



S•P•O•H•N•C

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

EAT RIGHT, THINK RIGHT, MAINTAIN A STRONG BODY:

Three Things Head and Neck Cancer Patients Can Do to Help Conquer Their Disease

JOHN O'BRIEN, MD

As a head and neck surgeon, I have been asked to write an article for the SPOHNC newsletter regarding some of my thoughts on nutrition and other factors that I feel are important in the treatment of head and neck cancer patients. Please keep in mind that everyone is different, and what works for my patients and me, may not work for others. Just as patients respond to their treatments differently, so do they respond differently to suggestions and recommendations made by their doctors.

I tell my patients that their doctors will do everything in their power to cure them of their cancer. The most important thing that they, as patients, can do is eat right, think right and maintain a healthy body. These three activities can help a patient maintain a healthy immune system, a healthy mind, and a healthy body.

Eat Right

Good nutrition helps patients tolerate their treatments, heal their bodies, and return to good health as soon as possible. We know that healthy bodies fight cancer more effectively than unhealthy bodies. Each person gets one "health" per lifetime and it is our responsibility to maintain that health in optimal condition. I don't believe in diets that completely exclude food groups such as the all carbohydrate/no fat diet or all protein/no carbohydrate diet or a no fat diet/low calorie diet. The body needs a balanced diet with adequate caloric intake to maintain normal body functions and heal itself.

Nutrition is one of the important facets in a patient's treatment regimen. Nutrition puts the building blocks into the body to aid healing. Many, if not most, head and neck cancer patients have some degree of malnutrition due to interference with the process of eating.

In order to have the opportunity to heal and recover from the treatments of the cancer, patients must EAT RIGHT.

Patients who are able to eat normally should consume a balanced diet. The cancer treatment period is not a time to lose weight even though the patient may be overweight. This is not a time to worry about cholesterol and fat ingestion. Losing weight results in an anabolic or tissue breakdown state. This diminishes the ability of the body to repair itself. Nutrition is also very important for support of the immune system. Any type of stress has an immune-suppressive action. Stress may result from poor nutrition, chemotherapy, radiation therapy, surgery, psychological issues, and depression.

Carbohydrates and protein have four calories per gram and fat contains nine calories per gram. There is more nutrition per gram of fat than from the other two elements. I believe a diet should be balanced with 40-50% of the calories from carbohydrates, 20-30% of the calories from protein and 20-30% from fat. This type of diet will help the patient before, during, and after treatment.

Patients who are not able to eat normally can obtain nutrition by two other methods. Nutrition given intravenously with an indwelling catheter in one of the major veins is called total parenteral nutrition (TPN). When patients are in poor nutritional status and are unable to take food by mouth due to tumor or treatment, TPN is a way of improving nutritional status until the time that the patient is able to resume oral or intestinal feedings. The second method of nutritional support is by intestinal feedings, either by mouth or feeding tube. Feeding tubes can be passed through the nose into the stomach or small bowel. Tubes can also be placed directly into the stomach or small bowel surgically, *via* a small incision or by using an intestinal endoscope to place the tube through the skin. Generally, tubes that are placed into the stomach can be used for bolus feedings. A can or two of a nutritional formula and water can be placed into the stomach intermittently throughout the day. This is the easier and more physiologic of the two methods. Small bowel feedings generally are given on a continuous infusion basis 24 hours a day or, at times, overnight. The continuous feedings require the patient to be attached to a pump to receive the nutrition. Once feedings are started, weight will often stabilize and begin to increase. It is of the utmost importance that all feeding tubes be flushed on a regular basis prevent blockage. If a tube becomes blocked, a slurry of Adolph's Meat Tenderizer plus water, Coca-Cola, or just water under pressure can be used to relieve the blockage.

If a feeding tube comes out, it should be replaced immediately. Patients and families can be instructed in the method of tube replacement. Tubes that have been passed through the skin of the abdominal wall must be reinserted quickly, as the opening to the stomach or the small bowel usually closes within hours. If it is not possible to reinsert the tube, the placement of a new tube may be necessary. A feeding tube acts much the same as a splinter: both are foreign in the body. When the body tries to reject a splinter, redness and pus may develop around it. This is also true of a feeding tube. I generally do not recommend dressings around the feeding tube where it

EAT RIGHT continued on next page



SUPPORT FOR PEOPLE WITH
ORAL AND HEAD AND NECK CANCER
S•P•O•H•N•C, INC.

