

CHAPTER 6

Alternative Therapy Considerations

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RESOLVING ALTERNATIVE (COMPLEMENTARY) MEDICINE CONFUSION

In the United States and other countries, alternative medicine use is quite popular. For people with chronic diseases, such as multiple sclerosis (MS), the use of these unconventional therapies appears to be especially common. If you have MS and are interested in determining whether a particular unconventional therapy is worth using, it can be confusing, frustrating, and time-consuming. There is so much information given to you in support groups, Web chat rooms, and so forth. How do you make sense of and evaluate all this information? To start, read this chapter. It will provide you with background information and approaches that will help you be thoughtful and careful in your evaluations of specific alternative therapies.

WHAT IS “ALTERNATIVE MEDICINE”?

The question posed above is surprisingly hard to answer. Part of the difficulty is that there are many different terms used to describe this area. In addition to “alternative medicine,” other commonly used terms are “complementary medicine,” “unconventional medicine,” and “integrative medicine.”

The broadest of these terms is *unconventional medicine*. This is often defined as those therapies that are not typically taught in medical schools or generally available in hospitals. However, this definition is unusual in that it states what unconventional medicine is not, as opposed to what it is. Also, most American medical schools now have at least limited coursework in unconventional medicine. A more complex but precise definition is that provided by the National Institutes of Health (NIH). This definition divides unconventional medicine into subcategories. The subcategories, with representative examples, are as follows:

- Biologically-based therapies (diets, dietary supplements)
- Mind-body therapies (guided imagery, meditation, stress prevention)
- Alternative medical systems (traditional Chinese medicine, homeopathy)
- Manipulative and body-based therapies (chiropractic, reflexology, massage, acupuncture)
- Energy therapies (therapeutic touch, magnets)
- Lifestyle and disease prevention (exercise, diet, sleep)

Several of the other terms used in this area are based on the way in which these unconventional therapies are used. *Alternative medicine* refers to unconventional therapies that are used instead of conventional medicine, while *complementary medicine* refers to the use of these therapies in conjunction with conventional medicine. A broader term is *complementary and alternative medicine*. In this chapter, CAM, an acronym for *complementary and alternative medicine*, is used. The combined use of unconventional and conventional medicine is known as *integrative medicine*.

IF YOU ARE INTERESTED IN ALTERNATIVE MEDICINE, YOU ARE NOT ALONE

Several studies have evaluated the use of CAM in the general population and in people with MS. According to one large survey of the general population in the United States, about 40 percent of people use some form of unconventional therapy. This survey found that people actually visited unconventional medical practitioners more frequently than primary care physicians. Nearly 20 percent of those surveyed were taking some type of herb or vitamin in addition to their prescription medications. Almost half of those surveyed were using CAM without the advice of a physician or unconventional medical practitioner, and more than half (60 percent) did not discuss their use of CAM with their personal physician (Eisenberg et al. 1998).

Studies indicate that CAM use is more common among people with MS than in the general population. One-half to two-thirds of people with MS have used some form of unconventional therapy (Bowling and Stewart 2003). The majority of you with MS are mid-career at the onset of disability, well-educated, and open to exploring options. Interestingly, people with MS usually use the phrase “unconventional medicine” along with “conventional medicine.” In other words, the term is nearly always used in a complementary fashion. Only a very small fraction of you with MS use “unconventional medicine” instead of “conventional medicine” (Bowling and Stewart 2003). The CAM therapies used

most commonly by people with MS include diets, dietary supplements, prayer and spiritual practices, chiropractic medicine, and massage.

THE QUALITY OF ALTERNATIVE MEDICINE INFORMATION VARIES

If you've tried to research some kind of CAM therapy, you've probably found that it can be difficult to find reliable information. There are a variety of information sources, but all of these sources have limitations.

Books

Books are one possible source of information. To evaluate the quality of information about MS found in books about alternative medicine, we conducted a survey with the Rocky Mountain MS Center (Bowling, Ibrahim, and Stewart 2000). Examining the stock of two large bookstores, we reviewed the sections on MS in fifty different alternative medicine books. In these books, MS was sometimes incorrectly defined as a form of muscular dystrophy, five to six different therapies were generally recommended, and no two books carried the same recommendations. Furthermore, it was rare for any CAM therapy to be discouraged and, sometimes, dangerous therapies were actually recommended. Given this type of information, it's easy to see how you can become very confused and, after reading a few books, you can wind up with a list of fifteen to twenty different CAM therapies for treating MS.

