



# A patient's guide to choosing unconventional therapies

Unconventional therapies (UTs) are therapies not usually provided by Canadian physicians or other conventionally trained health care providers. Examples of common UTs available in Canada are herbal preparations, reflexology, acupuncture and traditional Chinese medicine. UTs may be used along with conventional therapies (complementary) or instead of conventional therapies (alternative). Surveys have shown that many Canadians use UTs, usually as complementary therapies, for a wide range of diseases and conditions.

Reliable information about UTs is often difficult to find. Your doctor may be unable to give you specific advice or recommendations, since UTs are often not in a physician's area of expertise. However, he or she will usually be able to provide some general advice and help supervise your progress. For your own health and safety, it is important to keep your doctor informed of the choices you make.

This document is intended to (a) provide you with questions to consider when making your treatment choices, (b) help you find information about UTs, (c) help you decide whether a specific UT is right for you, and (d) provide tips to help you evaluate the information you find.



## What

## should I consider when making treatment choices?

People use UTs for many reasons: for example, to feel that all possible approaches have been tried, to gain personal control and take responsibility for some of their healing process, to minimize side effects of conventional therapies and to promote a sense of well-being. To help you decide whether you should choose a UT and to help focus your search, it is important to be clear in your mind about what you want to gain. Ask yourself whether you are looking for a cure, longer survival, improved quality of life, more control of your health care or something else.

The answer to this question will help guide your search for information.

Additional questions you should ask yourself include the following:

- ◆ Do I want to spend time doing my own research about UTs?
- ◆ Do I want to take on the responsibility for my choices of UTs?
- ◆ Am I sure of my diagnosis? Do I understand the pros and cons of the conventional treatments that my doctor has recommended?

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This document was prepared by Dr. Elizabeth Kaegi with the support of the Ontario Division of the Canadian Cancer Society. It is intended to be an information aid that physicians are free to photocopy and give to patients interested in exploring unconventional therapies. Individual copies may be obtained from your local office of the Canadian Cancer Society, or the Cancer Information Service (1 888 939-3333).





## do I find information on unconventional therapies?

You should try to gather information from proponents *and* opponents of each UT you are considering. This will give you a balanced view of the evidence concerning its safety and effectiveness. Contact various sources for information, including individuals, organizations, and sources of publications and product information.

### INDIVIDUALS

Many individuals will be willing to provide you with advice about UTs. Check the person's training, qualifications, licences and experience. Ask about his or her approach to evaluating the safety and effectiveness of a therapy. If the individual promotes a specific therapy, ask for information about it (in writing if possible) and about his or her willingness to share the information with your doctor. Consider the person's motives in providing information, including his or her personal or financial interest in the product or service being recommended. The many individuals you can approach include:

- ◆ **Your doctor and other conventional health care providers:** The training and practices of these providers are controlled by professional licensing bodies. However, they may have limited access to information on UTs.
- ◆ **Unconventional health care providers:** Providers of UTs include naturopaths, herbalists, massage therapists and practitioners of Chinese medicine or Ayurvedic medicine. Provincial regulations governing the training and practices of UT providers are limited, but some providers may be licensed by professional licensing bodies. Information on the training and supervision of these practitioners may be available from your provincial or territorial ministry of health. Titles such as "Doctor" or "Professor" can be misleading. Do not hesitate to ask individuals about their training, licences and experience.
- ◆ **Pharmacists:** Many UTs are available as tablets, capsules or tinctures and are sold in pharmacies. Some of the larger chains manufacture their own brands. Look for clear lists of ingredients, statements about standardized activity and an expiry date. Pharmacists should be able to answer some of your questions and to provide additional information about the products they sell.
- ◆ **Individuals using the UT in question:** UT providers may be able to refer you to other clients with your condition. Such references are likely to be "success stories," but you may learn valuable practical information.

