Clear Thinking about Alternative Therapies

STAYING WELL

National
Multiple Sclerosis
Society

Clear Thinking about Alternative Therapies

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Understanding your options

How do you choose the right medical treatment from everything that is available to you? This is one of the biggest questions you face as a person with MS.

Not so long ago, you wouldn't have had a choice. Your doctor would have decided for you from a limited list of possibilities. But today there are several ways to manage MS and a long list of ways to ease MS symptoms.

In order to understand and evaluate your options, and manage your MS over time, you need to be an active, informed consumer.

This is particularly important if you choose to pursue an alternative or complementary therapy. Here, it is much harder to identify and evaluate the risks and benefits. Therapies range from the widely accepted to the truly bizarre. To protect your health and your pocketbook, you must track down and scrutinize information from as many sources as possible.

What are alternative therapies?

The term **alternative** is difficult to define. When applied to health care, it encompasses everything from drugs and diets to food supplements, mental exercises, hands-on techniques, and lifestyle changes — virtually anything that is not included in traditional Western medical practice.

Alternative therapies come from many disciplines and traditions. They include acupuncture, aromatherapy, biofeedback, chiropractic, guided imagery, herbal medicine, homeopathy, hypnosis, hypnotherapy, macrobiotics, naturopathy, reflexology, relaxation techniques, traditional Chinese medicine, yoga, "therapeutic touch," and various schools of massage, among others.

Some alternative treatments may be making their way into standard medical practice; some may be based on concepts that are impossible to translate into standard scientific thinking or to test with contemporary clinical trials; and some may be based on fads, fancies, or complete unknowns. Despite the challenges presented by such a wide range of possibilities, alternative medicine appeals to many Americans.

Advocates of alternative therapies sometimes claim that conventional medicine is ignoring or suppressing treatments that can alleviate symptoms or even cure some diseases.

Opponents of alternative therapies challenge the advocates of unproven treatments to produce the scientific evidence that will substantiate their claims. As one outcome of this challenge, the National Institutes of Health evaluated acupuncture studies and concluded that there is clear evidence for its effectiveness for nausea related to surgery or chemotherapy.

Why is it so popular?

People want to believe that someone, somewhere, has the answer — or, at least, part of the answer. The inability of conventional medicine to cure certain illnesses or alleviate difficult symptoms can be deeply frustrating and frightening.

In addition, people want to take responsibility for their own well-being. People with chronic diseases are often urged by their conventional health-care advisors to take a "wellness" approach to living with their disease. They are urged to improve their diet, exercise regularly, and take steps to support their emotional well-being. The distinction between these strategies and alternative therapies is very blurred.

If an alternative treatment appears to be harmless, many people feel it's worth a try. Perhaps you agree. "What do I have to lose?" you may ask.

Unfortunately, there is plenty to lose with some alternative therapies. Health, money, hopes — even one's life can be at risk. That's why we've prepared this booklet. We believe information can help people make their own best choices.

Separating fact from fiction

There are many misconceptions about alternative medicine. Here are some of the most common.

- ***Fiction:*** Alternative medicine is completely natural and nontoxic.

  Fact: Not all alternative therapies use natural substances. And even a natural substance can be toxic. Remember, poison ivy is completely natural.

- ***Fiction:*** Alternative medicine is non-invasive and painless.

  Fact: Some alternative therapies are invasive, painful, and may produce serious side effects. Examples include chelation therapy, colonic irrigation, and bee sting therapy.

- ***Fiction:*** Alternative medicine is risk-free.

  Fact: Every test, treatment, therapy, and medication — whether conventional or alternative — carries some degree of risk. The question is, do the benefits outweigh the risks? Well-conducted, scientific studies or documented clinical experience can determine this, but studies and reports are not available for every treatment. In the absence of this kind of evidence, the experience of a seasoned MS clinician can provide valuable guidance. So can reference books and web sites from unbiased sources.

- ***Fiction:*** If a person improves while using a treatment, that means it works.