P. O. BOX 53
LOCUST VALLEY, NY 11560-0053
Email: info@spohnc.org Web site: http://www.spohnc.org

BOARD OF DIRECTORS

Nancy E. Leupold, MS, President
James J. Sciubba, D.M.D., Ph.D., Vice President
Jean O. Cashin, Secretary
Walter E. Boehmler, Treasurer
Louis Frillmann
Karrie Zampini, CSW

MEDICAL ADVISORY BOARD

Linda K. Clarke, MS, RN, CORLN Greater Baltimore Medical Center	Herman Oliver, M.D., F.A.P.A. North Shore-LIJ Health System
David W. Eisele, MD University of California San Francisco	David G. Pfister, M.D. Memorial Sloan-Kettering Cancer Center
Keith Heller, M.D., F.A.C.S. North Shore-LIJ Health System	Jed Pollack, M.D. North Shore-LIJ Health System
Alex Keller, M.D., F.A.C.S. North Shore-LIJ Health System	James J. Sciubba, D.M.D., Ph.D. Johns Hopkins Medicine
Jesus E. Medina, MD University of Oklahoma Health Sciences	Elliot W. Strong, M.D., F.A.C.S. Memorial Sloan-Kettering Cancer Center
Eugene N. Myers, M.D., F.A.C.S. University of Pittsburgh School of Medicine	Denise M. Vey Voda, M.A., D.D.S North Shore-LIJ Health System
David Mysiorek, M.D. North Shore-LIJ Health System	David P. Wolk, M.D., F.A.C.S. North Shore-LIJ Health System

Karrie Zampini, CSW
Memorial Sloan-Kettering Cancer Center

NEWSLETTER EDITOR

Nancy E. Leupold, MS

WEBMASTER

Barry Sebastian

News From SPOHNC is a publication of
Support for People with Oral and Head and Neck Cancer, Inc.
Copyright ©2001–2002
All rights reserved.

DISCLAIMER: Support for People with Oral and Head and Neck Cancer, Inc. does not endorse any treatments or products mentioned in this newsletter. Please consult your physician before using any treatments or products.

IN THIS ISSUE

A Time For Sharing.....	4
Staying Positive When You're Feeling Negative.....	5
Clinical Trials Teleconference.....	7
Presidential Award.....	7

COMING IN NOVEMBER, 2002

Salivary Gland Tumors
David W. Eisele, M.D., F.A.C.S.

EAT RIGHT continued from page 1

penetrates the skin; however, many doctors do. Often there is a small amount of moisture or drainage around the tube. A dressing can keep the moisture against the skin causing maceration (breakdown of the skin) or irritation. If the penetration site is kept clean with several cleansings of soap and water daily, irritation will be minimized. Rarely do tube sites become infected. However, patients with poor nutrition and those with a persistent cough can have leakage and infection around the tube. If there is skin breakdown the doctor needs to know about it.

Formulae come in many types and brands. The formulae generally have a high carbohydrate/low protein content. When using bolus feedings, I recommend that patients and/or their families add a scoop of protein powder to two or three feedings per day to increase the protein content. A balanced feeding regimen should supply enough calories in the form of carbohydrates, protein, and fat to heal and rebuild tissues damaged or surgically manipulated by cancer treatment. One scoop of protein supplement has about 15-20 grams of protein. The method of adding the protein powder to the tube formula is important. I recommend that the patients put the formula into a blender, turn it on low speed, add the protein powder very slowly adding enough milk or water to make the formula thin enough to pass through the tube easily. If protein powder is placed directly into a can of formula, it will often form large lumps and will not pass through the feeding tube. Patients should receive full instructions from their doctors and nurses on the correct method of tube feeding and tube care prior to discharge from a facility. All tubes should be flushed after anything is passed through them, whether it is medication, tube feedings or vitamins. Diabetics should monitor their blood sugar carefully during tube feedings just as they do on their normal diet.

I recommend that my patients take multiple vitamins with minerals. It is rare in the United States that a person is completely vitamin deficient; however, he/she may not have the optimal levels of vitamins and minerals to help the body function properly and heal. The vitamin C level in smokers is low and this decreases wound strength and slows wound healing. Zinc is also important for wound healing and often patients with poor nutrition or those who are receiving their nutrition primarily through alcohol can have low zinc levels and wound healing problems. I suggest that patients take multiple vitamins with minerals plus supplemental vitamin C and Zinc twice a day until their nutritional status has improved. Thereafter, once a day will be sufficient. In most cases generic multiple vitamins with minerals are adequate for a patient's needs.

Patients may also have a low serum albumin. Albumin is a protein made by the liver which helps maintain fluid within the vascular system. When the albumin is low, as a result of poor intake of adequate amounts of protein, swelling can occur in the intestines thereby decreasing the ability of the body to absorb the tube feeding from the intestine. Consequently, the patient may experience diarrhea with nutrition passing through the body rather than being absorbed. Swelling can have an adverse effect on wound healing.

Patients who receive radiation therapy as part of their treatment often develop a sore throat and are unable to maintain oral nutrition. At this time it is important to institute tube feedings. Patients should begin oral feedings as soon as possible after treatment is concluded and the discomfort of the radiation therapy has decreased. Oral feedings will help to keep the throat open and functional. The patient's ability to swallow is maintained in most instances.