### ORGANIZATIONS

Consider the organization's goals, membership, funding, reputation and duration of service. Ask about its links to other agencies (e.g., professional or government) that provide access to additional information. These factors may influence the quality and reliability of the information provided. Because one UT may be used for many different diseases or conditions, information can come from many organizations. Some organizations you can approach are:

- ◆ **Societies representing specific diseases:** For example, the Canadian Cancer Society or its Cancer Information Service (tel 1 888 939-3333).
- ◆ **Your provincial or territorial ministry of health:** It can provide information about regulations for the training and licensing of all providers of health care (conventional and unconventional) and may have information about specific UTs.
- ◆ **The Health Protection Branch of Health Canada:** It can provide general information on the control of UTs and specific information on some UTs.

### SOURCES OF PUBLICATIONS AND PRODUCT INFORMATION

- ◆ **Libraries:** Public, university and medical school libraries usually have reference books that you can use, and some have periodicals such as *Alternative Therapies in Health and Medicine* and *The Journal of Alternative and Complementary Medicine*.
- ◆ **Bookstores:** There are no regulations requiring publishers to ensure the accuracy of the material they print in books or magazines. One way to determine if the material has been checked for accuracy is if the publisher states that a process of peer review (e.g., review of the material by a well-respected group of peers) was used. Some useful books are *A Guide to Unconventional Cancer Therapies* (Ontario Breast Cancer Information Exchange Project, 1994); *Choices in Healing: Integrating the Best of Conventional and Complementary Approaches to Cancer*, by Michael Lerner (MIT Press, Cambridge, Mass., 1994); and *Alternative Medicine, What Works*, by Dr. Adriane Fugh-Berman (Odonian Press, Tucson, Ariz., 1996).
- ◆ **Health food stores:** As with publications in book-

stores, the information about UTs in books, magazines, pamphlets and brochures available in health food stores is not regulated and may not be accurate. However, the information on product *labels* is regulated. A claim that a product can be used to prevent or treat a serious disease such as cancer cannot be legally made on a label unless there is good evidence to support the claim. Alternatively, if no claim that the product can be used to prevent or treat a disease

appears on the product label, you can probably assume that there is no scientific evidence to support such a claim. (See “Tips on how to evaluate the safety and effectiveness of an unconventional therapy”).

- ◆ **Online resources:** Many Web sites deal with UTs. Keep in mind, however, that there are no controls over the accuracy of the information provided and that some sites are clearly commercial in focus.



# Which

## unconventional therapy is right for me?

Once you have narrowed your search to a few UTs, you should ask yourself the following questions about each one:

### **CAN I USE IT ALONG WITH MY CONVENTIONAL TREATMENT?**

Most UT providers advise that UTs can be used along with conventional treatment. If you are advised to avoid or delay conventional treatment, be particularly careful. Check with your doctor, since a delay in starting conventional treatment may increase the risk of treatment failure and result in permanent harm.

### **AM I COMFORTABLE WITH THE PRINCIPLES ON WHICH IT IS BASED?**

UTs are often based on concepts about health and disease that differ from those of conventional medicine. Rather than trying to treat disease by attacking the specific factors thought to be the cause (e.g., bacteria, abnormal fat metabolism), as is the case with most conventional therapies, UTs are usually said to influence disease by restoring the balance of body systems, including our emotions and energy. They may also be said to boost the body's natural defences and immune system. UTs are often set apart from conventional therapies by being described as “holistic” (they consider your needs as a whole person and not just your specific disease or condition). However, today's conventional health care providers are also trained to be “holistic” in their treatment approaches. If you have illness-related needs that are not being met, ask your doctor for help.

### **IS IT SAFE FOR ME?**

Consider your overall health status. Do you have allergies? Kidney disease? Heart disease? Liver problems? Could

you be pregnant? Are you breast-feeding? Does any of the information about the UT suggest that your health status could put you at increased risk of complications? Ask your doctor if there are any special precautions you should take. People often assume that UTs are safe because they are made from natural substances, but this is not always true. Many naturally derived chemicals can be toxic, and many are used as prescription drugs in conventional medicine. “Natural” does not necessarily mean harmless.

