

# Coping with dual diagnoses



## How to prioritize when MS is only one of your health concerns.

by Aviva Patz



**Lisa Emrich, a musician, with her husband, Rob Osberg, manages the coexisting health conditions of multiple sclerosis and rheumatoid arthritis.**

Photo courtesy of Lisa Emrich

Just two years after being diagnosed with multiple sclerosis, 47-year-old Lisa Emrich, a professional musician in Falls Church, Virginia, suddenly was unable to play the piano. “My

fingers on both hands curled into fists, and I cried during the night because of the excruciating pain,” she recalls. “I fantasized that someone would chop off my arms just so I might get some relief.”

Emrich, who had already lost control of two fingers on her left hand the previous year due to MS, figured the new symptoms were just the next chapter in her struggle with the disease. But after several months and referrals to many other medical professionals, her finger issues turned out to be due to a whole other diagnosis—rheumatoid arthritis (RA).

“I was devastated,” Emrich says. “As if it wasn’t bad enough that I had previously lost my vision, lost the use of my left arm, even lost strength and dexterity, all due to MS, now I was faced with the possibility of further pain and disability from the RA.” Once her RA was diagnosed, however, Emrich worked with her team of physicians to pursue a course of treatment and learn strategies for managing it alongside her MS.



**Dr. David E. Jones says it's important to identify the condition that may be causing new symptoms in someone with MS.**

Photo courtesy of Dr. David E. Jones

### **Untangling the web**

Like Emrich, many people with MS develop other seemingly unrelated health conditions such as cancer or diabetes, another autoimmune disease such as psoriasis or RA, or a potentially temporary issue like headaches or anemia.

“More than 50 percent of people with MS are estimated to have another chronic health condition,” says Dr. Ruth Ann Marrie, professor of medicine and community health sciences at the University of Manitoba, Canada, and director of the Multiple Sclerosis Clinic at the Health Sciences Centre in Winnipeg.

However, like Emrich, many people with more than one health condition may simply blame the new or worsening symptom on their MS—especially if the symptom is consistent with MS, like pain or weakness. “Part of the problem is that MS is different for different people, so you can’t just pick up a book and say, ‘This is exactly what you’ll have,’” says Dr. David E. Jones, assistant professor of neurology at the University of Virginia and chair of the MS section at the American Academy of Neurology. Attributing new symptoms to MS may also provide some sense of comfort, Dr. Jones says. “People may think, ‘Phew—it’s just my MS and not another diagnosis.’ ”

But as awareness of dual diagnoses grows, it’s becoming increasingly clear that for people with MS, any new symptoms should be evaluated through a wider medical lens. “If there’s another condition that’s causing the [new] symptoms, it will not be treated successfully unless it’s identified,” Dr. Marrie says.



**Dr. Ruth  
Ann Marrie  
has found  
that  
depression  
and anxiety  
are common  
disorders  
that occur  
alongside  
MS.** Photo  
courtesy of  
Health  
Sciences  
Centre  
Winnipeg

## **Common comorbidities**

Dr. Marrie recently led an international committee of MS experts in an investigation into which coexisting health conditions, known medically as “comorbidities,” are most common among people with MS. The goal of the ongoing research, called The Comorbidities Project (which is supported by the National MS Society and the European Committee for Treatment and Research in MS), is to understand how other health conditions may affect the course and treatment of MS, and how best to manage all of the various symptoms.

After reviewing 249 earlier studies on MS and other medical conditions, Dr. Marrie’s team published seven papers in the **MS Journal** in 2015. Key findings include:

- The five most prevalent disorders that occur alongside MS are depression, anxiety, high blood pressure, high cholesterol and chronic lung diseases like asthma. Depression and anxiety are so common, in fact—affecting about 24 and 22 percent of people with MS, respectively, per Dr. Marrie’s analysis—that researchers are beginning to suspect they may actually be caused by the disease process itself. “In some cases, structural and functional changes in the brain due to MS likely play a role, and inflammation may also play a role,” explains Dr. Marrie. But she’s quick to add that depression should not automatically be attributed to MS. “Any of the stressors and circumstances that increase the risk of depression in people without MS—divorce, illness in family members, financial difficulties—can also cause depression in people with MS, and genetic factors are likely relevant in other cases.”
- Some autoimmune disorders—in which the immune system attacks its own body rather than predatory invaders like viruses—appear to be more common among people with MS. According to Dr. Marrie’s findings, more than 7 percent of people with MS have psoriasis, over 6 percent have thyroid disease and nearly 3 percent have RA. In the general population, only a total of 5 to 8 percent of people have any type of autoimmune condition.
- On the whole, cancer is less common in people with MS than in the general population. However, certain types of cancer may occur more often in people with MS—including cervical and digestive-system cancers.
- Heart disease, congestive heart failure, stroke, arthritis, inflammatory bowel disease, irritable bowel syndrome (IBS), seizure disorders, bipolar disorder, sleep disorders and alcohol abuse are found more often in people with MS.