With the advent of concurrent radiation/chemotherapy, greater
EAT RIGHT continued on page 3

EAT RIGHT from page 2

difficulties with swallowing are being observed. The late effects of fibrosis (scarring) can prevent the throat from functioning properly resulting in patients having problems with aspiration (food going down the wind pipe). Some patients require permanent tube feedings after treatments are completed and healing has occurred.

Patients who have surgery may experience interference with the swallowing mechanism also. Modern reconstructive methods are very sophisticated and patients may be able to eat normally following surgery. However, in certain surgical procedures such as a total glossectomy or removal of most of the jaw bone, reconstructive efforts may not provide adequate tissue or function to permit swallowing. Patients in these circumstances often aspirate as they try to eat, necessitating a permanent feeding tube and/or tracheostomy.

Patients should avoid things that disagree with them or cause discomfort. They should have multiple small meals or feedings each day; monitor daily weight when first getting up; and, drink plenty of fluids like water, Gatorade, etc. Patients undergoing radiotherapy or chemotherapy should avoid acidic foods and liquids and hot and spicy foods. Maintenance of weight is important.

I also tell patients to eat as much as they can for as long as they are able during radiotherapy and/or chemotherapy. This helps keep the throat open and prevent strictures (narrowing). Following radiation treatment, many patients may find bread and similar foods difficult to swallow due to the dryness in the mouth. I ask patients to keep a diary of the foods they eat. Foods that cause problems now may not do so in the future, and foods that are difficult to swallow, may be handled more easily later. Many patients who have problems swallowing can be helped by a speech pathologist specializing in swallowing techniques. Patients should not become depressed or downhearted because they are not able to eat particular foods immediately following treatment or at any time. The effect of radiation therapy continues for several weeks after treatment has ended. Recovery from treatment is gradual and may continue for quite some time. A doctor's encouragement goes a long way under these circumstances.

During head and neck cancer treatment, I feel that the patients should completely stop smoking and drinking alcohol. There are some cancer treatment centers that feel that moderation or a small amount of alcohol is okay. It is my belief that this keeps patients who may be alcoholics in touch with one of their

demons that probably contributed to the development of their cancer. Smoking and drinking may also increase the severity of the side effects of radiation therapy. Studies have shown that patients who continue to smoke during radiation therapy have less chance of successful treatment and more severe side effects than those who do not smoke.

The membranes of the mouth, throat, and lungs are very sensitive and can be likened to the skin and its reaction to sun exposure. Some people with fair skin go out into the sun for a very brief time and burn whereas others, tan. Each person is an individual and his/her response to sun or cancer treatment is dependent upon his/her individual characteristics. Some patients are able to tolerate radiation therapy very well with only a mild reaction. Others have severe reactions. The same is true for alcohol and tobacco. Some patients have very brief, low intensity exposure to tobacco and/or alcohol and can develop oral cancers, while others can drink and/or smoke heavily on a daily basis and live to be 90 without any problems. However, patients who have had a cancer of the upper aerodigestive tract who continue to smoke have a higher incidence of second primaries (new cancers) than those patients who quit smoking. Hence, it is my recommendation to patients that they stop smoking and drinking completely. Often the first cancer, such as a small cancer of the tongue or floor of mouth or tonsil, is one that can be treated successfully. The second cancer which may appear in the throat, lung, or esophagus, may have a much worse prognosis and be less curable.

As with reactions to radiation therapy, patients' abilities to eat, swallow and tolerate foods are very different. All patients have different life histories; they also have different capabilities of function during and after cancer treatment. Some patients are able to eat hot and spicy foods right after radiation therapy is completed, whereas others may never be able to eat them. Each patient will learn by trial and error which foods he/she can tolerate. Keep a diary.

Most patients find that they can eat mashed potatoes mixed with a lot of gravy or milk. I recommend that they cook some ground meat, crumble it, and add it to the mashed potato mixture. They generally are able to swallow this mixture quite well. A patient may have a milk intolerance which is manifested by gas, cramping, and upset stomach. These patients should avoid milk products or buy lactase enzymes from the pharmacy which will help to digest milk products. None of the tube formulas have milk products in them so

this should not be a problem in most cases.

Some patients like to cook a meal, put it in a blender with some milk or water, and then use this mixture as a tube feeding. This is a perfectly viable option and if the patients are in a home setting with family, this can be done rather simply by putting food from the table into a blender with milk or water, making a smooth, thin tube formula. This is less expensive than purchasing the canned tube formulas. If this is done, canned formula can be kept available for trips and other outings.

