Complementary Medicine Education and Outcomes (CAMEO) Research Program

# **CAM & Cancer in Canada**

An evidence-informed resource for patients, support persons, and health care providers



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Many people living with cancer and their support persons are interested in using complementary medicine (CAM). This booklet will help you:

- Know that there may be risks as well as benefits in using CAM.
- Know where to find credible sources of information and support to help you make decisions about CAM and cancer.
- Know how to find and work with CAM practitioners.
- Know how to monitor your response to a CAM therapy.

CAMEO provides in-depth, free education courses for patients and health care providers. Visit www.cameoprogram.org

# DISCLAIMER

This booklet is based on research done by the CAMEO Program (See p.21) about CAM information and decision support needs of people living with cancer. It is not intended to replace the advice of a qualified health care provider. Make sure you understand your medical plan and how you will be supported and monitored.

Talk to your health care provider about your interest in CAM to check:

- If there are any known benefits or risks associated with CAM therapies in your situation.
- If there are any potential interactions between the CAM therapies and the cancer treatment or medications you are receiving, or another health condition you have.



#### **Complementary and Alternative Medicine (CAM)**

Complementary and alternative medicine is "a group of diverse medical and health care systems, practices, and products that are *not* presently considered to be part of conventional medicine." The term "Complementary and Alternative Medicine" is frequently referred to as "CAM". (National Center for CAM: www.nccam.nih.gov)

*Complementary* treatments are used in combination with conventional medicine. *Alternative* treatments are used *instead* of conventional medicine.

For descriptions of common CAM therapies see pages 6 – 9

#### There are risks and benefits to using CAM

While some CAM therapies can be used safely during cancer treatment and care, others cannot. It is important to know if the CAM therapy works in your situation and is safe.

- Many CAM therapies have not yet been tested in controlled research studies. As a result, the effectiveness or safety of CAM may not be known for people living with cancer.
- There are currently no CAM therapies that have been shown to cure cancer, but several have been proven to help manage symptoms and improve overall quality of life. (See pp. 6 – 9 for benefits of common CAM therapies.)
- CAM can affect conventional cancer treatments, causing unwanted results.
- Natural health products (NHPs), in particular, are not recommended during chemotherapy or radiation treatments because they may prevent your treatment from having the desired effect. For example, some NHPs may reduce the amount of chemotherapy drug in your blood and cause fewer cancer cells to be destroyed.



People living with cancer give many reasons for using CAM. These often reflect personal and cultural beliefs and values, including:

1. Regarding CAM therapies as natural and less toxic than conventional treatments,

2. Past experience using CAM.

Other reasons include concrete goals:

- 1. Easing cancer symptoms or side effects from conventional treatments
- 2. Dealing with the stress of cancer and its treatment
- 3. Restoring a sense of hope
- 4. Strengthening the body's ability to heal
- 5. Offering a sense of control over one's cancer experience

Some of these goals can also be achieved through positive lifestyle choices (See pp. 10 – 11 ).

# **Setting Your CAM Use Goals**

Consider what you hope to achieve from your use of CAM.

Your goals may be similar to those listed above, or may be based on your personal reasons. Verify if there is evidence the CAM you are considering will help you achieve the goal or goals for which you want to use it.

Consider using the "SMART" tool to clarify your goals:

- **S** *Specific.* Make each one precise. What exactly does it look like?
- **M** *Measureable.* How would you know you achieved your goal?
- **A** *Attainable.* Is the goal realistic and possible?
- **R** *Relevant.* Is this an important issue for you to focus on?
- **T** *Time-bound.* Give your goal a time frame.

## **Biologics and Natural health products**

- "Biologics" includes special diets and foods, as well as natural health products (NHPs).
- NHPs are defined as vitamins and minerals, herbal remedies, homeopathic medicines, probiotics, and other products like amino acids and essential fatty acids. Like food, these act by producing chemical changes in your body.

Look for NHPs approved by Health Canada's **Natural Health Product Directorate** for safety, quality and health claims. These NHPs have a natural product number (NPN) or homeopathy number (DIN-HM) on the product label. Other NHPs (not yet approved or bought outside the country) may be at risk for contamination from drugs, pesticides and other substances, and may be of poor quality.

• Aromatherapy is the practice of using essential oils, mostly from plants. By smelling the aroma, messages are sent to your brain. Aromatherapy may help lessen pain, ease nausea, and promote sleep.



