugs have been used to treat MS since the 1940's. They are also used to treat other health conditions in which inflammation plays a role, such as asthma and severe allergy attacks.

Steroids Used to Treat MS Relapses

Methylprednisone (methylprednisolone) is frequently administered as an infusion (Solu-Medrol). This is sometimes followed by a course of oral steroids for 1 or 2 weeks, during which the dose is slowly decreased. Methylprednisone can also be taken orally (Medrol), or as an injection (Depo-Medrol, Solu-Medrol). Depo-Medrol has a slower onset and longer duration of action, so it may not be as useful for acute flare-ups. Of note, while IV administration is the most widely used, a [recent study](#) suggests there is no significant difference between oral and IV methylprednisone in terms of efficacy and safety for treating MS flares.

Prednisone is an oral medication that is often used for mild to moderate MS relapses. As mentioned above, it is also used to taper off of IV steroids. Interestingly, a [2021 study](#) suggests that a prednisone taper following IV methylprednisone showed little benefit in people with MS being treated for an exacerbation.

Decadron (dexamethasone) was approved for the treatment of MS relapses in 1958. It is taken orally, either as a liquid or a tablet.

Celestone (betamethasone) is an injectable drug. It is also available in other forms, but those forms are rarely used to treat MS.

MS is a very individualized disease, with no two people having the exact same experience or symptoms. MS relapses are unique, too. Symptoms differ from person to person and from one relapse to another, depending on the nerves that are affected. There is also great variability in the degree to which relapses respond to corticosteroids. As a result, it's difficult to predict how fast or how completely these medications will work for an individual. Steroid therapy is often used repeatedly over the course of a person's disease. As a general rule, corticosteroids become less effective with subsequent treatments.

Occasional use of steroids is usually well tolerated, but these drugs can cause unpleasant side effects, depending on the dose and how long they are taken. Some may occur immediately and others with chronic use. For longer-term prescriptions, doctors may taper down dosages gradually to get them as low as possible without the return of MS symptoms. The pros and cons of treatment should be weighed on an individual basis and discussed with one's healthcare provider.



Steroid Side Effects

Short-term

Most short-term side effects of corticosteroids resolve quickly after treatment ends. It isn't uncommon to experience a metallic taste in the mouth during an infusion. One may also have a surge of energy that can make it difficult to sleep or even to sit still and rest. Steroids can also cause temporary mood and behavior changes. Other potential short-term effects include acne, rash, facial flushing, swelling of the hands and feet, headache, increased appetite, increased blood glucose, high blood pressure, heart palpitations or back pain.

Long-term

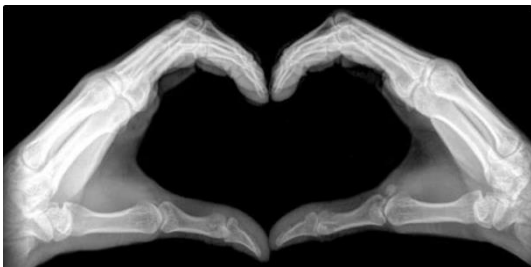
Individuals taking corticosteroids for a longer period of time may produce less cortisol on their own which can result in a variety of symptoms, such as severe fatigue, loss of appetite, nausea and muscle weakness. Other long-term side effects include cataracts, increased pressure in the eyes (glaucoma), ulcers, heart disease, diabetes, a round face ("moon" face), weight gain, increased risk of infections, thinning bones (osteoporosis) and fractures, thin skin, bruising and slower wound healing.

There are a number of ways to ease the side effects of these medications. It is essential for those taking steroids to eat a healthy, low cholesterol diet and to stay as active as possible. This is not only a good idea for general health, but also helps to minimize the risk of heart disease and diabetes from long-term steroid use. If possible,



avoid caffeine, chocolate, and foods that are acidic, fatty or high in sugar content. It's a good idea to stay hydrated by drinking a lot of water. Watching salt intake can ease water retention and swelling. [Research](#) suggests that potassium intake reduces blood pressure. Individuals with hypertension may benefit from eating [potassium-rich foods](#). Proactively filling up with healthy food, such as fruits and vegetables, may decrease food cravings. Exercise also helps to keep excess weight off, with an added benefit of building bone mass (and preventing osteoporosis).