Patients may require pain medication. Pain medications can be very constipating and this can be compounded by chronic dehydration. Therefore I recommend drinking or feeding plenty of fluids each day to avoid dehydration. The thirst sensation decreases as patients age. Patients may need to be reminded that adequate fluid intake is essential. The amount of fluid should be discussed with the doctor. If problems with constipation occur, patients should use a stool softener, a mild laxative, a suppository, or an enema.

If a patient has diarrhea, he/she should check with the doctor to be sure that this is not a serious problem such as an overgrowth of toxic bacteria. If this is not the case, Imodium, Lomotil, or something of that nature can be used to control the diarrhea. Nausea and vomiting may also occur and can be very serious. Be sure that the doctor knows about this so proper steps can be taken to alleviate the condition.

Generally, if a patient is single or living alone, he/she may tire easily, become depressed, or have other problems. In this setting, patients often will not eat properly. Home Health Care, families, friends, church groups, etc. can help to check on these patients to ensure proper nutrition on a regular basis.

Patients who take herbal supplements should speak with their doctors as some herbal supplements can be dangerous and some may conflict with other medications.

Following completion of radiation therapy, thyroid functions can gradually decrease. Consequently, thyroid function should be monitored. Patients can have a slow, insidious onset of hypothyroidism which slows down the metabolic process and can cause grave problems in the patient.

THINK RIGHT

Think right. Be positive: "I am going to overcome this cancer." This attitude helps strengthen the body, the mind and the immune system. The patient's faith and support system are important during these trying and

EAT RIGHT continued on page 6

A TIME FOR SHARING

I am a 55 year old woman and a 31/2 year survivor of throat cancer. I was diagnosed with cancer on Thanksgiving 1998 after I was rushed to the hospital for an emergency visit. After receiving this devastating news I pulled myself together and told my husband and two sons who were with me that I would beat it. My determination has never changed.

I tried to get as much information about this disease as I could to make the right decisions about what course of treatment I should take. My husband's cousin had a similar cancer 3 years prior to my diagnosis so my husband called her that night and we made an appointment with her doctor.

This head and neck surgeon examined me and answered all my questions. I was scared but I knew I had to take control. I went on the Internet looking for information and there, I discovered SPOHNC. Before I started any of my treatments I attend a local SPOHNC meeting and got all the information and support I needed to help alleviate a lot of my fears. One of my biggest fears was that I would need a temporary tracheotomy. After meeting people that had been through this and knowing how they handled it, I wasn't as frightened.

My first procedure was a biopsy on December 12, 1998. Having never been in an operating room before I was a bit nervous. But my surgeon put his arm around me and walked me into the operating room. This surgeon had been recommended to me because of his renowned surgical skills but I will never forget this act of compassion. The diagnosis was as expected: I had cancer. I was scheduled for surgery in January.

Instead of sitting around worrying, I focused on being prepared for what was ahead. I have always been a spiritual person and I did a lot of praying. I work in an elementary school library and continued to work up until the Christmas break. I made sure our Christmas holidays were very special, reassuring my family and friends I would be all right. I visited the hospital where my surgery would be performed and met with the patient advocate to make sure

one of my family members would be able to stay with me during the time that I would be unable to speak. I also met with the chaplain and asked him to visit with me during my stay.

On January 6, 1999, I underwent 10 hours of surgery, during which my epiglottitis, part of the base of my tongue and part of my larynx were removed. I was in the hospital for 11 days and received excellent care and lots of encouragement from my doctor and nurses. I healed well and with the help of my speech therapist I began talking and eating again.

Then in February, I began 6 weeks of radiation therapy. During that time, I returned to work part time. All went well un-

One thing I have learned is that your attitude and faith play a big part in the healing process.

til I completed the therapy in April and I began experiencing the side effects of treatment. This was the most difficult part of my recovery.

I have always been an active person, I love to cook, entertain, dance, walk, and play golf. Not being able to get out of my living room chair without help was very depressing. I tried to push myself, but physically I could not. I was having trouble eating and the lack of nourishment was affecting me.

The day before Mothers Day I woke up thirsty. I tried to drink a some water, but I could not swallow. My throat had closed. All that day I tried to swallow, but couldn't. That evening my husband called my surgeon who told him to bring me to the office the next day. Another act of compassion on this surgeon's part. He met us at his office on Mother's Day so that I wouldn't have to

wait in an emergency room. Unfortunately, I had to be admitted to the hospital so that he could give me the treatment that I needed.

All efforts to resume swallowing failed. Due to a build up of scar tissue caused by radiation, I needed to have a feeding tube put into my stomach. A gastroenterologist performed this procedure. This doctor was one of the kindest men I have ever met. He has been very supportive during the three years I have been using a feeding tube.