  Fact: It's always good news when someone's condition improves. However, the improvement may be due to the natural course of the disease, not to the treatment. MS particularly is notorious for being variable. It can stabilize for no known reason at any time. Or, the **placebo effect** may be responsible for the improvement. (See page 9 for more information on this.)

- ***Fiction:*** Conventional medicine has all the answers.

  Fact: No. Conventional medicine has not fully evaluated many of the treatments it currently uses. Doctors do not always know how or why some treatments work, but they use them anyway. However, reputable professionals avoid secrecy, and share information about their practices via journals, professional meetings, and correspondence.

- ***Fiction:*** Conventional physicians reject alternative medicine.

  Fact: Not necessarily. Today, the term **complementary medicine** is used by mainstream physicians to refer to alternative regimens or therapies that their patients choose to use along with their conventional treatments. In other words, these therapies **complement** but **do not replace** the conventional treatment plan. A growing number of physicians are interested in this approach.

  Some medical doctors refer their patients to alternative medical practitioners. Some even administer complementary treatments themselves. And a few non-conventional therapies, such as meditation, have been tested and found to have some positive effects and are accepted by mainstream medicine.

- ***Fiction:*** Alternative medicine is inexpensive and protects people from profiteering corporations.

  Fact: It is possible to spend hundreds of thousands of dollars on alternative medicine. The nutritional supplement business alone is a multibillion dollar industry, with corporations both large and small vigorously marketing their products.

Please Be Careful

BY ELLEN BURSTEIN MACFARLANE

The diagnosis of MS is a shattering experience. This disease is unpredictable, the prognosis a question mark. While medicine can alleviate symptoms and, in some cases, slow progression, there is, as yet, no cure.

I want to warn you that MS can make you desperate, and desperation makes you vulnerable — an easy target for snake-oil salesmen selling false hope and phony cures.

I know. I was a victim.

In 1986, I was working as an investigative consumer reporter for WCPX-TV in Orlando, Florida, when I learned I had a slow, progressive form of MS. In my job, I warned the public about bad people and bad deals, and I thought I knew every con. But illness is a great leveler.

By 1991, my MS had become severe and progressive, and I was struggling to stay on my feet. As my condition deteriorated, so did my judgment.

I first learned of Dr. Irving I. Dardik when a well-respected magazine did a nine-page cover story on him. Dardik, an impeccably credentialed vascular surgeon and former head of the Olympic Committee's Sports Medicine Council, claimed

his stress/recovery exercise program called Superesonant Wavenergy (SRWE) would correct imbalances in the immune system and cure multiple sclerosis, Lou Gehrig's disease, chronic fatigue syndrome, and other chronic and fatal illnesses.

When we met, I believed Dardik's enthusiastic assertion that he had the answer to MS. He emphasized he was not talking about a remission; he could cure me. It would take a year and I would walk again. My family gave in to my plea to pay this man $100,000 — $50,000 of it up front.

Within seven months, my condition deteriorated. Dr. Irving I. Dardik's worthless cure and greed had taken a year of my life that I could not afford to lose. I had to quit my job, I needed 24-hour nursing care, and I now used a wheelchair full-time. Dardik offered no restitution.

In July 1995, based on my complaint, the New York State Administrative Review Board for Professional Medical Conduct upheld a hearing committee's decision to revoke Dardik's medical license in New York State. There was also a penalty fine of $40,000.

While there are honest and honorable people who offer alternative medical treatments, there are too many charlatans who will prey on your desperation to be cured of MS.

Please be careful!

How is alternative medicine different from conventional medicine?

Conventional medicine quantifies the risks and benefits of a new treatment. Before the Food and Drug Administration (FDA) approves any new drug or medical device, the product **must** demonstrate its safety and effectiveness in controlled clinical trials. (See page 9.) The trials not only compare outcomes between those who received the therapy and a matched group who did not, they also ensure that the exact same therapy was delivered in exactly the same way to all participants. This is the only way a true comparison can be made. Once the FDA has cleared the product for marketing, people are protected by disclosure requirements such as detailed package inserts in prescription drugs and "informed consent" procedures.