It remains to be seen which of those disorders are linked with MS in some way, and how many are the result of simply living with the disease or the side effects of medication. For example, poor-quality sleep could be due to MS symptoms or adverse effects of medication, Dr. Marrie says.

## **Managing multiple conditions**

Dr. Marrie and her colleagues are now planning to examine MS comorbidities worldwide. Their goal is to determine which diseases tend to strike people with MS of different ages, genders and ethnicities, and the best ways to manage treatment—especially for the most

urgent diagnoses like cancer.



**Margaret Barney, at age 52, dealt with breast cancer alongside her MS.**

Photo courtesy of Margaret Barney

Margaret Barney, who was ultimately determined to have secondary-progressive MS when she was 31, learned at age 52 that she also had breast cancer. “I was already facing one serious disease and the ongoing process of coping with those symptoms and losses of function,” she says. “It never occurred to me that I would have to deal with yet another major disease in my life.”

In balancing cancer and MS simultaneously, Barney’s cancer treatment took priority because it was potentially life-threatening. Her surgeon recommended a lumpectomy—the same treatment that someone without MS would get.

The surgery was followed by chemotherapy, and Barney was very nervous about the drugs interacting with her MS medications. “I called my neurologist, who talked to my surgeon,” she recalls.

Ultimately, her oncologist suggested a chemotherapy cocktail that included a drug she was already taking as part of her MS therapy. “We consolidated the medication so I wouldn’t be overdosed,” Barney says, noting that she didn’t develop any adverse reactions between the MS and cancer treatments.

**Finding a link**

Experts don't yet understand how comorbidities are related—or whether they're related at all.

Some conditions may simply be linked to aging, which increases the risk of developing high blood pressure, high cholesterol, diabetes and heart disease.

There's also the possibility that MS-related lifestyle changes can lead to other diseases. For example, if you're not physically active because of weakness or balance issues, you may develop decreased bone density, or you may become overweight, which can in turn heighten your risk of conditions like heart disease.

There's growing evidence, however, that there may be connections between MS and other medical issues. Research shows some health conditions share common risk factors. For instance, Dr. Marrie says smoking is a risk factor for both MS and inflammatory bowel disease. These two diseases also share some genetic factors, which makes it even more plausible they would happen concurrently.

Inflammation is also a common factor in many of the diseases that seem to go along with MS. "Many of the diseases that afflict us are inflammatory in nature—heart disease, atherosclerosis, arthritis, inflammatory bowel disease and, of course, MS," Dr. Jones says. "These diseases may share a systemic connection as problems of the immune system."

### **Impact on MS**

The key question that researchers and healthcare providers are asking now: Does having another condition on top of MS make the MS worse? For at least some conditions, signs point to yes.

A 2015 study in the **Journal of Neurology, Neurosurgery & Psychiatry** shows that cardiovascular risk factors such as hypertension, heart disease, overweight/obesity and type 1 diabetes are associated with a greater chance of developing new MS lesions.

Being obese also seems to be associated with a greater risk of MS progression, according to a 2014 study published in the journal **Autoimmunity Reviews**. Researchers aren't certain why but postulate it may be because obesity generates inflammation that's likely to worsen MS progression and make it harder to treat.

Even if they don't advance the disease itself, some coexisting conditions can worsen everyday MS symptoms such as fatigue and pain. Barney remembers the extra toll that cancer treatment, especially the three-plus months of radiation, took on her MS. "It really magnified my fatigue," she says.

She relied on her support network while managing both conditions. Her husband took over some of the housework while she was recovering, and friends drove her to chemotherapy appointments. "I tried to accomplish my most important tasks early in the day, and rested more," Barney says. She also got a scooter and then eventually switched to a motorized

wheelchair.