This situation has been a true test of my determination. I refuse to let this change my life. After spending ten days in the hospital regaining my strength I began feeling like myself, again. Being able to get the right nutrition made all the difference. Exercise was also important and I started going for walks with my husband everyday. The challenge of the situation was planning my feedings so that they would not interfere with the way I wanted to live. I talked to the gastroenterologist and he told me there were no restrictions on what I could do.

During the last three years, I have learned to do feedings in the car while my husband is driving or in a tent on camping trips, and I have learned to schedule my feedings to give me the most strength on the golf course so that I play well. Although I cannot "eat", I still enjoy going to restaurants with my family and friends for the enjoyment of their company. I still love to cook and entertain. Planning my feedings makes it possible for me to feel full and not hungry. Consequently, I am able to enjoy doing the things I have always loved. I have more energy now than I had before and I try to use it in a positive way. One thing I have learned is that your attitude and faith play a big part in the healing process.

With the continuing advances in medical research, perhaps someday there will be a way for me to regain my ability to swallow, but for now, I have a very good life... one for which I am very grateful. ■

*Lynn Gormley
Syosset, NY*

Coping with Cancer: Staying Positive When You're Feeling Negative

by Sandra Haber, Ph.D

Think positive! Stay hopeful! Be optimistic! If you are a cancer survivor, chances are that you've heard this advice ad nauseum. But exactly how do you stay positive when you are coping with cancer? What do you do with worry, fear, anxiety or depression? Are these feelings unhealthy? Should you push them away? How can you learn to fight back?

Many survivors wonder...If I worry about my cancer, will I be causing a recurrence? If I feel depressed, am I making myself sick? If I'm anxious about a recurrence, am I compromising my immune system? The answer to these questions is a resounding "No!"

It may surprise cancer survivors and their loved ones to learn that positive coping includes many "negative feelings." These negative feelings are normal and healthy and are an important part of the adjustment process. After all, being diagnosed and treated for cancer is a life changing trauma. Life as you knew it no longer exists. For the first time, your sense of immortality is challenged and your daily life is defined by doctors schedules and treatments. For awhile, your physician's waiting room may feel like your second home. With all of these changes, it is perfectly normal to have feelings of sadness and anxiety.

As you recover, your emotions will again change. You may wish to put this all behind you, but will probably find that forgetting is an impossible option. Like other life traumas such as a car accident, fire, tornado or robbery, there is a normal process of shock, disbelief, grief and recovery. The post treatment period includes integrating the cancer experience into your life. In other words, as a cancer survivor, you do not simply return to your old life. Rather, you will remember and use the cancer experience to move forward in a different, hopefully, improved manner. You will change and grow from this experience, difficult as it may be.

Permitting oneself to go through this psychological process is to positively cope with your cancer experience. It is important to remember that each person's path is different. Unlike standardized medical procedures that treat the physical aspects of cancer, the psychological process by which people cope is more individualized and unique.

Consider the following positive coping

choices and see which ones might be right for you.

1. There is good evidence that expressing your feelings has a positive impact on your health. Begin to give yourself permission to verbally express negative feelings of sadness, worry and grief. You may decide to talk to a close friend, to seek a cancer support group, or speak with an informal network of survivors. Recent research has indicated the overall positive impact of being part of a cancer support group. One of the most helpful aspects of a cancer support groups is the immediate sense of normalization, since having cancer is the requirement for joining this group. A cancer support group offers shared experiences, useful tips and an opportunity to freely express your thoughts and feelings, knowing that others will offer understanding and acceptance. Of course, this doesn't mean that support groups are right for everyone, but if the idea appeals to you, consider participating in a cancer support even if it is for a brief period of time.

2. Consider finding a non-verbal outlet for your feelings. Examples of non-verbal expression of feelings include music, art and journal writing. In fact, recent studies has shown that disclosing emotionally upsetting events through journal writing have resulted in clear improvements in well being and health. Journal writing simply requires 20 minutes of private time during the day to reflect on your most intimate thoughts and feelings.

3. Give the cancer experience meaning. It's helpful to use the cancer experience to "do life better" whether that means working fewer hours, being more positive with your spouse, playing with your children or simply taking time to "smell the roses." Some cancer survivors report that life is better after cancer taught them to appreciate their families, friends and experiences.

4. First person accounts of cancer experiences can help you feel more positive about your experience. Many cancer survivors have written "their stories." It is helpful to read about a survivors journey and relate to the feelings they have had. You will notice both similarities and differences between your experiences and their experiences, but typically these first person accounts are useful in decreasing feelings of isolation and aloneness. An added

benefit is that you will often discover helpful coping tips and outside resources.

5. Pay attention to creating a healthy lifestyle that includes diet, exercise and sleep. Try to minimize any unnecessary stress and let daily hassles remain small hassles.