Other Information Sources

Other information sources also have limitations. The Internet has variable quality CAM information, particularly the chat room information. Vendors of products, such as dietary supplements, and providers of CAM services may have limited MS-specific information or exaggerate claims about the effectiveness of their products. Finally, conventional health providers, almost by definition, have limited CAM knowledge and experience.

WHAT CAN YOU DO?

Given these limitations in CAM information, you can really feel "at a loss" as people make different recommendations. There are several strategies, however, that can be very helpful. They are as follows:

- Develop a knowledge base and a set of skills that will help you assess CAM therapies.
- Take a thoughtful approach to using CAM therapies.
- Know what sources of CAM information are reliable.

The remainder of this chapter will focus on helping you to develop the strategies discussed above.

Using Evidence to Evaluate Therapies

It is extremely important for you to know the different types of evidence that may be available about the safety and effectiveness of a particular therapy. This type of evidence applies to conventional medicine as well as to unconventional medicine.

Theory

Theory is the least reliable information about any given therapy. An example of a theoretical argument about a CAM therapy for MS would be that a certain dietary supplement, “Compound X,” is thought to suppress the immune system because its chemical structure is similar to another chemical that suppresses the immune system. Since suppressing the immune system may be therapeutic for some people with MS, it theoretically could be argued that Compound X may be helpful for MS. The problem with this type of information is that it is pure theory. If the compound were actually to be tested, it might be found that it does not, in fact, suppress the immune system and has no effect whatsoever on people with MS.

Experimental Evidence

Information established by experimental evidence is more reliable than theory, but it still has significant limitations. In terms of MS therapies, experimental evidence often involves studies of the effects of a therapy on the immune system and on animals with an MS-like disease known as EAE (experimental allergic encephalomyelitis).

In the case of Compound X, experimental evidence might be test-tube experiments showing that Compound X does inhibit certain components of the immune system and that it does have therapeutic effects in the animal model of MS. But this type of information still has potential problems. It could be that, in spite of the experimental evidence, actual testing of the compound on people like yourself would show that it has no effect. In fact, there is a long list of potential MS therapies that looked very promising in experimental studies but proved to be ineffective for treating the disease. Most importantly, some of these promising therapies actually ended up worsening the disease. For this reason, clinical evidence is essential.

Clinical Trial Evidence

Clinical evidence is the highest quality evidence. The best type of clinical evidence is obtained through studies known as multi-center, randomized, double-blind, placebo-controlled clinical trials. This can sound intimidating, but what this would mean in the case of Compound X is that a large number of people were randomly chosen to receive a placebo or Compound X (randomized, placebo-controlled). The patients and the clinical staff did not know who received the placebo or Compound X (double-blind), and the study was carried out at multiple institutions (multi-center). If people treated with Compound X fared significantly better than those who were on the placebo, then this is the strongest evidence that Compound X is an effective therapy.

Conducting formal clinical trials is very expensive, especially in the field of MS. For studies of CAM therapies, high levels of research funding are not readily available. Consequently, if you are interested in

exploring CAM, it may be necessary for you to gamble with the information that is available. In such a situation, it may be most reasonable for you to consider therapies that are possibly effective and have very little associated risk.

It is important to recognize that the best clinical evidence that is available for altering the course of MS is that of the FDA-approved MS medications, which include interferon beta-1a (Avonex, Rebif), interferon beta-1b (Betaseron), glatiramer acetate (Copaxone), and mitoxantrone (Novantrone). If you have MS, you should strongly consider these medications, regardless of your interest in CAM therapies.

Theoretical or Experimental Evidence Is Not Clinical Evidence

Some CAM literature confuses the various levels of evidence or makes strong recommendations on the basis of relatively weak evidence. For example, you might read that a CAM therapy is highly recommended for MS because it suppresses the immune system, produces beneficial effects in the animal model of MS, and has very few side effects. At first glance, that might seem convincing. However, as noted above, all of that may be true but, unfortunately, it is still quite likely that this therapy would not be an effective treatment for MS.

When Is It Reasonable to Use Unconventional Therapies?

If you are interested in CAM, it's important to have a sense for when it may be appropriate to consider using CAM therapies. If you have a symptom that is relatively mild, such as a low level of fatigue or muscle stiffness, then it may be reasonable to use CAM. Moreover, if you have a condition for which conventional medicine has no effective therapies or only partially effective therapies, then it may be reasonable to use CAM.