### **WHAT ARE THE POSSIBLE SIDE EFFECTS?**

Ask about the possible side effects — rare and common — of the UT being considered and look for reports from individuals who have used it. Although few UTs cause serious side effects, some can aggravate pre-existing health problems (see above), or they may cause infections, skin disorders, allergies and liver damage. Some UTs that are usually safe may cause side effects if they are contaminated. Check the label to see if the UT has been prepared by a reliable company.

### **WILL IT INTERACT WITH FOOD, ALCOHOL OR OTHER DRUGS?**

Some UTs cannot be taken with certain foods or with alcohol. UTs may interfere with the absorption, action or excretion of conventional drugs you are currently taking. Consider possible interactions between UTs if you intend to use more than one at the same time. Information about possible interactions may be hard to find. You can start by asking the manufacturer or provider of the UT you are considering.

### **IS IT EFFECTIVE FOR MY CONDITION?**

Gather all the information you can about the effectiveness of the UT used in people with your condition. Decide whether the UT seems likely to meet your expecta-

tions. (See the next section on evaluating the safety and effectiveness of a UT.)

### **AM I WILLING TO SPEND THE TIME AND MONEY REQUIRED FOR THE UT I HAVE CHOSEN?**

Some therapies require major changes in personal and family lifestyles. The costs of UTs are rarely covered by provincial or private health insurance plans. Although the costs of most UTs are relatively modest compared with those of conventional therapies, travel to distant clinics or prolonged use of a UT may cause financial hardship.

### **DO I HAVE CONFIDENCE IN THE PROVIDER OF THE UT I HAVE CHOSEN?**

If your chosen therapy needs to be individualized, administered or monitored by a UT provider, you should have confidence in the person's knowledge, skills, judgement

and professionalism. Also, determine whether the provider is willing to communicate openly and clearly about the therapy and your progress, and whether he or she will share information with your doctor.

### **HOW LONG SHOULD I TAKE THE UT AND HOW WILL I KNOW IF IT'S WORKING?**

Your doctor may be able to help you answer these questions. The proponents or manufacturers of the UT usually provide advice on how much to take and for how long. You should consider who will supervise your care, what tests will be done to monitor the UT's effects and who will order them. Before increasing the dose or extending the duration of treatment, you should check your health status and consult your providers, including your doctor. If you notice any unusual changes in body functions or possible allergic reactions while taking the UT, report them to your doctor immediately.



## **on how to evaluate the safety and effectiveness of an unconventional therapy**

You need to ask 3 main questions about UTs, and indeed any therapy: Is it safe? Is it effective? Do the possible benefits outweigh the possible harms?

### **IS IT SAFE?**

Establishing whether the UT you are considering is safe is most important. This is sometimes a difficult question to answer. Look for information about side effects and any effects on existing health problems. Find out how common these effects are and whether they are likely to be mild or severe, temporary or permanent. Look for information about adverse interactions with foods, drugs and alcohol. Try to use products that are manufactured by established companies, since good manufacturing practices will minimize the risk of contamination.

The safety of a conventional therapy is usually established by systematic animal and human research before it is released to the public. However, a UT is often assumed to be safe if it has been in widespread use without reported harm. Unexpected harms from conventional therapies have to be reported to Health Canada, but regulations governing the reporting of such harms from UTs do not yet exist.

All products intended to be ingested are regulated by Health Canada as a "drug" or a "food." A drug is a substance that will restore, correct or modify a body function or one that is sold or represented for sale as a treatment, prevention or cure of a disease, disorder or abnormal state. A food is something that is normally expected to be consumed for its nutrient value. Most UTs intended to

be ingested do not carry health claims on their labels and fall in the "food" category. For those that make a "drug" claim on the label, there should be a drug identification number (DIN) or a general public (GP) number on the label as well. The presence of this number is helpful because it indicates that the Health Protection Branch of Health Canada has reviewed and approved the product's formulation, labelling and instructions for use.