6. Consider physical activity as a natural medicine. Aside from being helpful for overall physical health and well-being, physical activity works wonders as a natural antidepressant to lift your spirits. Find something you like to do like water aerobics, dancing, yoga or simply walking. Remember that exercise is often more fun when you have company. Look for an exercise companion and make an ongoing exercise date!

7. Get the most out of your medical team. Many survivors so appreciate their physicians that they "don't want to bother them" with seemingly trivial questions. However, most physicians are trained to respond to questions and rightly or wrongly assume that a problem does not exist unless a question is raised. Feel free to share your concerns with your medical team. They are well trained in issues involving sexuality and sexual desire, anxiety, fatigue and depression. It often helps to make a list of questions to bring with you to your next office visit. If a particular item seems complicated or you suspect it will require some consideration or research, consider faxing the question to the office a day or two before your scheduled visit.

In conclusion, know that most cancer survivors experience the full range of emotional feelings. Most survivors have had some bad days. Most survivors have some sleepless nights. You are not alone. Experiencing some negative feelings is all part of the process of successfully coping with cancer. Learn to express your feelings and seek out supportive relationships. Communicate any problems or concerns to your medical team. Most of all take pride in your cancer survivorship. ■

Editor's Note: Sandra Haber PhD. is a psychologist practicing in New York City and an adjunct associate clinical professor of psychology at the Derner Institute of Adelphi University. Dr. Haber teaches continuing education workshops for health care professionals on the psychological treatment of cancer. She is an author, co-author and editor of several books and has appeared on numerous TV talk shows. Dr. Haber may be contacted at www.DrHaber.com.

EAT RIGHT continued from page 3

stressful times. Patients should be encouraged to talk about their fears. This is not a sign of weakness. Faith can play a very important role in "thinking right." Depression and loneliness suppress the immune system. If patients feel depressed they should discuss this with their doctor, family, friends, or clergy. It is normal to be depressed when diagnosed with cancer and told that you need serious treatment, or that the cancer may not be cured. Antidepressant medication can be used to help get patients over the rough spots. I urge patients to get assistance. Let others help.

MAINTAIN A STRONG BODY

During cancer treatments and after surgery, the body is expending most of its energy healing. During these times I recommend that patients do some light walking, but nothing strenuous. I tell patients to listen to their bodies: when the body is tired, rest, and when it is rested, go. Try to do some physical activity on a daily basis, with gradually increasing duration and effort. Patients need to maintain their physical strength to avoid problems such as pneumonia, falls, lack of equilibrium, etc. As patients get back into a healthy state following cancer treatment, they should exercise their bodies to improve and maintain vigor and good health.

Patients who have had irradiation therapy and have their own teeth must be sure that their dentists are familiar with the effects of radiation treatment on teeth, soft tissue, salivary glands and bone. To help keep the teeth healthy and to prevent tooth decay, topically applied fluoride gel treatments are necessary. Care by an experienced dentist must be exercised if dental restorations or tooth extractions are needed. Antibiotics to prevent infection may be required if oral surgery procedures are to be done. Hyperbaric oxygen therapy may also be indicated to promote healing and to help eliminate infection in the jawbones in some cases prior to planned surgery. Patients with dentures should be checked for proper fit to prevent ulceration and possible loss of the jawbone resulting from osteoradiation necrosis and infection.

The mouth should be kept very clean. I recommend using a solution of salt and baking soda. (1/2 teaspoon of table salt and 1/2 teaspoon of baking soda mixed in one quart of water). This solution can be stored in the refrigerator. Rinsing with a mouthful of this mixture after each meal and at bedtime and as needed will help to keep the mouth fresh and clean. Patients should avoid mouthwashes

containing alcohol and toothpastes flavored with mint or cinnamon since these may be irritating to the membranes in the mouth. Finally, frequent maintenance visits to your dentist's office are necessary in order to deal with any dental or periodontal problem in their early stages so that any potential radiation-related complication can be avoided.

Following radiation therapy, the mouth should be watched for the signs and symptoms of thrush or Candidiasis, a yeast infection. Signs include white spots that are slightly raised associated with the symptoms of a sore, red throat and pain with swallowing. Thrush is often treated with Mycostatin, Mycelex oral troches, or Diflucan. If the patient has been irradiated there is a higher incidence of thrush and treatment may be prolonged to achieve control. There are a few cases of resistant candidiasis that recur or won't go away even with adequate treatment.

I tell patients to be patient with their bodies. It takes a long time to heal. Healing is never as rapid as we would like. The patient is helped with good nutrition and vitamin supplements to achieve the normal, optimal healing rate. With poor nutrition, lack of vitamin C and zinc and other nutritional elements, the healing process is slowed. Irradiated tissues heal more slowly and are more prone to bleeding and infection.