**Mind-body practices** are techniques that use the mind to affect the body. These therapies can improve quality of life, relaxation and well being, and decrease stress or anxiety.

- Meditation uses focused attention on one's moment-to-moment experiences, letting go of day-to-day thoughts, relaxing your body and calming your mind.
- A Mindfulness-Based Stress Reduction (MBSR) program combines mindfulness meditation, yoga, stretching, and group work.
- Hypnotherapy causes a state of deep focus, where you are fully relaxed yet aware. A hypnotherapist will use suggestion to help you in different ways, such as to gain control over certain symptoms or to change some behaviours. People can also be trained in self-hypnosis for managing some symptoms.
- Guided-imagery (also called *visualization*) involves focusing your imagination on pleasant scenes, sounds, smells or other sensations to achieve a relaxed, focused state. It can be directed by yourself or by a facilitator (storyteller, healer, etc.)
- Biofeedback uses simple machines to teach you how to control certain body functions such as heart rate, blood pressure, temperature, sweating and muscle tension. It can be helpful in regaining urinary and bowel function, and enhance the effects of muscle strengthening exercises.
- Music therapy involves listening to music or using musical instruments under the guidance of a music therapist. It can help encourage emotional expression.
- Art therapy involves the expression of feelings or emotions such as fear, isolation, anger, and hope through painting, drawing, sculpting or other types of art or craft with guidance of an art therapist.

- **Manipulative and body-based practices** include spinal manipulation and massage, as well as exercise and movement therapies. Many of these practices enhance well-being, muscle tone, agility, and flexibility. Yoga, tai chi and massage can have benefits similar to mind-body therapies, such as reduced stress and anxiety.
- Tai chi incorporates meditation, breathing exercises, and slow body movements.
- Yoga incorporates meditation, breathing exercises, and a series of stretches and poses.
- Massage therapy a regulated health profession in some provinces. It involves applying pressure to muscle and connective tissue to reduce tension and improve circulation.



- **Energy therapies** focus on the energy fields that are said to flow within and around your body. They are based on a theory that changing these energy fields can affect healing and wellness.
- Acupuncture is a regulated health profession in some province. Acupuncture is believed to regulate the flow of *qi*, or vital energy, by stimulation with needles, heat, or pressure on certain points on the body. It can help relieve nausea and vomiting associated with chemotherapy and cancer-related pain.
- Reiki involves a series of hand positions held either directly on or just above the patient's body, allowing for the flow of energy through the body.

**Whole Medical Systems** are based on distinct theories about treatment and health and include multiple products and/or practices.

- Traditional Chinese medicine a regulated health profession in some provinces. It is based on strengthening and balancing the movement of vital life-giving energy, both in nature and in the body. Acupuncture is one part of traditional Chinese medicine (often abbreviated as TCM)
- Naturopathic medicine is a regulated health profession in some provinces. Naturopathic doctors (NDs) aim to address the root causes of illness and supports the body's ability to heal. FABNO NDs (Fellows of the American Board of Naturopathic Oncology) have passed examinations representing advanced experience and knowledge in cancer care.
- Traditional native/aboriginal medicine uses a holistic model of wellbeing through the integration of emotional, physical, mental, and spiritual aspects of being.

**Lifestyle choices** like a balanced diet, exercise, and quitting smoking are still the most important things you can do to improve your health, support your own healing, and improve your quality of life. There is growing evidence that lifestyle choices will improve your cancer treatment outcomes and help prevent recurrence.

The next two pages look at lifestyle choices in more detail.



#### Nutrition

The Canadian Cancer Society (CCS) outlines general guidelines on nutrition for people living with cancer, including information on ways to increase calories and protein, adjust alcohol consumption, and what to do when you just can't eat, found at the CCS website:

#### http://bit.ly/1mWFpdZ

While many cancer centres will provide nutrition guides, the British Columbia Cancer Agency has developed nutrition information for specific cancers. These guides are found on the Nutrition web page at:

## http://bit.ly/1l39uUo

- Nutrition Guide for Men with Prostate Cancer
- Nutrition Guide for Women with Breast Cancer
- *Patient Guidelines for the Prevention of Osteoporosis* for Breast Cancer, and for Prostate Cancer
- Nutrition and Lung Cancer guideline
- Ginger and relaxation techniques appear in the document *Food Choices to Help Control Nausea*