### **IS IT EFFECTIVE?**

The effectiveness of a therapy is a measure of its ability to improve health and well-being. It is usually assessed in relation to specific health outcomes such as improved survival, reduced pain or discomfort, reduced tumour size or spread (in the case of cancer), improved appetite or weight gain, or other measures of improved quality of life. Although the desired or expected health outcomes of different treatments will vary, how evidence of the effectiveness of each treatment is gathered is basically the same. The strength of the evidence that a therapy "works" depends on the design of the study — how the subjects were selected, how systematically the treatment was provided, how well other factors that could affect the outcome were controlled and how completely the results were reported. The same rules apply to both UTs and conventional therapies. Evidence of effectiveness may come from anecdotal reports, studies of a series of cases treated at a particular clinic or institution, and randomized controlled trials.

## Anecdotal reports

Frequently, testimonials from individuals who have used the therapy are presented as the main evidence of the effectiveness of UTs. This type of evidence is of interest and can help to identify promising new treatments; however, a therapy may be effective in one person but not in another. Collections of anecdotal reports are sometimes available, but look at these critically. Testimonials from people in whom the treatment had no effect are usually not reported. Key information that might influence outcomes (e.g., the person's diagnosis and previous treatments) may be neither provided nor considered.

## Case series from a particular clinic or institution

These studies have more value than individual testimonials, but they can also be misleading. Good case series ensure that each patient enrolled has an established diagnosis and has followed a prescribed treatment. All cases are included regardless of whether the outcome was good or bad. The studies usually compare the results in the group that received the treatment (study group) with those in a group of patients who are matched to the study patients, for example by age, diagnosis and prior treatment, but who are not given the treatment being tested (control group). If the control group is not carefully matched, any positive results reported in the study group might reflect their better general health, less severe disease or better prior treatment.

## Randomized controlled trials

A randomized controlled trial gives the strongest evidence for the effectiveness of a therapy. In such trials, informed,

consenting patients who meet preset criteria for inclusion in the study (e.g., age, sex, a confirmed specific diagnosis, known stage of illness, known prior treatment) are randomly assigned to receive either the therapy being tested or the usual treatment, or sometimes a placebo. (A placebo is a treatment that is known to have no biological effect but that may affect outcomes in other ways. The placebo effect may be good, but the treatment being studied must do better to be considered effective.) All outcomes are measured and reported in a preset manner. Wherever possible, steps are taken to reduce the chance that prejudices and expectations of the patients or the providers will influence the results.

For some therapies (both unconventional and conventional) it is not possible to do a randomized controlled trial. In these cases, carefully designed controlled case series together with expert review and opinion will guide treatment recommendations.

## DO THE BENEFITS OUTWEIGH THE HARMS?

Once you have gathered all the information you can find on your chosen UT, it is most important to review the possible benefits and harms carefully and objectively as they apply to your situation. Seek help if necessary. Don't let a fear of conventional treatment or personal prejudices cloud your judgement.

You will probably find that the information available to you is incomplete. There is a serious shortage of good research studies on which to base decisions. Nonetheless, your knowledge of your own health situation, the pros and cons of all the treatments open to you (conventional and unconventional) and your own health preferences and values will help you reach the best decision possible.



## Talk with your health care providers

Decisions regarding the use of UTs are extremely difficult to make and very personal. Whatever you decide, it is most important that you inform both your conventional and your unconventional health care providers and share information with them regarding any UTs you decide to use. With your consent, your health care providers can share information about your care with each other.

Before starting a UT, arrange for follow-up and supervision by your doctor. If you notice any unusual changes in body functions or possible allergic reactions, report them to your doctor immediately.

## Doctor's notes