



S•P•O•H•N•C

A PROGRAM OF SUPPORT  
FOR  
PEOPLE WITH ORAL  
AND  
HEAD AND NECK CANCER

## COMPLEMENTARY AND ALTERNATIVE MEDICINE (CAM) THERAPIES IN CANCER CARE

GEORGIA M. DECKER MS, RN, CS-ANP, AOCN, CN

### Introduction

There has been a consistent increase in the use of complementary and alternative medicine (CAM) therapies in the United States. However, the interchangeable use of the terms *complementary* and *alternative* has led to miscommunication and confusion among the public. These terms are not interchangeable. They describe the *intent* with which a therapy is used, not the therapy itself.

A therapy is “alternative” when it is used *instead of* conventional therapy. “Complementary” therapies are those used *in addition to* or *to complement* conventional therapy. The more contemporary term *integrative* means combining conventional and CAM therapies. It is very important that you inform your healthcare providers of any therapies that you are using. Legally you share the responsibility with your physician/practitioner if you have an undesirable outcome.

There is much to be learned regarding safety, efficacy and mechanism of action of these therapies. This is especially true in respect to the person receiving cancer therapy. The National Institutes of Health-National Center for Complementary and Alternative Medicine (NIH-NCCAM) was created in 1998 to “facilitate the evaluation of alternative medical treatment modalities” to determine their effectiveness. The NCCAM does not provide referrals for CAM therapies or practitioners. It does

support research and training and provides information on CAM therapies (<http://www.nccam.nih.gov>).

A CAM therapy survey conducted in 2000 showed that patients with cancer who were participating in clinical trials used: Spirituality (94%), Imagery (86%), Massage (80%), Lifestyle, diet, nutrition (60%), Relaxation (50%), Herbal/botanical (20%) and high dose vitamins (14%).

### CAM THERAPY CATEGORIES

#### Alternative Systems of Medical Care

Alternative systems of medical care stress prevention of disease and promotion of health that includes personal responsibility and self-healing. These systems are a way of being and a way of living. Examples include Traditional Chinese Medicine (TCM), Naturopathy and Homeopathy.

#### Mind-body Medicine

Understanding that the body is influenced by the mind is not new. Mind-body medicine therapies are based on the connection of the mind to the body and the potential for a person to influence healing. Examples include meditation, guided imagery/visualization, relaxation and creative art therapies

#### Bioelectromagnetic Therapies

The study of bioelectromagnetic therapies is based on electromagnetic field theory in terms of making corrections in human energy fields. There is much research yet to be done in this category. Examples include acupuncture and magnet therapy.

#### Herbal Medicine

The goal of herbal medicine is to assist the body to restore and maintain balance. Herbal remedies can be taken internally or applied to the skin. Just because herbs are *natural* they are not necessarily *safe*. *Herbs have the ability to interact with pharmaceuticals*. Herbs should be discontinued if any unpleasant side effects occur: **when in doubt, do without.**

#### Pharmacological and Biological Therapies

These therapies claim to cure everything from obesity to cancer. Scientific proof is lacking for many of these therapies. Examples include laetrile and shark cartilage.

#### Manual Healing Methods

Manual healing methods involve touch. These therapies appeal to us because human beings (in our culture) have a strong desire to touch and be touched. Examples include Reiki,

CAM continued on next page



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IN THIS ISSUE

Denial: Is it Healthy or Unhealthy?.....4  
 All I Really Needed to Know About Wellness.....5  
 A Time For Sharing.....6

COMING IN SUMMER, 2003

Lingering Effects of Head and Neck Cancer and Its Treatment  
 Bruce H. Campbell, MD, FACS

CAM continued from page 1

chiropractic, reflexology, massage, Therapeutic Touch/ healing touch (actually a misnomer since actual touch may not be involved).

Diet, Nutrition and Lifestyle Changes

Much has been written about nutrition and its effect on health and disease. Caution should be taken with very restrictive dietary programs. Controversies regarding the effects of antioxidants and/ or vitamins during certain cancer therapies continue. Examples of CAM diet therapies include macrobiotics, the Gerson Program, and Kelley-Gonzalez.