It's worth noting that while drugs and medical devices are evaluated by the FDA, surgical procedures are not federally regulated. Studies to determine the safety and efficacy of surgical interventions are often sponsored by government health agencies to review outcomes, and the American College of Surgeons supports an office of Continuous Quality Improvement to review and disseminate best practices.

People who use an alternative therapy often have little or no idea of the risks that may be involved. There is little published documentation to substantiate claims about these therapies, and the documentation that is available may be unreliable. Claims are often based on anecdotal evidence. An anecdote is a story about an individual's experience. It typically has not been measured against baselines or checkpoints to assure objectivity.

The uneven application of standards reveals some of the problems. Dietary supplements and herbals are only lightly regulated by the FDA. The manufacturer is responsible for ensuring that the product is safe but is not required to disclose information about the product's content, safety or benefit. However, a manufacturer is not allowed to make a claim that the product is a treatment or cure for a condition. If a supplement label makes a general health claim, it must include a disclaimer saying that the FDA has not evaluated the product. The FDA's document, "Tips for the Savvy Supplement User," has helpful information for those exploring supplements. (Go to **http://www.fda.gov** and type the document title into the search box.)

The controlled clinical trial

Most clinical trials divide participants into two groups. One group gets the experimental treatment, the other gets a **placebo**, a look-alike but inactive treatment. Or they receive a standard, already proven treatment. The most reliable clinical trials are "double-blind," which means that neither the patients nor the researchers know who is receiving which treatment.

This kind of double-blind, placebo-controlled study allows researchers to separate the response to the test agent from responses produced by what is called the **placebo effect**. This refers to benefits caused by a patient's or a researcher's **expectations** about a treatment rather than by the treatment itself.

You can't assume that a therapy works just because it is currently undergoing clinical trials. It may well be proven ineffective. In fact, only a small percentage of products that undergo clinical trials ever gain FDA approval.

Doing better research on alternatives

In 1992, the U.S. National Institutes of Health established the Office of Alternative Medicine to fund research on the safety and effectiveness of alternative therapies. This office is now the National Center for Complementary and Alternative Medicine (**www.nccam.nih.gov/research**). It awards grants to researchers in educational and research institutions around the country. Individuals can enroll on this site for a quarterly newsletter, "CAM at the NIH."

Belief — a potent medicine

Our bodies respond to suggestion. Some scientists think that a person's belief in a therapy causes the body to produce hormones called endorphins which act as natural pain-killers. This may ease pain and reduce discomfort. In other words, believing can literally make it so for some period of time.

The catch is that the placebo effect tends to diminish over time even when the person's belief remains strong.

About 32% of people in clinical trials respond positively to placebos according to a groundbreaking 1955 study by H.K. Beecher. He was not studying MS. Experience in clinical trials for MS suggests the effect is even stronger in this disease. Up to 60% of people with MS have responded to an inert drug or sham treatment — at least for a short while. This demonstrates that the power of suggestion can be a powerful tool to improve the quality of life for many people with MS. But it can also lead people to believe that an expensive and ultimately useless treatment is essential.

Belief can work in the opposite direction as well. Participants in clinical trials may experience negative effects, such as headaches or nausea, even when they are in the placebo arm of the study receiving an inactive look-alike treatment. This response is called the nocebo effect.

Special issues in MS

Clinical trials are particularly important in establishing the safety and effectiveness of new treatments for MS. MS is a disease famous for spontaneous remissions. So much is still unknown about this disease, and its course can be so different from one person to another, that it can be difficult to determine what works and what doesn't.

Thus a new MS therapy is tested on a large number of people with similar forms of MS over a long period of time. The results give information that assures everyone that the treatment is likely to do more good than harm.

Sorting it out

Some alternative treatments may improve general health or make it easier to deal with a troubling symptom. Others could trigger a helpful placebo effect, if only for a limited time. Others are ineffective and a waste of money and time. And still others are actually dangerous.