Vitamin D and sun exposure recommendations can be found at: http://bit.ly/1cvKVju



#### Exercise

The Canadian Cancer Society (CCS) outlines general exercise guidelines during cancer treatment as well as safety precautions: CCS website: http://bit.ly/1fldgTT

The Physical Activity Line provides information on how to pace yourself and recommends activities for people living with cancer: Physical Activity Line website: http://bit.ly/1gSLnVC



#### **Managing Stress**

The CCS provides instructions on how to engage in various mindbody practices, such as relaxation techniques and visualization, to manage stress:

CCS Website: http://bit.ly/MORfpy

Many cancer centers will have stress-management programs. The British Columbia Cancer Agency Psychosocial Oncology department shares information on how to engage in deep breathing, muscle relaxation, positive thinking, and problem solving:

BC Cancer Agency website: http://bit.ly/1idkVvq

Contact your regional cancer centre to speak with a social worker or a counselor for individual counseling and to obtain information on support programs that are available in your region.

A good decision balances what is known about a therapy (evidence) with your preferences, goals, and values. This booklet provides some ideas on how to pull that information together so that you will feel more confident in any choices you make.

#### What is your goal for using the CAM therapy? pg. 5

• Goals may be physical, emotional, and/or spiritual

#### Find out what is known about the CAM therapy

pg. 16

• Look for credible evidence about the therapy to determine if it would be appropriate in your situation

#### Sources of CAM information and support in Canada pg. 18

• There are multiple sources of information and support that you can draw on for finding the knowledge you need to make a decision

#### **Evaluating CAM evidence**

- Understand the strength and reliability of the **pg. 15** evidence you find.
- Sometimes you may feel there is not enough information. **pg. 22** How do you approach this situation?

What are the costs of using the therapy?	pg. 24
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Consider the financial, time, and your energy costs

#### How do you use this information to make a decision? pg. 25

A brief introduction to making decisions about using CAM



# If You Decide to Use CAM

Make sure you know how to find and work with anpg. 26appropriate CAM provider

- What are the training, credentials and experience of the CAM provider?
- Do you have the resources to travel to where it is available?

#### Working with your cancer care team

- pg. 32
- Working with your health care provider is the best way to organize your care and get the support you need

#### How will you monitor the results of using CAM? pg. 33

- Is there a health care provider in your area who can help you monitor your CAM use?
- If you experience an unexpected side effect, you can report it at: www.healthcanada.gc.ca/medeffect

#### What do we mean by evidence?

Evidence is what is known about something that has been confirmed by research. To make an evidence-informed choice about a CAM therapy you are interested in, you should ask these questions:

- Will the therapy meet your goals?
- What evidence is available about the benefits of the therapy?
- Is there evidence that the therapy benefits people with your type of cancer? (Cell or animal study results may not apply to people.)
- Is there evidence that the CAM therapy complements your conventional medical treatment plan?
- What is the risk of harm of using a therapy? Has the therapy been shown to be safe, or does it cause side effects or interact with other treatments?
- What is the recommended dose? More is not always better!
- When is the most appropriate time to use the therapy: before, during, or after cancer treatment?

# Will the therapy interact with other treatments or health conditions?

- Multiple CAM therapies can interact with each other too, creating unexpected results.
- Some natural health products (NHPs) can speed up or slow down how cancer drugs are processed in the body, causing ineffective treatments or toxic levels of the drugs

# **Credible CAM Information**

In the case of CAM therapies—and in health care generally—evidence is obtained from research studies or expert opinion to determine if a CAM therapy is effective.

Different types of studies provide different strengths of evidence.



Different types of research studies are often described using an *evidence pyramid*, like the one shown here. The different layers are referred to as the "levels of evidence". The strength of evidence from a study type increases as you approach the top of the pyramid. The pyramid shape symbolizes how many studies are done at each level.

There are many 'test-tube' studies done, but they produce the lowest strength of evidence for making treatment decisions. Conversely, a meta-analysis produces the strongest type of evidence, but far fewer of this type of study are done.

Interpreting research results can be difficult. Understanding the implications of different research types, their strength of evidence, and how they apply to your situation is a skill that takes time to learn.