**COMMONLY USED HERBS**

Ginkgo Biloba

Ginkgo Biloba has been used for vertigo and tinnitus. This herb makes platelets “slippery” and interferes with normal blood clotting. It is believed to improve memory.

Side effects: mild stomach upset and headache, allergic skin reactions; possible risk for stroke at higher doses.

**Contraindicated** with anti-coagulant drugs, NSAIDS (nonsteroidal anti-inflammatory drugs (eg. motrin, ibuprofen) and aspirin.

St. John’s Wort

St. John’s Wort has been useful in the treatment of mild depression and Seasonal Affective Disorder (S.A.D.)

Side effects : photosensitivity, fatigue, itching, dizziness, dry mouth and anti-clotting.

**Contraindicated** with Digoxin, cyclosporine, Indinavir, antidepressants, certain anesthesia, and other drugs. May interfere with some cancer chemotherapy.

Ginseng

There are many kinds of Ginseng. This herb has been used to reduce fatigue and improve concentration. It has estrogenic properties.

Side effects: overstimulation, insomnia, gastrointestinal upset. Long term use may cause Ginseng Abuse Syndrome: hypertension, nervousness, insomnia and diarrhea.

**Contraindicated** in persons with high blood pressure and those with estrogen-influenced tumors.

Echinacea

There are several kinds of Echinacea that are believed to provide immune enhancement and improve resistance to flu-like illnesses and colds.

**Contraindicated** in persons with autoimmune illnesses or on drugs like prednisone that suppress the immune system. Should not be taken by persons allergic to the daisy (compositae) family. Should not be taken for indefinite periods of time. Can fatigue the immune system.

Kava Kava

Kava Kava has been used for nervousness, anxiety, stress and insomnia. **It should not be used for depression.**

CAM continued on page 3

CAM continued from page 2

Side effects: Allergic reactions, gastrointestinal discomfort, decreased reflexes and motor judgment, changes in eye movement, liver toxicity, and rash. Drug interactions with alcohol (increased risk of toxicity), Xanax (risk of coma) and other prescription drugs.

(Blumenthal, 1998; Tyler, 1999; PDR for Herbal Medicine, 2001).

**COMMONLY USED SUPPLEMENTS***Vitamin C (ascorbic acid)*

Food sources: citrus fruits, broccoli, peppers, potatoes, and Brussels sprouts. Antacids and smoking deplete Vitamin C in the body. Vitamin C regenerates oxidized Vitamin E. Current dosage recommendation is 500 mg. daily. Side effect (higher doses): gastrointestinal distress and/or diarrhea.

*Vitamin A*

Food sources include liver, kidney, butter, whole milk, and fortified skim milk. Some carotenes can be converted into vitamin A (provitamin A carotenes):

*Provitamin A Carotenes*

Food source: dark green leafy, and yellow orange vegetables. **Beta carotene supplementation has been associated with an increased risk for lung cancer in those who smoke.** Do not take provitamin A carotenes as supplements.

Toxicity: carotenoderma (yellow discoloration of skin) irritability, headache, fatigue, vomiting and elevated liver enzymes.

*Vitamin E*

Food sources: polyunsaturated vegetable oils, seeds, nuts, asparagus, green leafy vegetables, whole grains, and berries. Increases the effects of anticoagulants (blood thinners) including aspirin. Interferes with Vitamin K's clotting effects. Do not take more than 400 IU/day unless medically supervised. Stop vitamin E one month prior to surgical procedures due to increasing the risk of bleeding.

*Folic Acid*

Food sources: green leafy vegetables, whole grains and legumes. Side effects at doses higher than (the recommended) 400

micrograms (mcg) per day: nausea, flatulence, anorexia, and the potential to increase seizure activity in persons with seizure disorders. Estrogens, alcohol, methotrexate, barbiturates, and anticon-vulsants interfere with the absorption of folic acid.

