

DOUBLE

Another look at **MS** and **something else**

WHAMMY

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As if it weren't tough enough to deal with MS, what happens when you get the one-two punch of MS and another disease?

"Even though my MS diagnosis was devastating, it wasn't as much so as cancer," recalled Jane Stone*, 50, a medical secretary in New York City, who was diagnosed with breast cancer in 1998. "You can die of cancer. Yet cancer doesn't affect me physically now, and MS does."

"Cancer was scarier than MS," agreed Kathleen Rand, 43, senior buyer and procurement card administrator for the city of Sparks, Nevada, whose longtime thyroid problems culminated in a cancer diagnosis in January 2001. "MS isn't going to kill you, and cancer can be deadly."

Having MS is no protection

Unfair as it may be, having one disease doesn't make you immune from another. "Having one lousy disease won't keep the other bugs away!" is how Patricia Ken-



10 coping tips

Finding ways to deal with the huge burden is on the minds of everyone affected by a dual diagnosis. Some suggestions:

1. Join a support group. As the manager of online communities for a national association, "I see the incredibly positive effect of self-run group therapy," Bob Henderson said. "Go where people understand the language you're speaking and are going through the same things."

2. Stick to your treatment plan. Easier said than done. "If one of my patients is having a hard time staying motivated," Kennedy said, "I take them back to why they chose this treatment plan. I bring them back to that moment and let them re-make that decision. What doesn't work are threats, such as saying, 'If you don't take this med,

you'll end up in a wheelchair.'" Kennedy might also recommend a mental-health professional to help with what she calls the "psychological pow" of handling so many issues.

3. Educate yourself—and your doctors, if need be. No one can pay as much attention to all aspects of your health as you can. You may need to make it your responsibility to make sure that lab reports, prescription lists, and even drug interaction information go to all health-care personnel.

4. Stick to routines. Kathleen Rand's evening routine is "to light a candle, write in my journal, and watch **Star Trek**. If I don't, I feel like I don't have control of the disease or my life."

5. Think outside of the box. Margaret Barney has been a support group

nedy, RN, a nurse-practitioner at the Rocky Mountain MS Center in Denver, put it.

Kevin Ott, 40, of Aurora, Colorado, warehouse operations manager for an office supply company, has both MS and Crohn's disease, the latter currently in remission. He takes methotrexate for MS, the only drug he's found that his system tolerates. When the Crohn's was active, "I kind of forgot about the MS," he said. "Now I'm back with the MS and forgetting about Crohn's."

That's typical: Many people pick one disease to deal with and put the less

pressing one on hold. "They still have MS, but right now it may take a back seat," said Kennedy. "Maybe we don't do active physical and occupational therapy during chemotherapy. However, if it's another chronic disease, neither takes a back seat. It becomes a constant conversation: Is the treatment for one OK with the other?"

Sometimes they overlap. Bob Henderson*, 56, has MS and type 2 diabetes. "I think of myself as having diabetes more than MS because diabetes is in my face every day," he said. "There's nothing I can do for my MS that I'm not also doing for

leader for people with MS and cancer in both Olympia, Washington, and Houston. "We talk on the phone if fatigue prevents us from meeting in person," she said. She also helped set people up with computer hardware and training for an Internet support group.

6. Avoid extremes. Medications and stress can affect your judgment. "I tend to be more impulsive than I used to be," Rand noted, "so I try to take a step back and make sure of what I really want to do."

7. Treat yourself well. "I believe in milking my illness," Jane Stone said. "I'm being tongue-in-cheek, but there's some truth in it. Because my life can change, I don't deprive myself of little pleasures, things that make me feel good, like a fancy lotion or a new CD."

8. Focus on now. "I try to take one day at a time—really, one minute at a time," said Rand, whose MS has recently

gotten worse and who not long ago tested positive for lupus. "Worrying is one thing, and worrying about what you have no control over is another. I only worry about **now**."