So how can you tell what to avoid and what might be worth a try?

The answer: **Gather information** (see checklist on page 22). Carefully and thoroughly inquire about any therapy you are considering. Keep asking questions until you get the answers you need. This is the only way to fully understand what you are getting into.

- What does the treatment involve?
- How and why is it supposed to work?
- How effective is it?
- What are the risks?
- How much does it cost?

Three sample therapies, analyzed

Here is the bottom line on three therapies that have been promoted for use by people with MS:

Chelation therapy — Ineffective and dangerous

Description	Chelation means "the process of combining with and dissolving." A crystalline acid (EDTA) is injected intravenously over several hours. It chelates, or binds, heavy metals in the bloodstream, which are then excreted through the kidneys. Chelation is accepted therapy for lead poisoning and a few very rare disorders involving heavy metal accumulation. It is advocated by some alternative practitioners as a treatment for diseases as diverse as cancer, arthritis, heart attacks, strokes, MS, and Parkinson's disease.
Evaluation	The Food and Drug Administration, the Veterans Administration, and other professional associations call chelation therapy ineffective or inadequately studied for purposes other than heavy metal accumulation. There is no evidence that MS is caused by heavy metals in the bloodstream.
Risks/Costs	The therapy carries significant risk. It can cause kidney damage and is potentially lethal without adequate supervision. A course of treatment extending over several months can cost thousands of dollars.

Removal of mercury-based fillings — Ineffective

Description	Dental fillings made of silver and mercury amalgam are removed and replaced. Proponents claim that mercury leaks from amalgam fillings and damages the immune system, causing a broad range of problems, including MS.
Evaluation	There is no scientific evidence to connect the development of MS with mercury-based dental fillings. Poisoning with heavy metals, such as mercury, lead, or manganese, can damage the nervous system and produce symptoms, such as tremor or weakness, similar to those seen in MS. However, the underlying mechanism of the nerve damage is completely different from MS.
Risks/Costs	Although it can be painful and might cause dental complications, the procedure is medically harmless. However, it is usually very expensive.

Tai chi — Harmless and may benefit general health

Description	Tai chi is an ancient Chinese system of meditative exercise. The participant concentrates on performing gentle patterns of movement that are described as bringing the body and mind into harmony. Tai chi is practiced by people of every age and physical condition.
Evaluation	Tai chi may lower stress, promote relaxation, relieve fatigue, and improve balance.
Risks/Costs	The exercises are safe. If necessary, they can be done in modified form from a seated position. The only costs are for instruction in a class or for a video.

Danger signals!

Alternative medicine attracts many quacks and frauds. They claim their treatments can produce miracles. Quacks may be well intentioned and deeply convinced about the value of their remedy — or they may be crooks, plain and simple. Either way, fraud produces misery in the form of wasted money, dashed hopes, and even direct physical harm.

Suspect fraud if:

- Promoters suggest an alternative treatment is a "cure" for MS. The grander the claim, the more alarming this signal is.
- You must pay in advance.
- The treatment is available from only one source or works by a "secret" formula.
- A practitioner does not want to work with your medical doctor.
- The promoters claim there is a medical or scientific conspiracy against them.
- Advertising uses testimonials from "satisfied customers."
- The product or treatment is promoted by:
  - telephone solicitation, direct mail, or the Internet
  - a TV infomercial that uses a talk-show format
  - newspaper ads designed to look like news articles
  - a salesperson working for a multilevel marketing organization (known as "pyramid marketing")