*Selenium*

Current dosage recommendation: 200 mcg per day to reduce the risk of colon and other cancers. Higher doses can be toxic.

*Coenzyme Q 10 (CoQ10)*

The heart is most vulnerable to CoQ10 deficiencies because it is the most metabolically active organ of the body. CoQ10 levels naturally decline with age. The beneficial aspects of CoQ10 include energy production and antioxidant activity. CoQ10 may be helpful when you have been treated with cancer chemotherapy that affects the heart. Current dosage recommendation: 100 mg/day.

SAFETY TRUMPS EFFICACY" is the advice offered by Dr. David Eisenberg of Harvard. That is, a particular therapy may be effective for a particular symptom but it may not be safe for this particular person, at this particular time, under these particular circumstances. To report an adverse event involving an herb or supplement: access the web site: <http://vm.cfsan.fda.gov/~dms/aems.html>. Scroll down to "Source of Reports" and click on *Medwatch*. This information is also available by calling toll-free at 888-SAFEFOOD.

*Editor's Note: Georgia Decker's career in nursing has included roles as a staff nurse, clinical nurse specialist and nurse practitioner. More than 22 years of her 34 years in nursing have been in oncology. She is actively involved in the Oncology Nursing Society at the national and local levels. Ms. Decker's interest in CAM therapies began as a result of conversations with patients and her oncology practice has included CAM therapies for over 7 years. She is the editor of An Introduction to Complementary and Alternative Therapies, published by the Oncology Nursing Press and she is the column editor for Integrated Care in the Clinical Journal of Oncology Nursing (CJON). Ms. Decker has made numerous presentations and written publications on the subject of CAM therapies and cancer care.*

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## DENIAL: IS IT HEALTHY OR UNHEALTHY?

BY PAUL R. SACHS, PH.D.

Denial is one of those words that gets thrown around all the time when we talk about people who have cancer and their families. But what exactly do we mean when we say that someone is “in denial?” If a person is *in* denial, does that mean the person is *out* of something else? Out of touch? Out of his/her mind? Out of luck?

Denial is a normal psychological reaction to stressful events. Healthy denial helps us to cope with a difficult or stressful situation by making the situation seem less likely to happen or less intense than it might otherwise be. When we use denial, we create or hold on to a belief that changes our perception of the situation.

For example, when you get into a car or a plane, you know that a crash could occur. But, it would be impossible to keep such a terrible thought in the front of your mind all the time and still concentrate on driving. So, you deny it. You may put the thought of a crash out of mind entirely. Or you may create, in your mind, a belief or fantasy that somehow makes such a crash seem less likely to happen to you. You may believe that car crashes only happen to bad drivers, or on long trips, or on certain types of roadways. Regardless what your belief, the process of denial allows you to control anxiety about driving in order to get where you want to go.

However, in extreme cases, denial can be unhealthy and create as many problems as it tries to solve. If you cannot deny a problem, you will be overcome with anxiety and unable to manage everyday situations. In the driving example, you might be afraid to drive at all or afraid to drive under certain circumstances. On the other hand, if you deny too much you may become reckless because you feel that nothing terrible could ever happen to you.

The same thing happens in response to the diagnosis and treatment of cancer. You may develop beliefs or fantasies about cancer that allow you to minimize distress. These beliefs can be healthy or unhealthy. Some common beliefs/fantasies are as follows.

“It won’t happen to me.” One way of reducing the distress associated with cancer is by believing that somehow you are different than the people who have cancer. To some extent this is a healthy attitude. Life would

be much less enjoyable and you would be much less productive if you panicked about every ache or pain.

On the other hand, sometimes this belief can create problems. For example, a person with a family history of colon cancer may tell himself that it won’t happen to him because he is more careful with what he eats than his relatives were. When a person holds this belief, he may avoid medical examinations or self-examinations. Or he may participate in risky activities that are associated with an increased cancer risk. Look how many people still start smoking or “bake” in the sun despite evidence of cancer risk.