Other strategies to prevent bone loss from steroid treatment include taking a calcium supplement or eating [calcium-rich foods](#). Limiting smoking and alcohol consumption may also be helpful. Getting enough vitamin D is important for bone health. It's a good idea to have vitamin D levels checked to see if supplementation is necessary. To preserve its integrity, many doctors recommend having a bone density test at the beginning of, or before, steroid therapy



(especially if the steroid dose is high or treatment is prolonged). Those with low bone density may be put on [bisphosphonate medications](#). This testing can be repeated over the course of treatment to assess the effectiveness of measures to prevent bone loss and make adjustments, as necessary.

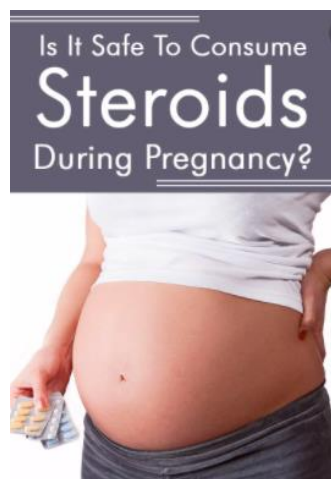
Because of their gastrointestinal side effects, it's important to take steroid pills with food. If treatment causes stomach upset or ulcers, there are a number of [over-the-counter medications](#) that may be of benefit. Eating [bland foods](#) or adding protein to a meal may also help settle the stomach. Consuming ginger tea (or even ginger candies) is another way to reduce this type of discomfort. Some people find peppermint to be soothing. It may also help to eat smaller, more frequent meals.

The use of lotions to keep the skin moisturized is often helpful during steroid treatment. Eating [foods high in Vitamin E](#) can also help with skin issues. [Sleep medications or sleep aids](#) can be used to get a good night's sleep during treatment. It may also help to take steroids in the morning to reduce their effect on sleep later at night. Letting family and friends know about the temporary effect steroids have on mood may help everyone ride the ups and downs a bit more smoothly.



It's important to follow a doctor's instructions at the end of steroid treatment. These medications can affect the natural production of cortisol, especially if they are taken for a prolonged period of time. Stopping or tapering them too fast may cause withdrawal symptoms, such as body aches, muscle and joint pain, fatigue, lightheadedness, weakness, confusion, drowsiness, headache, loss of appetite, weight loss, peeling skin, nausea, upset stomach and vomiting.

Some medications cause negative interactions if used with corticosteroids, including [blood thinners](#), [anticonvulsants](#) and [non-steroidal anti-inflammatory drugs](#) (NSAIDs). Steroids can make the liver less sensitive to insulin. Individuals with diabetes should be extra vigilant about monitoring and controlling their blood sugar while taking them. If one's steroid and diabetes medications are prescribed by different doctors, it's important that both are aware so they can coordinate treatments. Because steroids have the potential to raise blood pressure, individuals with hypertension should have it monitored regularly while taking them. Corticosteroids



should be used with caution in pregnant women. According to a [2020 literature review](#), women in their first trimester of pregnancy should avoid taking these medications because they increase the risk of miscarriage and birth defects. Results show IV methylprednisone is a better option for pregnant women than oral prednisone because the body processes the IV drug before it crosses over the placenta. Data suggest that dexamethasone and betamethasone shouldn't be used during pregnancy at all. The researchers conclude that steroid use during pregnancy should be restricted to treating relapses that substantially affect daily function.