Credible information comes from a trustworthy source and is unbiased. Ideally the information should be published within the last five years and is based on objective results of research studies.

# **BEWARE if:**

• The information is anonymous or does not cite any evidence



- The information is biased or one-sided
- The information is outdated
- There is a conflict of interest (e.g., a company published a study about a product they make or sell)
  - The source claims a "miracle," "secret cure," "treats all kinds of cancer," or "no side effects/risk"

Credible CAM research information can be found in databases of published CAM research.

Credible CAM research evidence is:

- Published in an academic scientific journal
- Peer-reviewed by other researchers
- Specific to people with your type and stage of cancer.
- Based on randomized clinical trials (people randomly assigned to different treatment groups) or large systematic reviews and meta -analyses that include a large population of patients. (30 is tiny, 300 is better)
- Done on humans (cell or animal study results are early stages of research and may not translate into useful results in humans)

Summaries of what is known about different CAM therapies (monographs) have also been published on credible CAM websites.

#### WEBSITES

For a list of credible, evidence-informed CAM websites see pages 34 –35.

Check to make sure the website:

- States their purpose clearly (e.g., for education, for sales and promotion). Look for sites that do not profit from your decisions.
- Is from a reliable source (e.g., university, medical facility, government, scientific society)
- Is backed up by evidence from published research articles to support the claims made
- Has been recently updated

The British Columbia Cancer Agency library website (pg 34) has excellent guidelines on *Evaluating Websites*, under *Recommended Websites*. http://bit.ly/1p2c0wE

## BOOKS

Check to make sure the book :

• Has been published in the last 5 years

**Note:** Research in books is often out of date due to the time it takes for the book to get printed

- Is written by an author(s) with good credentials (e.g., researcher connected with a university)
- Is published by a recognized scientific publisher (e.g., Mosby, Elsevier, Sage)
- Provides information that come from research on humans

#### WORD OF MOUTH

Check to make sure that what you heard comes from a trustworthy source and that there is scientific evidence to back up the information.

A wide variety of services related to CAM information and support are available at various cancer centres for patients and their families. In the following section, a description of common services offered is provided.

**Information and support** for CAM decision making will vary province by province and territory by territory. A summary of resources specific to each Canadian province and territory can be found in the resources section of the CAMEO website: **www.cameoprogram.org** 

#### **CANADIAN CANCER SOCIETY**

The Canadian Cancer Society (CCS) website provides some information on uses and claims, evidence, potential side effects, and risks of different types of CAM as well as deciding about CAM:

#### CCS website: http://bit.ly/1kzNVxF

The CCS also has a Cancer Information Service. Call them at **1-888-939-3333** (toll free nationwide) and speak with an information specialist for information on CAM therapies.

The CCS has provincial and territorial divisions. This booklet has provincial/territorial supplements with contact information for your regional CCS office in the sign-in resources section of the CAMEO website **(www.cameoprogram.org).** 

## LIBRARY AND CANCER INFORMATION CENTRES

Many cancer centres have a library or an information centre with a librarian who can provide consultation and assistance with:

- Finding sources of information about CAM
- Loans of CAM-related materials (books, CDs, videos, etc.)
- Contact information for relevant health care professionals within the cancer centre and in local community health care settings

This booklet has provincial/territorial supplements with your local contact information in the sign-in resources section of the CAMEO website **(www.cameoprogram.org)**.



# DIETICIANS

Most cancer centres have registered dietitians and/or nutritional information classes available to help patients who are receiving treatment and are having eating challenges. Find out what nutritional support you can receive in your area by looking at the support documents. This booklet has provincial/territorial supplements with your local contact information in the sign-in resources section of the CAMEO website **(www.cameoprogram.org).** 

## PHARMACISTS

Most cancer centres have a Pharmacy Department with a pharmacist who can provide information about the safe use of natural health products, **including possible interactions with conventional cancer treatments**. This booklet has provincial/territorial supplements with your local contact information in the sign-in resources section of the CAMEO website **(www.cameoprogram.org).** 



## PATIENT AND FAMILY COUNSELING, & SUPPORT SERVICES

Social workers or counselors are available at most cancer centres to provide individual, couple, and group counseling for registered patients, and their family members.

Many cancer centres also offer classes and support groups that are run by trained professionals.