A person already diagnosed with cancer may choose alternative treatments. Sometimes this choice is healthy because it leads the person to investigate new treatments and find things that the physician may not know. At other times, however, the person may use this approach to avoid facing the implications of his/her condition, or avoid making plans and complying with a known treatment protocol.

“I’m in control.” Cancer can make you realize how little control you have over life. You may show denial by making a special effort to stay in control of your life. Again, this attitude can be healthy by helping you to manage home or work responsibilities and diet or exercise as well as possible. In extreme cases, you may try to maintain too much control. For example, a person may be reluctant to share information about the diagnosis with others, or may become very domineering and controlling in interactions with family members or with healthcare workers. The person may try to do more activities or treatment than is advised as a way of showing that he/she really is in control.

“I can’t do this to my family.” Families also engage in denial and may encourage the person with cancer in his/her denial. The healthy expression of this denial is seen in families who support and encourage their family member with cancer. Family support is vital to a person’s recovery and quality of life. Family denial can also be disruptive to treatment. A wife may avoid seeking medical consultation for a problem because she feels that it would be upsetting to her husband. Parents may encourage their child to blame a

physician or therapist for not helping the child make more progress rather than helping the child to see the limitations of that doctor’s healing powers.

### Helping Your Family Member To Manage Denial.

It can be frustrating to deal with a person in denial. You want to help the person and he/she seems to reject your help. You think you know what would be best for the person and he/she doesn’t seem to see the light.

Never underestimate the power of denial. Denial serves an important purpose for the person with cancer; it keeps feelings of fear and anxiety at bay and helps the person maintain hope. If you want to take away someone’s denial, you’d better be ready to give that person an awfully good substitute. No one will give up denial just by some arguments or debates, no matter how persuasive they may be. Arguments will only make the person hold more tightly to his/her denial. It will also create antagonism. Your family member will feel mistrustful or unsupported at a time when he/she needs support.

A better approach is to support denial. Paradoxically, this approach can have the effect of helping the person to let go of some of their denial. For example, instead of saying to your family member, “You’ve just got to realize this is a problem and accept it,” you might say, “You know, it’s amazing how you can keep going despite all that’s happening to you. How do you do it?” Often, when the person feels less threatened and more supported he/she will be more willing to share some of the fear that is behind the denial you see.

Another approach is to focus on setting short-term goals and solving short-term problems without challenging the person’s long term hope. If your family member feels that his/her long term beliefs are not being challenged, he/she may be more willing to consider some different approaches in the meantime. A period of several months is often a good time frame for this approach. The person may be able to discuss ways to “make it through the winter” or “make it through radiation treatment.” Thinking too far into the future may make a person anxious and encourage an unhealthy denial.

Your family member may also be willing to try something just to humor you. You might say, "Look I know you don't buy this approach, but humor me. Just try it. And think of the satisfaction you'll have in proving me wrong if it doesn't work."

#### Helping Yourself To Manage Denial

By its very nature, denial is difficult for us to notice in ourselves or in our families. Education is one way to overcome this problem. If you understand that denial can occur and how it can show itself, you will be more alert to it.

It is also important to keep open communication with people whom you trust.

Isolating yourself may seem safe but it limits you. Cancer is the kind of disease that needs to be attacked from many different directions if you are to overcome it. You can do this best when you let other people help you. That's why it's good to have family members accompany you on doctor's visits. They may hear things that you missed and together you can get the full picture.

Pacing is important if you are to make it through the marathon of cancer treatment and recovery. Pace yourself emotionally and physically. Some people like to dive in and get as much information and talk to as many people as possible in order to deal with cancer.

Other people work at a different pace and digest things that happen to them more slowly. One person is not a better cancer patient than the other. You need to find the pace that is right for you. When you do, denial will help you stay in control, turn down the volume on your noisy fears and, best of all, nourish your feelings of hope for recovery.