For patients suffering from xerostomia (dry mouth), I suggest that they get cool mist humidifiers and place them in rooms where they spend a lot of time. Heating and cooling dry the air. These situations make the dryness of mouth and throat after radiation therapy even worse. Moisture is best placed back into the air with cool mist humidifiers, not steam vaporizers. Many patients find this works very nicely; others do not find much improvement. The ubiquitous water bottle that patients carry is a good method of moistening the mouth. There are products on the market today such as artificial saliva that may help. There are also medications that stimulate saliva secretion which have been used by many patients with a salutary effect. We have recently heard of acupuncture being used to stimulate saliva production. Our recommendation to patients is: try different things. If it works, do it; if it doesn't work or if it causes any problems or pain, stop.

Remember, everyone is different, everyone reacts to treatment differently. Even though there is a natural tendency to compare notes with other patients who have had similar problems, there are many factors that doctors consider when making treatment plans

and recommendations for therapy. Factors include: the size and location of the tumor, cell type, adjacent structures and nerves that might be affected, and whether the cancer is localized or has metastasized. Patients who are in a poor nutritional state, have had organ transplants with immune suppression, are on steroids, or have autoimmune diseases may have significant problems with control of their cancer.

IN GENERAL

In treating cancer, we stress cancer control, function, and the aesthetic result (appearance). We are interested in having the patient function properly and look good after surgery; however, if a less than adequate surgical procedure is done in an effort to preserve function or appearance, there is a higher chance of recurrence. The recurrence destroys function and appearance to a greater extent than an appropriate surgical procedure, with a diminished chance of survival.

Quality of life issues are being studied thoroughly. Not only do we want to save lives but we want the lives to be worth living. Rehabilitation goals of having teeth that can be used to chew, a tongue that moves, voice rehabilitation after laryngectomy or vocal cord paralysis, the ability to swallow and not be dependent on tube feedings, and the need for a permanent tracheostomy are very important to the patient and to the doctors. Doctors are interested in caring for the whole patient.

Think right. Learn about yourself and others by becoming a member of a support group like SPOHNC. Encourage others to join. At support meetings you will learn that you are not the only one with problems and that different patients have learned to cope with these problems in various ways. Some will work for you, some won't. You won't know about these other possible solutions to your problems unless you avail yourself of the opportunity to attend support group activities and share experiences. You will hear many heartwarming stories at support group meetings as well as some that may be disturbing, but you will realize that you are not alone with your problems. Support groups can provide you with information, support and encouragement. ■

Editor's Note: John O'Brien, MD is Attending Surgeon at Baylor University Medical Center, Dallas, Texas and Attending Surgeon, Sammons Cancer Center, Dallas, Texas. Dr. O'Brien has been in private practice specializing in head and neck surgery for the past 27 years. He presently serves as treasurer of the American Head and Neck Society.

FREE TELECONFERENCE

**HOSTED BY
CANCER CARE, INC.
AND
SPOHNC, INC.**

Cancer Care and SPOHNC will once again co-host a free teleconference for people with oral and head and neck cancer patients, their families and friends and health care professionals involved in their care. The topic of this teleconference workshop will be "Clinical Trials for Oral and Head and Neck Cancer.

Clinical trials are research studies that test new treatments to help people with cancer. These trials seek to answer specific scientific questions to find better ways to prevent, detect, and treat diseases and to improve care for people with diseases. Clinical trials may test many types of treatment such as new drugs, new approaches to surgery or radiation therapy, new combinations of treatments, or new methods such as gene therapy.

Please join us for a most informative teleconference workshop on Wednesday, October 30, 2002 at 1:00 P.M. (EST). This free teleconference workshop will address facts and myths about clinical trials, the types of clinical trials available for oral and head and neck cancer, the FDA drug approval process and the importance of chemotherapeutic drugs and novel therapies presently being investigated.

TO REGISTER PLEASE CALL
1-800-813-4673

**Nancy Leupold Awarded Presidential Citation
by the American Head and Neck Society**



On Saturday, May 11, 2002 in Boca Raton, Florida, SPOHNC president and founder Nancy Leupold was awarded the Presidential Citation of the American Head and Neck Society at the opening session of its annual meeting. Keith S. Heller, M.D., president of the Society, and a member of the advisory council of SPOHNC, presented the award. In his introductory remarks, Dr. Heller stated that Ms. Leupold "has created a national organization dedicated to the needs of head and neck cancer patients and their families. Her advocacy efforts have increased both public awareness and research support. Her accomplishments prove that one individual with vision and determination can improve the lives of many."

The Citation was presented before an audience of several hundred head and neck surgeons from the United States and around the world. Ms. Leupold was the only lay person to receive this prestigious award this year. She is not a stranger to the American Head and Neck Society. For many years she has encouraged the Society to support the work of SPOHNC and to help in its efforts to establish new chapters across the country. She has also attended the quadrennial International Head and Neck Conference sponsored by the Society. Many leaders of the Society have worked with SPOHNC as members of its Advisory Council and as supporters of new chapters across the country.

