

BY JOHN RICHERT, MD

What we are doing about symptoms that can't be measured easily

Pain. Fatigue. Mood alterations. Pins-and-needles sensations. These are common and often disabling effects of MS. Indeed, they are complex symptoms that need to be treated.

We often hear from people with MS that the treatments recommended by their doctors are not providing adequate relief. As a result, many alternative therapies are espoused by people both inside and outside established medical circles.

Bee stings. Marijuana. Low-dose naltrexone. Vitamin B12. Desensitization related to potential allergens. Dietary changes. Antibiotics. All of these, and many others, have been recommended for the treatment of MS symptoms—with limited scientific evidence to back them up. What should we be doing about it?

The National MS Society is often asked to advocate for unproven treatments for MS symptoms, precisely because the symptoms are so trou-

bling and the available conventional treatments fail to provide adequate relief for many. But, instead of giving advice based on insufficient knowledge, we must acquire the knowledge we lack. Our priorities must be to learn how to evaluate convincingly the therapeutic potential of any treatment that might relieve troubling and disabling MS symptoms.



Hard to measure, harder to live with
The symptoms that are the subject of this article have one thing in common: They are difficult or nearly impossible

to measure objectively at the present time. They are largely felt—not seen—and a health-care provider or a researcher is unable to gauge their severity through observation. We have to rely on what our patients tell us. And since individuals are certain to describe their feelings differently, researchers have a problem.

In order to prove that a treatment is effective, researchers need to measure the beneficial effects of that treatment by a uniform standard.

The National MS Society is beginning to address the question of how to evaluate symptoms for which we currently lack good objective measures. The goal is to help researchers devise ways to measure “unmeasurable” symptoms so that clinical studies can be designed that reliably answer questions about efficacy. This is the only way we will be able to make recommendations based on data rather than on hope or opinion.

That old placebo question

These issues have been with us for a long time. Fifteen years ago many of my patients reported to me that bee stings improved their energy levels, lessened spasticity, and lifted their mood. I had no objection to people subjecting themselves to bee sting treatments if they were not allergic to bee venom. Dozens of my patients tried it. However, all but two eventu-



ally abandoned it because the beneficial effects quickly disappeared.

Most of the people who reported a brief benefit after receiving bee stings were almost certainly experiencing a placebo effect, which is an entirely normal phenomenon. The human system often responds to hope and positive expectations by producing some relief.

It's not necessarily important to distinguish between a placebo effect and the more robust, physiologic response if we are dealing with a benign form of treatment. Even brief relief is, after all, a good thing. So over the years, my advice about alternatives that have been neither proven nor unproven (due to



lack of adequate study) hasn't changed: "If it's safe, and it doesn't break the bank, and you don't choose an alternative treatment to the exclusion of therapies of proven value, I have no objections."

When hope carries a big risk

The issue becomes problematic with unproven alternatives that do carry degrees of risk. Usually the risk:benefit ratio is unknown; for example, there may be a known degree of risk but an unknown degree of efficacy. If we could prove that there were efficacy—a physiological effect over and above a placebo effect—we'd be able to discuss the choice with more confidence that a rational decision would emerge for each individual.

Alternative treatments that have abuse potential add a particularly vexing dimension to the problem. When a drug or substance is legally available only for medical purposes, a doctor can be faced with having to decide which people need the treatment for medical reasons and which ones simply want a way to obtain the drug.

Marijuana merits study

Because marijuana has been described as having therapeutic value for some of the symptoms that are so difficult to measure objectively, and because its study has suffered from the problems that we are discussing here, the National MS Society has convened a special task force to evaluate all of the current evidence for the efficacy of marijuana for MS symptoms, and all the evidence relating to adverse effects. The task force will then determine if an appropriate risk:benefit analysis

can be conducted or, alternatively, what additional research studies are needed to answer the open questions. If a drug with abuse potential is convincingly shown to have therapeutic benefit that significantly outweighs its risks, we must have valid data to convince the legal authorities that its use is justified.

To increase available data, we have already initiated funding of our first grant to study the effects of cannabis on MS-related spasticity. This trial is going for-



ward thanks in no small part to improved methods for objectively measuring the severity of spasticity.

As a physician and as a leader in the National MS Society, I want you to know that we will follow what the best data tell us, pursue ways to acquire more knowledge, and push to make all treatments proven to be effective available to all who need them. ■

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