*Editor's Note: Paul R. Sachs, Ph.D. is a licensed psychologist in Pennsylvania. Dr. Sachs is presently Division Director of Behavioral Health Services at the Congreso de Latinos Unidos, in Philadelphia, PA. He can be reached at 215-763-8870, ext. 1405.■*

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## *All I Really Needed to Know About Wellness I learned From Cancer Survivors*

(with apologies to Robert Fulgham)  
by Morry Edwards, PhD

In a cartoon by Shanahan that appeared in the New Yorker in 1906, a doctor is relating good news to a snowman that his lumps were just coal. Of course, we would like to hear these results from tests all the time. Unfortunately, three of the most dreaded words you can hear are: "You have cancer." You can't dress it up or put a smiley face on it.

Cancer wellness may seem like an oxymoron, but working with cancer survivors has taught me as much about living and thriving as about dying. No one in his or her right mind would volunteer to contract cancer, but many people use it as a transformative experience, a chance to re-evaluate their priorities and make positive changes in their lives. I hear this from long-term survivors, as well as from people who are undergoing treatment and are touched by the outpouring of love and acknowledgement they never knew existed.

I have learned from listening to cancer survivors, and it has prompted me to develop the following 12 Important Principles of Cancer Wellness. Make this your cancer survivor's checklist"

◆ There are a number of health factors that I can control or modify in taking responsibility for my health. I will explore all areas that can improve my health.

◆ Cancer, like any crisis, represents an opportunity to change my life in a positive direction. I didn't need it and I don't have to be a good sport about it. Having some intense feeling does not mean I am not coping.

◆ While I cannot change my diagnosis, I can control my attitude and reaction, particularly in the way I handle stress and my emotions. The past is unimportant unless I make it so. The future has not happened yet. The only reality is being full alive in the present.

◆ A wide range of feelings and reactions to cancer is normal, but I need to redirect my energy from unproductive emotions such as worry, anger, fear, and resentment, into acceptance, love, and healing.

◆ A positive attitude refers more to dealing honestly with my feelings rather than maintaining a happy face. I will try not to avoid any of the feelings I experience.

◆ I do not have to be a professional cancer patient. This is not my occupation and there are many other aspects to my life. I need to set constructive and realistic goals in all areas of my life.

◆ I have the power to make a difference in my care. I need to look within myself for proper direction

◆ My doctor and I are partners. We both have things to learn. I will be comfortable

and confident with the treatment path I choose.

◆ Cancer is a social disease. Improving the quality of relationships can become a source of healing support for me. This also includes my spiritual relationships.

◆ Acceptance is not giving in. As Norman Cousins said, "Don't deny the diagnosis. Try to defy the verdict." Keep in mind that statistics apply to groups, not to a given individual. At least one person has defeated each type of cancer.

◆ There is always hope, but what I hope for may change over time. As Dr. Carl Simonton said, "In the face of uncertainty, there is nothing wrong with hope."

◆ My personal dignity and quality of life are always the best measures of success. It takes only a split second to die and all the rest of my time goes to living as best and joyfully as possible.

*Editor's Note: Morry Edwards, PhD is a licensed psychologist and certified biofeedback practitioner. He has specialized in treating people with cancer and other chronic illnesses for 25 years. Dr. Edwards is currently on staff at Neuropsychology Associates and director of Psychological Services at the West Michigan Cancer Center in Kalamazoo, MI and consultant to the Mind-Body Connections Department of the Center for Cancer Care in Goshen, IN. He is the author of Mind/Body Cancer Wellness available through [www.acornpublishing.com](http://www.acornpublishing.com).■*

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## A TIME FOR SHARING A TRANSATLANTIC EXPERIENCE

**H**ead and neck cancer is a worldwide phenomenon. We who live in the developed world are lucky. We are, in the main, well treated and have a good chance of survival. Here in Western Europe, treatment is available free of charge to all. Personally, I benefit from health insurance, but the only difference to my treatment has been a private room in hospital and individual access to the Consultant Surgeon in his consulting rooms, rather than in a clinic with his team.

Over a period of four years, I have had modified radical dissections performed on both sides of the neck, accompanied by courses of radiotherapy. I am an “occult” primary case, because the tumours discovered in the lymph glands are associated with a primary tumour. This tumour has never been found, despite extensive and uncomfortable searches.