9. Stay optimistic. "When the surgeon called to tell me my biopsy was positive, I thought I'd never have fun again, never be lighthearted again," Stone recalled. "But at some point you **will** feel good again. When you get these diagnoses, you feel so overwhelmed, and for a period of time it's your whole life. I wish someone had told me back then that one day this wouldn't be the largest fact of my life."

10. Learn what you can and can't do. This may mean finding out what medications interact with one or the other condition, or what can cause injuries or symptom flares. "And rest when you need to," Stone summed up. "Don't try to be a soldier."

diabetes: eating right, exercising, keeping myself as healthy as I can. Both MS and diabetes require a lot of personal responsibility. It's hard for people who are not self-starters, who are looking for doctors to take care of them. Doctors aren't there to treat you—you are there to treat yourself."

Barriers to diagnosis

Just identifying a second health issue can be a challenge. Financial, transportation, and mobility issues can make getting to routine checkups difficult. Many doctors and dentists aren't accessible for someone in a wheelchair. If a person can't be transferred to a table, an exam might be less than optimal.

For some people, time is the big obstacle. "If you already have one disease, it takes up a lot of your time. You may be less likely to take care of other screenings, such as for cancer," suggested MS specialist D. Joanne Lynn, MD, of Ohio State University.

For still others, it can be the fear of lightning striking again. Kevin Ott turned 40 not long ago. "If I didn't have MS, I would probably have had a full physical by now," he admitted. "In the back of my mind, I think if I do go, they'll find something else."

Having MS may increase risks

While no one seems to know just how many people are affected by a dual diagnosis, people with MS have the same risks for serious diseases as anyone else. And maybe a bit more. Having one autoimmune disease (MS) does mean a slight statistical increase in the risk of having another (such as lupus or rheumatoid arthritis).

In addition, issues common to people with MS, such as bladder infections, can lead to added health problems. A decreased ability to exercise can mean getting less exercise, which often leads to weight gain and diminished fitness—both



Go primary

One step, recommended by patients and medical personnel alike, is to establish a solid relationship with a primary-care doctor. People tend to bond with their neurologist, since they see that doctor regularly and on a long-term basis. They may come to think of this specialist as their primary-care provider. "But," said neurologist William H. Stuart, MD, medical director of the Multiple Sclerosis Center of Atlanta, "after we deal with the MS issues, we have no time for the rest."

A checkups checklist

The Society's fact sheet **Preventive Care Recommendations for Adults with MS: The Basic Facts** spells out what everyone should know. Go to nationalsmsociety.org/Brochures-PreventiveCare1.asp and download a copy—or call your chapter at **1-800-FIGHT MS** and ask for one.

Effects and side effects

Cancer treatments often have benefit for multiple sclerosis, according to William H. Stuart, MD. "The third or highest level of treatments for MS includes cancer drugs," he said. "If someone has cancer, we generally pull back on the MS treatment. Surprisingly, some people come back after cancer treatment with their MS stable for a long time."

risk factors for heart disease and diabetes. Cognitive impairment can make it tough to work one's way through the health-care system. Depression, which disproportionately affects people with MS, is yet another barrier to getting those regular health checkups, working out, and eating a healthy diet, Dr. Lynn noted.

Complicating matters further, people with MS and their physicians tend to perceive all new symptoms as MS-related. "Once there's an MS diagnosis, we might not pick up on the subtleties of something else," Kennedy said. "For example, if someone comes in with new-onset numbness in the right arm, many times the doctor assumes it's an MS exacerbation.



tion. But it could be a disc in the cervical spine causing radicular pain." Similarly, visual problems might be routinely chalked up to optic neuritis when there are other possible causes.

"What's the lesson for doctors?" Dr. Lynn asked. "We need to keep an open mind about each new complaint and make a fresh assessment, based on history and exam." People with MS can have what anybody can have. Back pain may be exacerbated by poor gait but could be a herniated disk; hand numbness could be carpal tunnel; foot pain could be plantar fasciitis. Added Dr. Lynn, "The whole nature and art of taking care of people with MS is that they're not just 'people with MS'—you have to treat them for what else is going on in their lives." ■

*Jane "Stone" and Bob "Henderson" asked to use pseudonyms.

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