It's important to determine the cause of an MS relapse before taking steroids. It may be due to an underlying condition that is treatable (for example, an infection). While these medications do provide temporary relief from MS symptoms, they do not treat the disease itself and they have significant side effects. Comorbidities and certain medications may increase the risk of severe side effects from steroid use. To minimize this risk, people with MS should discuss their medications and other health conditions with their doctor before beginning treatment.

The Indispensable Role of Caregivers

It's vitally important to support caregivers and pay attention to their needs, as they are the backbone of many families living with chronic disease. Their perspective is valuable in many respects. As the closest and most constant observer of their loved one, a caregiver has first-hand knowledge of their challenges, symptoms, and the effectiveness of treatment. His or her knowledge of side effects, as well as physical or cognitive changes, and how these affect functioning and quality of life is relevant and crucial in both the healthcare and research settings.



In MS, the role of the caregiver is constantly changing. When a person with the disease is in remission, there may be less caregiving required, whereas if they are in the middle of a relapse or have advanced disease, caregiving may be a round-the-clock requirement. As MS caregivers are generally unable to anticipate the onset of a relapse, the progression of the disease, or even the functional ability of their loved one over the course of a day, the resulting ups and downs can be stressful and draining for everyone. Those providing support are often so focused on their partner's needs they may not have time to take care of their own. In this situation, over a long period of time, it's conceivable that MS caregivers could become second victims to the disease. All of these things have dire consequences for administering care.



iConquerMS continues to expand its research collaborations to include caregivers to those living with MS, in hopes of easing their burdens and improving MS research in the process. In 2019, ACP partnered with [UsAgainstAlzheimer's](#) to apply for a grant from [Genentech](#) aimed at advancing health equity in patients with neurologically based diseases. With this support, the organizations developed two surveys to learn more about the challenges that caregivers face and their relationships with healthcare providers. Recognizing that there are features that are unique to providing care to someone with MS compared with Alzheimer's disease, questions focused on the common ground between the two conditions. These surveys were sent out to both communities, with very interesting results, which are summarized below.

Our data show the top three stressors experienced by caregivers are uncertainty about the future (54%), stress (46%) and not having time for oneself (42%). Other common challenges include not getting enough sleep (35%), the inability to leave home (33%), safety (32%) and financial concerns (28%). These percentages apply to those who indicated they experience these stressors "frequently or always." The remaining participants may have also experienced them, but less frequently. On the positive side, survey respondents also shared strategies they found helpful in managing these issues. Some said they benefit from physical activity or having a massage regularly. Others indicated they seek relaxation in music. Still others find it helps to take their loved one for a ride in the car or take a break and leave someone else in charge for a while.

According to the surveys, 77.5% of caregivers do not have sufficient access to the help and support that they need. Respondents were interested in using these services, with information and referrals, support groups, case management, and respite services at the top of the list. Our data suggest



information and referral resources were used most often, however participants were not aware of a variety of other valuable services, such as care management, transportation, and respite services. The vast majority of respondents (72%) had not received training or information to better prepare them for their role as caregiver. About half of those receiving training indicated it was given at the right time, the rest responded training was too soon, too late, or only given during a crisis. Our data suggest that training was partially effective, as only 21% of survey respondents indicated it helped them address all situations (75% of participants said it helped them address some situations, and 5% said that training did not help them address the most key situations).



Regarding caregiver relationships with healthcare providers (HCPs), 6% of caregivers responding to the survey did not have their own physician. 22% of those seeing a doctor indicated that their doctor is not aware of their role as a care partner. 59% said their HCP is aware of these responsibilities, but the majority (79%) have not gotten help or advice from them about this role. Almost all respondents had accompanied their loved one to a doctor's appointment. Results were revealing about many aspects of these visits. On the plus side, HCPs were respectful, made eye contact and gave clear information in understandable language. Most participants didn't have a language barrier. However, more than half who needed language accommodations did not receive them. According to the survey, HCPs rarely asked caregivers how they were coping, and whether the cared-for person wanted them in the exam room. They didn't always ask for the caregivers' name or relationship to the cared-for person. HCPs were also less likely to discuss mood changes or treatment effects with caregivers and rarely provided information about research studies, despite the fact that all of these things were important to the vast majority of caregivers that responded. These data will be instrumental as ACP develops new materials to educate caregivers and HCPs about best practices, and resources for caregiving and self-care in the coming months.