I am lucky too to live in central London, with access to the Royal Marsden Hospital, the centre of excellence for the whole country. Those of my compatriots who live in the remoter parts of England may not get such good treatment. Has my treatment then been exactly the same as that which I would have received in a major metropolitan area of the US? From my research on the Internet, and from what I have read in the SPOHNC magazine, it would seem that in general this is the case. However, I was operated on one side of the neck, when the lumps appeared. The second operation took place a year or so later, when lumps appeared on the other side of the neck. I understand that in the US, I might have had both neck dissections performed immediately. British surgeons believe, however, that it is better to proceed gradually to retain the best possible quality of life for the patient for as long as possible.

I did not react badly to the radiotherapy, in that I never felt exhausted. I continued to have an active life and to play golf after the first operation. My problem was that my skin broke down and

became extremely sore towards the end of both treatments. I made matters worse by treating the skin with creams. It only recovered when the Radiologist told me to stop all treatment and let the skin dry out.

Like most patients I suffer from a very dry mouth. I use a gel at night and this helps me to sleep. Acupuncture has had no effect and I live with my bottle of water close to hand. Luckily, it has become very fashionable among the young to carry water and to drink it in public, so I have become a rather trendy septuagenarian.

My face is slightly swollen because the fluids cannot drain easily. Apparently, the situation is worse than the normal, because my jugular vein has been removed. This lymphoedema, is relieved by a massage technique: Manual Lymphatic Drainage. The hospital provided a month’s course, supplemented now by weekly home visits from a physiotherapist specialising in the treatment.

The Professor of Oncology at South London University has accepted me into a small group of neck cancer patients for an experimental immunology trial. We take high daily doses of aspirin and anti-oxidants and are injected with a vaccine every two months. I do not know what the treatment is achieving, but it is comforting to be examined regularly by an experienced cancer physician as a supplement to the quarterly checkups by of my consultant surgeon

The radiotherapy has affected my teeth. Some fillings have fallen out and I have lost a few teeth. There seems to be no way of recovering dental bills from my insurance company, so my dentist has become a richer man, and me a slightly poorer one. It is important to keep the mouth absolutely clean and, immediately after every meal, I use an excellent and conveniently portable water pump, called the EW0175 Nais Dentacare.

The sequels of the surgery and radiotherapy are disagreeable. My neck is

stiff and feels as if it is held in a clamp. Cramps are frequent and very disagreeable – they seem to occur most often just as I lean back on my pillow. I always feel as if I am wearing a mask and am looking at the world from behind it. However, the slight swelling and the high colour of my face apparently make me look very well. In any event, people are always complimenting me on how well I look.

All this is a small price to pay for what has developed into a very acceptable quality of life. Golf has been abandoned for lawn bowls, a more companionable and gentlemanly sport, played in England in the summer on beautiful lawns and in the winter indoors on a green carpet, always in strict white dress. Daily yoga and stretching exercises also help to keep me fit. I work at the computer and attend business meetings, and have written and published my memoirs “*Blame Cokey*”, urged on by the thought that I may not have as long here as I previously thought. My family is close and loving and I have been surprised to find just how many friends there are to help in the difficult times. I will always be grateful to one much younger friend, who came to see me early on. He asked me to reflect on any unfinished business I might have, and advised me to get on with it. This enabled me to pick myself up, wipe the tears away, and convert self-pity into more constructive activities.

*Bill Blackburn*  
St John’s Wood  
London, UK

*Editor’s Note: Bill Blackburn, an English lawyer, spent most of his career with IBM in London, Paris and Brussels. He was Secretary of the IBM UK Group and Managing Director of IBM European Office. He is Honorary President of the Franco-British Lawyers’ Society and, in 1997, was made an Officer of the Order of the British Empire and Chevalier of the Legion of Honour for his services to Franco-British relations. “Blame Cokey” is available at [www.amazon.co.uk](http://www.amazon.co.uk) or [www.leadpublishing.co.uk](http://www.leadpublishing.co.uk)*

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