Examples of mind-body therapy programs that may be available at your cancer centre are:

- Mindfulness-based stress reduction classes
- Relaxation training classes
- Support groups for specific cancers

Get more information by contacting your regional cancer centre; contact information can be found in the provincial/territorial supplements in the sign-in resources section of the CAMEO website (**www.cameoprogram.org**).

• The Canadian Cancer Society can help you find cancer-related services including emotional support programs in your area through their Community Services Locator:

# www.cancer.ca/en/support-and-services/support-services/find-services-in-your-area

• Cancer Connection is the Canadian Cancer Society's online community with online support groups and blogs to help people living with cancer, their families and friends share their experiences and build supportive relationships:

#### www.cancerconnection.ca

• Cancer Chat Canada offers professionally-run online groups that meet in a live "chat" room on the Internet, where you can connect with others facing similar challenges, found at:

#### www.cancerchatcanada.ca

# The Complementary Medicine Education and Outcomes (CAMEO) Research Program

CAMEO has been a collaborative University of British Columbia / BC Cancer Agency (BCCA) research program. The CAMEO program was developed to address the needs expressed by cancer patients in BC for complementary and alternative medicine (CAM) information and support in making decisions about CAM.



The mission of the CAMEO research program is:

"To integrate and evaluate evidence-informed CAM education and decision-support strategies within the context of everyday conventional cancer care, and facilitate the development of new CAM research."

#### **CAMEO Programs and Services**

The following resources can be found under "Resources" and "Participate in Research" on the CAMEO website,

#### www.cameoprogram.org

- CAM education programs for people with cancer and their support persons (family / friends)
- CAM education programs for health professionals
- Clinical tools/guidelines to assist health professionals in supporting informed decisions about CAM
- Self-directed decision-making tools and support services, like this booklet.



# Balancing the Benefits and Risks of Using CAM

It can be challenging to balance the evidence of whether or not a therapy works against the known risks of harm, like side effects or negative interactions with medication or health conditions. Work with your health care provider in understanding complex situations, and in developing your CAM use monitoring plan.

The following diagram may be helpful when evaluating the balance of risks and benefits. Each box is explained in greater detail in the scenarios following the diagram with their corresponding numbers.



 $\bigcirc$  = evidence to date indicates relative safety or that it works

? = evidence to date is contradictory or unclear.

S = evidence to date indicates it is not safe or that it doesn't work Based on Cohen et al.. Ann Intern Med, 2002

# **SCENARIO 1**

There is some credible evidence that CAM might work for you and is likely safe to use. If you want to try the therapy, it is important to:

- Be aware of what to watch out for, when it may not be appropriate and what situations may be problematic.
- Monitor its effects
- Involve your health care provider

#### **CONSIDER USE, AND MONITOR EFFECTS**

### Scenario 2

While you have found some credible evidence that the CAM therapy is safe to use in your situation, there is evidence it might not work or there is no evidence or conflicting evidence about its usefulness in your situation. You <u>may</u> choose to test this therapy on yourself, but remember to:

- Be clear about the possible side effects
- Partner with your healthcare provider to monitor all effects on you.

#### USE ONLY UNDER SUPERVISION OF YOUR HEALTH CARE PROVIDER

## Scenario 3

There is some credible evidence that the CAM therapy may work in your situation. Of concern, there are or may be documented safety concerns, or there is conflicting evidence about its safety in your situation. You may choose to test this therapy on yourself, but remember to:

- Be clear about the possible side effects
- Partner with your healthcare provider to monitor all effects on you.

#### USE ONLY UNDER SUPERVISION OF YOUR HEALTH CARE PROVIDER

## Scenario 4

You have found no or conflicting evidence about the effectiveness of the CAM therapy. Of concern, there is evidence it might harm you (e.g. adverse reactions or side effects) or there is no evidence or conflicting evidence about its safety in your situation.

There is nothing here that would suggest possible benefit or value in experimenting on yourself.

Talk to your health care provider about finding CAM options with better evidence that fit your CAM goals.

#### DO NOT USE IN THIS SITUATION

Do you have the resources (time, energy, money) and support (information, people, other) to commit to the CAM therapy?

#### Financial

The costs of most CAM therapies and natural health products are not covered by the Canada's national health insurance program (Medicare) or provincial drug benefits programs. As a result, CAM use can be expensive. Therefore, it is important that you carefully consider the costs involved when making your decisions about CAM, and look into what insurance coverage you may have.