ACP has a number of other ongoing activities aimed at relieving [caregiver burden](#) and increasing the voice of this important population in MS research. We very recently received an Engagement Award from the [Patient-Centered Outcomes Research Institute](#) (PCORI) to more intentionally expand iConquerMS enrollment to include care partners. This will be accomplished in a way that is similar to the pediatric expansion of the network, discussed in [last month's newsletter](#). Through this effort, caregivers will be able to participate in iConquerMS in two dimensions – both as an observer and partner to the person living with MS, and as a person with their own needs and priorities. We hope that all MS caregivers will consider [joining](#), there are some upcoming opportunities where your input will make a difference!



ACP's Care Partner Advisory Board (CPAB) is a dedicated group of 8 people working to identify the challenges faced by MS caregivers and develop a "Care Partner Protocol," which will be a living set of recommendations for them. This valuable resource will be provided by health care providers at the time of diagnosis and throughout the MS journey. It will also be available online. Members of the CPAB represent a wide variety of care partner roles including spouses to those living with MS, a parent with a young adult daughter who was diagnosed with MS in her teens, and a woman who has provided the primary caregiving for her mother since childhood. The group plans to survey the broader MS community through iConquerMS to obtain input from other caregivers for this important resource.



There's also a movement underway to include care partners in [patient-focused drug development](#) (PFDD) because they not only bring a different perspective than a person with MS, but they also play a significant role in participation in clinical trials and adherence to medication. In 2019, ACP received funding from [EMD Serono](#) to gather information from the MS community on this important subject, as well as in support of the CPAB and the development of the Care Partner Protocol. As part of this effort, we will be surveying care partners to see if they know what PFDD is, whether or not they would be interested in participating in this type of activity as a care partner and what would be necessary for PFDD to be successful for caregivers.

MS caregivers play an indispensable role in their loved ones' lives. They may also play a pivotal role in research. Are you interested in ACP's work to more fully understand and address the

needs of MS care partners? Please take a moment to complete a [short survey](#). We will use the information you provide to keep you up to date on our activities. Want to be a part of the movement to put patients and their caregivers at the center of MS research? If you are a care partner to someone with MS and haven't already done so, please consider [joining](#) the iConquerMS community with your loved one today. By sharing your experience of the daily burden of disease, your interpretation of unmet needs, and the types of research questions most important to you, you can transform the research process from one directed by sponsors and investigators to one driven by the needs of patients and their caregivers. This change in impetus has the potential to improve healthcare and outcomes not only for people affected by MS, but for the general population.



April 2021 iConquerMS Spotlight



Share your experiences with COVID-19 vaccines

[iConquerMS](#) is now collecting information from people affected by MS related to their experiences with COVID-19 vaccines. The data collected will be securely shared with researchers studying the effects of COVID-19 vaccination on people affected by MS. If you are an iConquerMS member that has received a COVID-19 vaccine, please [login](#) today and share your experience by clicking on “Participate in the COVID-19 Vaccination Study.” Not yet a member? Please [join](#) iConquerMS now and start adding your data!