Having another health condition can also make it that much harder to cope with everyday activities. With a lung disease such as asthma, for example, walking will be extra challenging when breathing is difficult, Dr. Jones says. Chronic lung disease is estimated to affect some 10 percent of people with MS. Acute infections, too, can cause a small increase in body temperature that exacerbates symptoms such as spasticity.

Osteoarthritis (OA) can further compromise mobility. This has been a problem for Emrich, who has OA in addition to her MS and RA. “I notice that spasticity in my legs from MS makes pain from the osteoarthritis in my knees worse,” she says, noting that the types of pain can be similar, but they affect different parts of her body. “It took quite some time to unravel that connection so that I could get relief from severe knee pain by treating my spasticity more aggressively.”

In addition to MS, OA and RA, Emrich is also managing high cholesterol, depression, anxiety and low thyroid function. Doctors say when there are dual or multiple diagnoses like this, it’s key to have a team of healthcare providers that carefully coordinate care.

### **Coordinating care**

If you’ve received one or more diagnoses on top of your MS, it’s critical that your providers work together, making sure the most urgent conditions and tests are prioritized, medications don’t interact negatively (or duplicate each other) and side effects are effectively managed. Follow these steps to ensure you get the best possible care.

1. **Get the right people on your medical team.** For most new problems, you’ll want to see a primary care physician (PCP) for a referral to a specialist like an oncologist, cardiologist, pulmonologist or psychologist, Dr. Jones says. Your PCP can also act as the central point in care, coordinating all of the various healthcare providers and treatments you may be getting. This can help streamline your medications (possibly dropping any that are redundant) and ensure you don’t end up with drugs that interfere with one another or cause dangerous interactions. (Use one pharmacy if possible for all of your medications, too, as today’s prescription software will automatically flag some of those problems.) “Having a PCP is of paramount importance, as MS is not protective against other diseases,” Dr. Jones says.
2. **Get everyone talking.** Your PCP might keep all of your healthcare providers informed, but you shouldn’t count on it. To be proactive, Dr. Marrie suggests you write down all of the names and contacts for your physicians and bring the list to every appointment. The same goes for your medications: Keep a running list of each one you’re taking, the dose, why you’re taking it and who prescribed it. After each visit, make a point of asking the physician’s office to share a record of the appointment—including any treatments recommended or medications prescribed—with all of the medical specialists on your list.

Barney says she regularly reminds her doctors of her dual diagnoses and special needs, and urges them to send records to each other. “It’s hard work, but it’s well worth it,” she says. “It’s constant. One request often will not do it. We need to stand firm and advocate for ourselves.” Barney’s advocacy efforts led her to co-found the MSplus Foundation ([msplus.org](https://msplus.org)), an organization that supports, informs and educates people who have diagnoses of both MS and cancer.

Emrich’s doctors seem to need less nudging. “Without prompting, they send reports to each other following each office visit,” she says. And yet Emrich still maintains her own records, with the help of her smartphone. She uses the note-taking app to keep track of medications and any questions she has for the doctor, and the calendar to keep track of appointments.

3. **Keep your eyes on the prize.** While your medical team can work together to prioritize and manage your treatment needs, Dr. Marrie says it’s a general rule that more urgent, life-threatening illnesses should be dealt with first, over your MS. Your team will also consider whether the same treatment could be used to manage both conditions (like a healthier diet and exercise to help with high blood pressure, high cholesterol and MS fatigue), and which treatment is most affecting quality of life and daily function.
4. **Ask the experts.** The Society offers a free service in most areas of the country that could make managing your care a whole lot easier. Call an MS Navigator (1-800-344-4867) and ask for care management resources; once you connect, a care manager will meet with you one-on-one to assess your various needs and develop a customized care plan. That might mean helping you navigate your insurance; setting up home care; applying for government programs like Social Security, Medicare or Medicaid; connecting you with providers who offer discounted rates; or helping you apply for a grant to purchase a piece of equipment, like a wheelchair. “The goal is to connect people who have MS to the resources they need to improve their quality of life,” says LeeAnn Bellum, care management director of the Society’s Colorado-Wyoming chapter. “We may not have all the answers, but we can connect you to the people who do.”

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For help locating care-management resources, call an MS Navigator at 1-800-344-4867.