Public health insurance —and coverage for CAM services—is different in each province and territory. Take a look at the support documents we created for Canadian provinces and territories with in the sign-in resources section of the CAMEO website (www.cameoprogram.org).

Some private health insurance programs may offer coverage for some CAM therapies and practitioner visits. Check your individual policies for details. When you travel, check your coverage; you may require private health insurance.

#### Other "costs"

You must carefully consider you ability to commit to using the CAM product or participating in the CAM therapy sessions. Things to consider include transportation, energy levels, fatigue, and the frequency of the treatments.

# **Approaching Your Decision**

A *good* decision is an *informed decision* that incorporates the available evidence, clinical judgment and experience from health care providers, your own values and beliefs, your goals (why you are making this decision), and input from your social network.

CAMEO has produced a patient workbook to help you pull this information together. Find it in the resources listed with this booklet on the CAMEO website, **www.cameoprogram.org**.

#### An informed decision requires:

- 1. Knowing your goals for using CAM
- 2. Knowing the benefits and risks of each choice
- 3. Knowing which benefits and risks matter most to you
- 4. Having the support and advice of reliable support persons (your network of family, friends, and health care providers).

Once you have gathered your information, considered your goals and values, and identified your support persons, you are ready to make your informed decision.

The CAMEO program has used the SCOPED process, developed by Dr. Balkora (see **www.scoped.org** for details) SCOPED stands for:

Situation, Choices, Objectives, People, Evaluation, Decision

Situation: clarifying the facts about my conditions

**Choices:** clarifying my options

**Objectives:** clarifying what my goals are

**People:** who can support me in this decision, and what are their roles and responsibilities?

Evaluation: how do my choices affect my objectives

Decisions: what is my best option? How do I move forward with this?

CAMEO has included a SCOPED worksheet with the supplements to this booklet on the CAMEO website, **www.cameoprogram.org**.

# **Taking Action**

Once you have made your decision, it is time to take action. Make a plan for implementing your choices:

- Outline what will be needed to put your choice(s) into action
- Follow up with any people whose help you will need
- How much time will you need for each of your choices?
- Think of barriers and make plans to manage them.
- Monitor your progress (see page 33)
- Notify the people who need to know about your decision

Selecting a CAM practitioner is a personal decision. It is important to consider the training of a practitioner, whether they are regulated and/or licensed, and have experience in caring for people living with cancer. It is also important to consider how comfortable you feel with a practitioner.

Some practitioners who provide CAM are **regulated** by the provincial governments through established **regulatory colleges**. These regulatory colleges set practice standards to protect the public by defining the services **regulated** practitioners can provide as well as any practice limitations.

Regulatory colleges for CAM practices exist in some provinces and territories. In BC, for example, regulatory colleges exist for:

- Traditional Chinese medicine and acupuncture
- Chiropractic medicine
- Massage therapy
- Naturopathic medicine

Take a look at the support documents we created for the Canadian provinces and territories, to see which regulatory colleges are active in your area. If you choose to work with a practitioner of a CAM therapy regulated in your province, contact the regulatory college to learn if a practitioner is entitled to practice that therapy—you can often do a practitioner search on the regulatory college website. You should also contact the regulatory college if you have concerns about a registrant's practice or conduct.

Most CAM practitioners, regulated and unregulated, are members of **professional associations and societies** (see pg. 26). You can contact these organizations if you have questions about a therapy and its use in cancer, the credentials of members, concerns about a practitioner's conduct, or about how to find a practitioner in your region.

Remember to check if a member is in good standing and to interview potential practitioners.

Integrative oncology clinics may include a combination of regulated and unregulated health professionals. Regulated health professionals can include physicians, nurses, physiotherapists, chiropractors, naturopathic doctors, massage therapists, traditional Chinese medicine doctors, and acupuncturists. The clinics may also include any number of unregulated CAM professionals such as Reiki practitioners, or qigong or yoga instructors.

The method of integration can occur in a variety of ways, and will vary from clinic to clinic. For example, regulated healthcare professionals may offer some CAM services or refer to CAM practitioners in the clinic. This provides some co-ordination of service amongst the health care providers. In other cases, the practitioners may share clinic space but may not coordinate care.