April 2021 Research Spotlight

RESEARCH OPPORTUNITIES

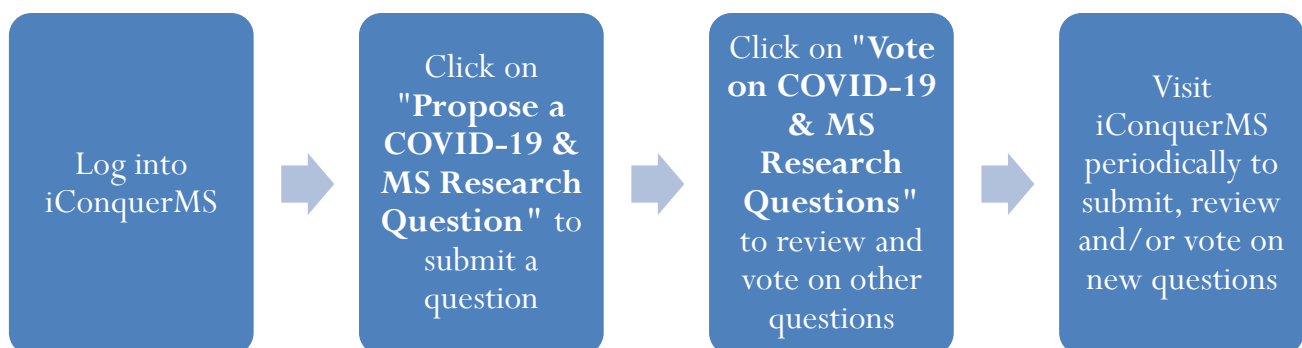


Announcing a New Program for iConquerMS Members!

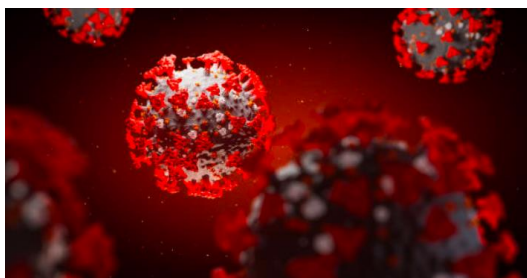
iConquerMS is leading the movement to include the patient perspective in every step of MS research. Now, network members can play a larger role than ever before in initiating and collaborating with researchers on studies that will expand knowledge in areas that matter most to people affected by MS.

iConquerMS members have always been able to submit research questions to the initiative. It's now possible to comment and vote on questions submitted by the community through the newly launched [Our Questions Have Power](#) program. Questions that are high priority for the iConquerMS community will be shared with researchers, who will work in collaboration with the iConquerMS community to develop them into research studies.

Participation is easy!



If you are not already a member, please consider [joining](#) iConquerMS, the only people-powered research network for MS. Add your voice to those working together to improve MS care and bring us closer to a cure!



Update your experience with COVID-19

As a supporter of Accelerated Cure Project, you know one way to deal with the uncertainty of MS is to **act** – to be proactively involved in research and to contribute your insights, expertise, and information so that key questions about MS may be answered.

The COVID-19 crisis has added an additional level of complexity and urgency for those affected by MS.

We have launched a follow-up survey on iConquerMS to update how people affected by MS are dealing with the COVID-19 pandemic and what their personal experience has been with COVID-19 over the past 12 months.

We are interested in responses from all – those with and without MS, whether or not you have been diagnosed with COVID-19 – and hope the information gathered through this survey will help people affected by MS and their doctors during the current pandemic and in the case of future viral outbreaks.

Participating in the COVID-19 in MS study is easy. If you are not already a member, please consider [joining iConquerMS](#). Your voice matters! Already a member? Please [login](#) to your account and complete your COVID-19 survey. Thank you for your participation!

NEW RESEARCH RESULTS



The FDA recently approved ponesimod (Ponvory), an oral treatment that inhibits [S1P activity](#) and reduces circulating lymphocytes, for the treatment of adults with clinically isolated syndrome, relapsing-remitting MS (RRMS), and active secondary progressive MS. The approval is partly based on a Phase III clinical trial in which Ponvory significantly lowered annual relapses by 30.5% compared to teriflunomide (Aubagio) in patients with RRMS. Ponvory was also shown to be effective at delaying disability progression. It has a proven safety profile and is generally well-tolerated.