On the other hand, there are some symptoms for which CAM should not be used or should be used only with caution. For example, severe conditions, such as intense pain or disabling muscle stiffness, should not be treated exclusively with unconventional therapies. However, in these situations, it may be reasonable to use conventional medicine along with CAM.

Checklist 9: Your Plan in Considering a CAM Therapy

If you are considering a CAM therapy, there are specific steps that should be taken. Please review those steps below.

Have you:

___ Considered all of the possible conventional and CAM therapies?

___ Assessed why you want to use a particular CAM therapy?

___ Secured reliable information about the safety, effectiveness, cost, and effort involved?

Note: Therapies worth considering are those that don't involve a large amount of effort and are possibly effective, probably safe, and of low to moderate cost.

___ Discussed it with your physician or other conventional health care provider?

_____ Monitored the therapy for a response, and discontinued its use if it produced side effects or was not effective?

Use caution. For most CAM therapies, information about safety and effectiveness is incomplete. As a result, there is some risk-taking involved with many forms of CAM. With an informed and careful decision-making process, however, this risk can be minimized and reasonable gambles can be made.

Watch Out for the “Warning Signs” of Questionable Therapies

There are some aspects of CAM therapies that should raise your suspicions. These “red flags” include the following:

- Little or no unbiased information available about safety or effectiveness
- “Secret ingredients” (this is always a glaring signal)
- Excessively strong claims about effectiveness
- Claims that a single therapy is effective for many different diseases
- Heavy use of “testimonials” in which very strong claims are made by individuals who claim to have used the product or service
- Much effort is involved, such as inpatient treatment, intravenous therapy, or injections
- Information about a therapy conveys a strong antiscience or anti-conventional medicine feeling

Be Aware of Myths About Dietary Supplements

In the area of dietary supplements, there are many myths, some of which are perpetuated by dietary supplement vendors. These myths include the following:

- Some supplements are claimed to have therapeutic effects and absolutely no side effects. This is not a realistic situation. Dietary supplements, like medications, contain chemicals that may be therapeutic but may also be toxic.
- More may not be better. It is sometimes claimed that if a low dose of a supplement is beneficial, then a high dose must be even better. This is not true and may be dangerous. For many supplements, high doses actually may produce side effects.
- “Natural” compounds may not be safe. There are claims that products that are natural must be safe and beneficial. This is certainly not true. There are many different natural products that are quite toxic, such as mercury, arsenic, poisonous plants, and animal venoms.

Remember That MS Involves Excessive Immune System Activity

Some alternative medicine books make an error about MS. In these books, it is stated that MS is a disease of the immune system, and that, as a result, you should take dietary supplements that stimulate your immune system. This may then be followed by a recommendation that you should take five to ten different dietary supplements to activate your immune system. **Note:** This is incorrect and is potentially dangerous! MS is an immune system disease, but it is characterized by *too much*, not too little, immune system activity. Consequently, effective MS therapies generally decrease the activity of the immune system.

In a related way, you should be wary of therapies that are claimed to be effective for MS as well as for cancer and AIDS. The treatment goals are usually the opposite in these diseases. In MS we try to decrease the immune system activity, while in AIDS and cancer we try to stimulate the immune system.

WHERE YOU CAN GET MORE INFORMATION ABOUT CAM

In addition to using the guidelines and approaches recommended in this chapter, it is important to have resources to go to for information about specific therapies. To assist people with MS in this process, the Rocky Mountain MS Center has established the Complementary and Alternative Medicine Program. One of the major aims of this program is to provide user-friendly, objective, MS-relevant CAM information. Much of this information can be accessed through this program's Web site (ms-cam.org/CAMbanner.htm), or that of the National Multiple Sclerosis Society (www.nationalmssociety.org/spotlight=cam.asp). Through the Complementary and Alternative Medicine Program, this chapter's author (Dr. Bowling) has published a book, *Alternative Medicine and Multiple Sclerosis*, with objective data on the most popular complementary or alternative medicines being used or discussed. Other information is available through the Web site of the National Multiple Sclerosis Society.

Conclusion

CAM can be both confusing and controversial. At the same time, for some people with MS, CAM may be an important component of an individualized treatment plan. Using CAM may provide many benefits, including therapeutic effects, hope, and a sense of control. Using the guidelines and approaches outlined in this chapter and the information referenced elsewhere should allow you to pursue CAM in a safe and effective manner.