The links to credible CAM associations for identifying credible practitioners (page 28), and recommendations on working with CAM providers (pages 29–31) apply to any CAM practitioners you may be working with in an integrated clinic. Recommendations on working with CAM providers (pages 29–31) may also apply to oncology health care providers providing CAM services in integrated clinics.

Not all CAM practices are regulated by the government. But many associations and societies uphold the same strict requirements as provincial regulatory colleges. These credible associations can help you find a trustworthy CAM practitioner.

A credible association will have practice standards, codes of conduct and ethics, and disciplinary procedures. A list of associations for CAM services commonly used by cancer patients is available on in the provincial/territorial supplements to this booklet, in the sign-in resources section of the CAMEO website (www.cameoprogram.org).

Not all qualified members of associations are listed on the websites. Contact the association to see if there is a practitioner closer to your region or one that better suits your needs.

Use the tips on pages 29 to 31 when choosing and working with all your health care practitioners.

It is important to talk to your oncology health care provider(s) about any care you are receiving in an integrated clinic to ensure that the conventional cancer treatments you receive are compatible.





Finding a credible CAM practitioner that is right for you can be a challenge. The questions on the following pages may help you select a practitioner with whom you will feel comfortable. (Adapted from http://nccam.nih.gov/health/decisions/practitioner.htm)

This section assumes you know about the therapy you want to pursue and the qualifications the practitioner should have.

#### **PREPARING FOR THE FIRST VISIT**

Before you visit a CAM practitioner for the first time, you should ask some questions about their services. Some of these questions may also be addressed during your first visit. Consider:

- What is your training or other qualifications?
  - Have you taken any cancer-specific training?
- Is there a brochure or website with more about your practice or your therapy?
- Can you do a brief consultation in person or by phone? (This consultation may or may not involve a charge.)
- Do you specialize in cancer care? How frequently do you treat patients with problems similar to mine?
- How will your therapy help address my situation?
- What will be involved in the first and on-going visits?
  - Time per session?
  - Clinic hours for appointments?
  - Costs?
  - Insurance coverage?

Determine whether the office location and hours convenient for you.

Observe how comfortable you feel during these first interactions.

#### THE FIRST VISIT

The first visit is very important. Come prepared to answer questions about your health history, such as surgeries and illnesses, as well as prescriptions, vitamins, and other supplements you take.

Not only will the CAM practitioner wish to gather information from you, but you will want to ask questions too. Write down ahead of time the questions you want to ask, or take a support person with you to help you remember the questions and answers. Some people record the appointment (ask the practitioner for permission to do this in advance). Here are some questions you may want to ask:

- What benefits/risks can I expect from this therapy? Do the benefits outweigh the risks?
- What side effects can be expected?
- Are there conditions for which this therapy should <u>not</u> be used?
- Could the therapy interact with conventional treatments for cancer (e.g., chemotherapy, radiation)?
- Will the therapy interfere with daily activities?
- What is involved in the therapy plan?
  - How long will I need to undergo treatment?
  - How often will my progress or plan of treatment be assessed?
  - Will I need to buy any equipment or supplies?
- Do you have scientific articles or references about using the therapy in cancer care?

Each CAM therapy is different in terms of length of treatment and when the therapy may be most appropriate. Make sure you talk to your CAM practitioner about your needs and expectations for treatment.

#### **AFTER EACH VISIT**

It is important to reflect after each visit on how satisfied you were with the care provided. Here are some questions you may want to ask yourself after each visit:

- Was the CAM practitioner easy to talk to? Did he/she make me feel comfortable?
- Was I comfortable asking questions? Did the practitioner engage with me, and were my questions answered?
- Was she/he open to how both CAM therapy and conventional medicine might work together for my benefit?
- Did he/she get to know me and ask me about my illness?
- Did she/he seem knowledgeable about the type of cancer I have?
- Does the CAM treatment recommended seem reasonable?
- Was he/she clear about the on-going time and costs associated with therapy?



#### **ON-GOING VISITS**

Remember to check in with your CAM practitioner each visit:

- Review your progress to date
- How you have been doing since the last visit
- Where you are in the on-going treatment plan

Discuss with your CAM practitioner the reasons you are not satisfied or comfortable with treatment. If you are not satisfied or comfortable, you can look for a different practitioner or stop the therapy. However, talk with your practitioner before stopping to make sure that it is safe to simply stop treatment—it may not be advisable to stop some therapies midway through a course of treatment.