In her comments to the Society at the award ceremony, Ms. Leupold stated that she accepted the award on behalf of all oral and head and neck cancer patients and the SPOHNC organization. She thanked the Society for recognizing the accomplishments of SPOHNC and emphasized the need for the two organizations to continue to work together in the care of head and neck patients.

The American Head and Neck Society, with almost 1000 members, is the largest professional organization in this country representing head and neck surgeons and other medical specialists devoted to the care of head and neck cancer patients. In addition to sponsoring its annual scientific meeting, the Society donates over \$100,000 annually for medical research related to head and neck cancer. It also supervises the training of head and neck surgeons in 13 different training fellowships in the United States.

**MEMBERSHIP APPLICATION
SUPPORT FOR PEOPLE WITH ORAL AND HEAD AND NECK CANCER, INC.**

Membership includes subscription to nine issues of *News From SPOHNC*

Name _____ Phone (____) _____

Address _____

Address _____

City _____ State _____ Zip _____

Please Check: Survivor ___ Friend ___ Health Professional (Specialty) _____

ANNUAL MEMBERSHIP

- \$20.00 individual \$30.00 family
- \$30.00 Foreign (US Currency)

CONTRIBUTIONS

- Booster, \$10+ Donor, \$50+ Sponsor, \$100+
- Patron, \$500+ Benefactor, \$1,000+ Founder, \$5,000+
- Leaders Circle, \$10,000+

404-284-8045
561-395-7100
617-731-1703
732-356-1939
972-373-9599
214-820-2608
303-798-3041
703-698-2813
281-259-4110
800-377-0928
631-444-7678
310-825-5707
212-288-5718
708-327-2147
305-596-6566
305-243-4952
973-586-3522
856-722-5574
402-559-2814
714-456-8609
412-647-9127
760-751-2109
202-784-3755

PHONE

Harmon Grotzky
DarcI Lipson-McNally, LCSW
Valerie Goldstein
Bernadette Maszczak
Dan Stack
Travis Maxwell
Virgil Holdridge
Pam Black
William A. Phelan
Nancy Leupold
Fran Tanzella
Sabah Qasim
Barney Phair
Thom De Vries, LSW
Blanche Bronwit
Penny Fisher, RN
Howard Sakolsky
Micki Naimoli
Robert Bayer, RN
Donna Baker
Marilyn Hudak, RN
Valerie D. Targia
Joanne Assarsson

COORDINATOR/FACILITATOR

SPOHNC-ATLANTA, GA
SPOHNC-BOCA RATON, FL
SPOHNC-BOSTON, MA
SPOHNC-BRIDGewater, NJ
SPOHNC-DALLAS, TX
SPOHNC-DALLAS, TX-Baylor/Sammons
SPOHNC-DENVER, CO
SPOHNC-FAIRFAX, VA-Heads
SPOHNC-HOUSTON, TX
SPOHNC-LONG ISLAND, NY
SPOHNC-LONG ISLAND, NY-East (now forming)
SPOHNC-LOS ANGELES, CA-UCLA
SPOHNC-MANHATTAN, NY
SPOHNC-MAYWOOD, IL-Loyola (now forming)
SPOHNC-MIAMI, FL
SPOHNC-MIAMI, FL-Mort Silverblatt Head and Neck
SPOHNC-MORRISTOWN, NJ
SPOHNC-NJ-PA
SPOHNC-OMAHA, NE-UNMC
SPOHNC-ORANGE, CA-UCI
SPOHNC-PITTSBURGH, PA
SPOHNC-SAN DIEGO, CA
SPOHNC-WASHINGTON, DC-LCC

SPONSOR

(SPOHNC)
SUPPORT FOR PEOPLE WITH ORAL AND HEAD AND NECK CANCER



**SUPPORT FOR PEOPLE WITH
ORAL AND HEAD AND NECK CANCER**
S•P•O•H•N•C, Inc.
P. O. Box 53
LOCUST VALLEY, NY 11560-0053

NON-PROFIT
ORGANIZATION
U.S. POSTAGE
PAID
LOCUST VALLEY, NY
PERMIT NO. 28

“Clinical Trials for
Oral and Head and Neck Cancer”
(A FREE TELECONFERENCE)

Wednesday, October 30, 2002
1:00 P.M. EST

Presenters
Ms. Margo Michaels & Barbara Conley, MD
National Cancer Institute
Ms. Patty Delaney
Federal Drug Administration
David Pfister, MD
Memorial Sloan Kettering Cancer Center

CALL 1-800-813-4673 to register
Hosted by Cancer Care, Inc. and SPOHNC, Inc.

*Made possible by an educational grant from
Bristol-Myers Squibb Oncology and ImClone Systems*