Look before you leap

- **Don't make your decision in a vacuum.** Contact a variety of sources to get reliable, objective information about any alternative therapy you are considering. Begin by calling the National Multiple Sclerosis Society at 1-800-344-4867. And use the resources on pages 19.
- **Discuss the alternative therapy with your doctor.** Ask for your doctor's views on the risks, benefits, side effects, and potential interactions with medications you are currently taking. Also ask about the experience of the doctor's other patients who have used the same therapy. A frank talk with your nurse may be helpful if you feel you and your doctor are not communicating well about this issue.
- **Find out if the alternative practitioner works with conventional doctors.** Be sure that the practitioner is willing to refer patients to a physician. Avoid those who do not want to work with regular doctors.
- **Talk to people who have used the treatment.** Firsthand knowledge is invaluable. Ask people who have used the therapy about its advantages, disadvantages, risks, side effects, costs, and the results they got from it. Try to track down these people yourself. Chat groups like those on MSWorld® can be helpful here. Don't rely on references supplied by the alternative practitioner or a person who is trying to sell you the product or service.
- **Investigate the background of any treatment provider.** Find out about the person's training and credentials. In particular, determine how much experience this person has had treating people with MS.

- **Thoroughly investigate any clinic that requires inpatient stays.** Be particularly vigilant about any clinic (in the U.S. or abroad) that will not treat you as an outpatient. Find out why they require inpatient treatment.
- **Determine the costs. Ask about the cost for a full course of treatment.** Some alternative therapies are very expensive and most are not covered by health insurance.

Proceed with caution

If you do decide to try an alternative therapy, continue to use your common sense.

- **Do not abandon your conventional therapy.** One of the greatest dangers of alternative medicine is quitting conventional treatment in a headlong rush to embrace an alternative. Only use alternative therapy in addition to, not in place of, treatment prescribed by a qualified physician.
- **Document your experience.** Keep a detailed log of your experience. Record whom you consulted, what you took or did, and what changes you observed. A log will help you keep your doctor informed.
- **Keep your doctor up to date.** Tell your doctor about all the therapies you are using. A physician who can't see the whole picture will be practicing medicine in the dark. Your doctor can alert you to possible side effects or interactions with your medications. He or she can also help you decide whether to continue a particular alternative therapy.

A final word

Stay tuned for further developments. New findings are now common in the fast-moving world of modern medicine. An alternative therapy that you've considered using may be proven harmful. On the other hand, some age-old folk remedy may prove to be the source for a new treatment.

The best advice: Remain open-minded but skeptical. Remember, every alternative treatment is suspect until it has been proven safe and effective.

References

Web sites

- The National MS Society offers local referrals, education programs, counseling, self-help groups, and other booklets and brochures on MS. Log on to **www.nationalMSsociety.org**.
- The Society recommends the Web site managed by Dr. Allen Bowling, which provides comprehensive information about complementary and alternative medicine and MS. Log on to **www.neurologycare.net/cam**.
- Official chat and message board site for the National MS Society. **www.msworld.org**.

Books

There are many books on CAM written for non-specialist readers. One book that specifically deals with MS and CAM is:

- Bowling A.C. *Complementary and Alternative Medicine and Multiple Sclerosis.* (2nd Edition). New York: Demos Medical Publishing, 2007. Web site: **www.demoshealth.com.** Tel: 800-532-8663.

Others with objective general information on dietary supplements and CAM are:

- Kalb R., Ph.D., Holland N, RN, EdD, MSCN, Giesser B, MD Giesser, *Multiple Sclerosis for Dummies.* Wiley Publishing Inc., 2007.
- Steven Foster and Varro E. Tyler, PhD, *Tyler's Honest Herbal: A Sensible Guide to the Use of Herbs and Related Remedies.* Binghamton, NY: Haworth Press.

* Note: The above-mentioned books may be available for loan at your local chapter of the National MS Society, or at your public library.

Technical reference books

Detailed technical references include:

- *2011 Physicians' Desk Reference for Nonprescription Drugs, Dietary Supplements, and Herbs*, Thomson Healthcare, NJ. Web site: **www.pdrbookstore.com**. Tel: 800-678-5689.
- *Physicians' Desk Reference for Herbal Medicines*, (4th Edition) Thomson Healthcare, NJ. Web site: **www.pdrbookstore.com**. Tel: 800-678-5689.
- Bowling, A., *Complementary and alternative medicine and multiple sclerosis.* Neurologic Clinics of North America, vol 29, pp. 465-480, 2011.
- Ernst, E., Pittler, M.H., Wider, B. *The Desktop Guide to Complementary and Alternative Medicine: An Evidence-Based Approach.* (2nd Edition) Edinburgh: Mosby, 2006.
- Fetrow, C., Avila, J. *The Professional's Handbook of Complementary and Alternative Medicines.* Springhouse, PA: Springhouse Corp., 2003.