# **Coordinating Your Care**

Communicating with all your health care providers is key to ensuring the best possible health care. It is important to remember that everything you do for your health impacts your body and your health care. CAM treatments, therapies, and diet and lifestyle changes can all interact with each other, and could also interact with your cancer treatment. It is therefore important to tell all your health care providers about the treatments you are receiving.

- Take control. Don't wait for your doctor to ask about CAM. State your values and goals for using CAM.
- Make a list of all CAM therapies and treatments, including any dietary or herbal supplements you are using—or plan to use—and ask your doctor about their safety, effectiveness, and possible interactions with conventional treatment.
  - This should include CAM therapies you may be taking for other health conditions or health goals.
- Be aware that your doctor may not have information about CAM. If needed, ask for a referral to a health care provider with more information.
- If you decide to stop a therapy or see another practitioner, make sure that you share this information with any other health professionals you may have, as this will help them make decisions about your care.
- If you are using a CAM Diary (see page 33), bring it in.

• Your goal for using the therapy: how this therapy will help you and when you expect to see the effects

Once you have decided to try a CAM therapy, it is important to

monitor how your body responds to the therapy.

Aim to use just one new CAM therapy at a time. This will help you see if the therapy is working or if it has unexpected or unwanted effects.

• How much and how often you are using the therapy

• The name or brand of the therapy

• Any known side effects to watch for

Keep track over time:

Write down:

- Is it helping you achieve your goal(s)?
- Are you experiencing side effects from it?

If you experience an unexpected side effect, you can report it at:

www.healthcanada.gc.ca/medeffect



## Using a CAM Diary

Some people find keeping a diary helpful in monitoring their CAM use and in evaluating how well it works. A diary may also be a helpful tool when talking to your health professionals about current and potential CAM use.

CAMEO has created a *CAM Use Diary* template to help you keep track of your CAM use and monitor outcomes and side effects. The diary can be found in the sign-in resources on the CAMEO website, **www.cameoprogram.org** 

Memorial-Sloan Kettering Cancer Centre — iPhone app available	Web address: www.mskcc.org/mskcc/html/11570.cfm Languages: English Content: Easy-to-search database of reviews of natural health products
MD Anderson Cancer Centre	Web address: http://bit.ly/1mJoEyf Languages: English Content: Video and audio lectures on CAM and integrative medicine in cancer topics
Office of Cancer Complementary and Alternative Medicine	Web address: www.cam.cancer.gov/health_patients.html Languages: English Content: Information about current CAM research, and CAM & cancer information
CAM-Cancer	Web address: www.cam-cancer.org Languages: English Content: Monographs (summarized research) of commonly used CAM therapies
Natural Standard	Web address: www.naturalstandard.com Languages: English, some Spanish Content: Fee-based searchable database of NHPs, conditions, & CAM practices
Natural Medicines Comprehensive Database	Web address: www.naturaldatabase.com Languages: English Content: Fee-based searchable database of NHPs and conditions. Medline Plus (below) offers access to the consumer version
National Centre for Complementary & Alternative Medicine (NCCAM)	Web address: http://nccam.nih.gov/ Languages: English, Spanish Content: Information about current CAM research, and general health information related to CAM

CAM on PubMed – mobile apps available	Web address: http://nccam.nih.gov/research/camonpubmed Languages: English Content: Tool to access research abstracts database, specific to CAM research
Medline Plus	Web address: Herbs: http://1.usa.gov/1hcxeF7 Web address: CAM: http://1.usa.gov/1of16kj Languages: English, Spanish Content: Database of information about drugs, herbs, dietary supplements, etc.
Office of Dietary Supplements	Web address: http://ods.od.nih.gov Languages: English Content: Database of information about dietary supplements including herbs, vitamins and minerals, and botanical supplements
Natural Health Products Directorate (NHPD)	Web address: http://bit.ly/VTKLLx Languages: English, French Content: Information about Canadian NHP regulations, legislation and guidelines
Passeport Santé	Web address: www.passeportsante.net Languages: French Content: Current, research-based information on CAM & conventional medicine

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*OR*, contact us directly to tell us how this booklet has helped you or with suggestions to help us make this a better resource for persons living with cancer and their support persons.

We welcome your feedback. info@cameoprogram.org

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