- Fragakis, A.S. *The Health Professional's Guide to Popular Dietary Supplements.* (3rd Edition) Chicago, IL: The American Dietetic Association, 2006.
- Jellin J.M., Batz F., Hitchens K., et al. *Natural Medicines Comprehensive Database.* (5th Edition) Stockton, CA: Therapeutic Research Faculty, 2005.

Information on health fraud

- Quackwatch. **www.quackwatch.com**.

Federal government sources

- Federal Trade Commission, Consumer Response Center, 600 Pennsylvania Avenue, NW, Washington, DC 20580. Tel: 877-382-4357. Web site: **www.ftc.gov**. Investigates false advertising.
- Food and Drug Administration, 10903 New Hampshire Ave., Silver Spring, MD 20993. Tel: 888-463-6332. Web site: **www.fda.gov**. In 1988, the FDA established the National Health Fraud Unit to fight medical fraud. This unit helps coordinate federal, state, and local regulatory actions against fraudulent products and practices.
- National Center for Complementary and Alternative Medicine Clearinghouse, P.O. Box 7923, Gaithersburg, MD 20898-7923. Tel: 888-644-6226. TTY: 866-464-3615. Web site: **www.nccam.nih.gov**. E-mail: **info@nccam.nih.gov**.
- U.S. Postal Inspection Service, Criminal Investigations Service Center, Attn: Mail Fraud, 222 S. Riverside Plz, Ste 1250, Chicago, IL 60606-6100. Web site: **www.usps.gov/postalinspectors.uspis.gov**. Monitors products purchased by mail.

Alternative Treatment Checklist

Do materials suggest this treatment is a cure? ❒ yes ❒ no

Do they suggest your current treatment is harmful? ❒ yes ❒ no

Does the treatment supposedly help a long list of different conditions? ❒ yes ❒ no

Do you need to pay in advance? ❒ yes ❒ no

Do you need to stay in a facility away from home to get treatment? ❒ yes ❒ no

Is treatment available from only one source? ❒ yes ❒ no

How did you hear about it?

❒ Telephone solicitation
❒ Direct mail
❒ TV infomercial
❒ Newspaper ads that look like articles
❒ Multi-level marketing
❒ Internet

Practitioner does not want to work with your physician? ❒ yes ❒ no

"YES" to any question is a red flag!

At the very least, seek more information.

Questions to ask

- What does the treatment involve?
- How and why is it supposed to work?
- How effective is it?
- What are the risks?
- How much does it cost?

Notes

The National Multiple Sclerosis Society is proud to be a source of information about multiple sclerosis. Our comments are based on professional advice, published experience and expert opinion, but do not represent individual therapeutic recommendations or prescriptions. For specific information and advice, consult your physician.

Early and ongoing treatment with an FDA-approved therapy can make a difference for people with multiple sclerosis. Learn about your options by talking to your health care professional and contacting the National MS Society at nationalMSsociety.org or 1-800-344-4867 (1-800-FIGHT-MS).

The Society publishes many other pamphlets and articles about various aspects of MS. Visit nationalMSsociety.org/brochures to download them, or call your chapter at 1-800-344-4867 to have copies mailed to you.

Some of our popular pamphlets include:

- Vitamins, Minerals and Herbs in MS: An Introduction
- Exercise as Part of Everyday Life
- Food for Thought: MS and Nutrition
- Taming Stress in Multiple Sclerosis
- Managing MS through Rehabilitation

MS STOPS PEOPLE FROM MOVING.

WE EXIST TO MAKE SURE IT DOESN'T.

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For Information:
1 800 FIGHT MS (1 800 344 4867)

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