



S•P•O•H•N•C

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

CHEMOTHERAPY-RELATED FATIGUE, MEMORY AND THINKING CHANGES

STEWART B. FLEISHMAN MD

Patients are living longer with cancer as a result of earlier detection and more effective, often more rigorous treatments. Although chemotherapy itself seems to “seep” into the brain at low levels, the effect of cancer or its treatment may affect the general constitution and the brain by a variety of proteins released by the cancer cells, known as “cytokines” (cyto=cell; kine=protein). Although there is much more to be learned about these substances, and their effect on the body, they are thought to be involved with weight loss, general energy maintenance and optimal brain function.

Breast cancer patients have been the most vocal about the effects of cancer and chemotherapy on their general well-being, energy level and memory. Since breast cancer is intimately connected to estrogen, its contribution to this constellation of effects has been hard to separate from the effects of the cancer or chemotherapy.

What moved our understanding forward in a quantum leap was a cover story in *New York Magazine*, which was an excerpt from the book, *Menopause & the Mind* by Claire Wurga. In this book, Dr. Wurga identified a cluster of symptoms that signaled the start of peri-menopause even before one’s periods become irregular. Claire’s eloquent description resonated familiar to cancer clinicians who had heard the same things from their patients, allowing concepts to gel just a bit. However, these symptoms were not just from women, and not just from breast cancer patients!

What was common in these descriptions were descriptions of “memory problems” of a very specific nature. Particularly concerned were two skills: difficulty retaining newly learned information and doing multiple tasks at once (multitasking). Patients described being at a “loss for words”, mis-naming people or objects, misplacing things (keys, eyeglasses, car in parking lot) or feeling “foggy.” Although called trouble “with my memory,” it really wasn’t difficulty

recalling information, or even recognizing it, but actually registering new information. For accuracy, that’s a *cognitive* problem, rather than a *memory* problem. At the expense of an impersonal comparison to the computer world, the problem is not with the “open file” function but with the “save as” function. Not a remembering problem, but an attention or storage difficulty in saving information for future use. Hence the difficulty with “multi-tasking” as well, needing to register many things at once.

Overall fatigue also compounds the situation. Hearing that one will be tired during cancer treatment no more accurately describes the situation than describing a major flood as a moisture problem! Extreme fatigue has no better descriptor. Yet most people tell us that they didn’t take the warning to heart as they just didn’t think it would affect them. We have been sensitized to the existence of fatigue and its connection to anemia (low red blood cell count; red blood cells carry oxygen for energy) with the discovery of erythropoietin replacement used during chemotherapy. With its use, we learned that fatigue and cognitive (thinking-memory) impairment tend to occur together. At this point in time, we can’t be certain if it is the cancer itself, the chemotherapy or both that cause these changes.

Chemotherapy for head & neck cancers generally involves three drugs, used singly or in combination: paclitaxel, (Taxol®), docetaxel (Taxotere®), carboplatin (Paraplatin®) cis-platin (Platinol®) or 5-fluorouracil or gemcitabine (Gemzar®). It is well known that the taxanes and platinum affect nerves in extremities (hands, feet) giving a pins & needles feeling or numbness and the platinum family can reduce hearing by affecting the nerves in the ears. These drugs when they “seep” into the brain can very rarely cause serious neurological side effects so it is logical to suspect them in less serious side effects such as energy and learning new information. Gemcitabine as a relatively newer chemotherapy agent, is beginning to be thought of as “fatiguing” as more and more patients and oncologists gain experience with it.

What We Can Do

Practical

Common sense interventions seem to be of help to minimize fatigue and optimize cognitive functioning: general aerobic exercise and muscle building exercise, good nutrition with adequate supplies of proteins, unsaturated fats, antioxidants and complex carbohydrates, “memory exercises” as used after traumatic brain injury (such as car accidents), and social support seem to be of help, as well. These logical interventions, with a minimal chance of side effects, have not been put through clinical trials for each type of cancer alone or together, but they do make sense.

General aerobic exercise is cardioprotective and helps to make sure the brain is well supplied with blood. It is well known that endorphins are released into the system, causing what has been called a “runner’s high”. Endorphins can help lift mood and relieve pain. Muscle building exercise also helps sustain energy. The nutritional prescription is important in that proteins, lipids and antioxidants help

See CHEMOTHERAPY 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

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, LaD
Karrie Zampini, LCSW

MEDICAL ADVISORY BOARD

David M. Brizel, M.D.

Duke University Medical Center
Linda K. Clarke, MS, RN, CORLN
Greater Baltimore Medical Center

David W. Eisele, M.D.

University of California San Francisco

Keith Heller, M.D., F.A.C.S.

North Shore-LIJ Health System

Alex Keller, M.D., F.A.C.S.

North Shore-LIJ Health System

Jesus E. Medina, MD

University of Oklahoma Health Sciences

Eugene N. Myers, M.D., F.A.C.S.

University of Pittsburgh School of Medicine

David Myssiorek, M.D.

North Shore-LIJ Health System

Herman Oliver, M.D., F.A.P.A.

North Shore-LIJ Health System

David G. Pfister, M.D.

Memorial Sloan-Kettering Cancer Center

Jed Pollack, M.D.

North Shore-LIJ Health System

James J. Sciubba, D.M.D., Ph.D.

Johns Hopkins Medicine

Elliot W. Strong, M.D., F.A.C.S., Emeritus

Memorial Sloan-Kettering Cancer Center

Denise M. Vey Voda, M.A., D.D.S

North Shore-LIJ Health System

Everett E. Vokes, M.D.

University of Chicago Medical Center

David P. Wolk, M.D., F.A.C.S.

North Shore-LIJ Health System

Karrie Zampini, LCSW

Fighting Chance, Sag Harbor, NY

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 ©2004–2005

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 Gift for the Holiday.....	3
A Time for Sharing.....	4
A Registry for Head and Neck Cancer Patients.....	5
A Message for Caregivers.....	6
Excitement over "Eat Well - Stay Nourished".....	7

COMING IN FEBRUARY 2006

Targeted Therapy in Cancer Treatment
Debra Wujcik, RN, MSN, AOCN

CHEMOTHERAPY continued from page 1

heal tissues; and complex carbohydrates provide energy slowly and steadily rather than in a burst, followed by a "let down."

Brain exercises may be helpful to optimize functioning. It is thought that learning a new task may be the most beneficial (a new language, how to type, how to use a computer, etc) in that it helps the brain practice the skills that seem to suffer the most after cancer treatment. Memory "tricks" as used in brain injury programs help organize one's life to avoid slip-ups and help compensate for them: post-it notes, color-coding and double checking (e-mails, bank deposits, check writing). Routinizing certain tasks: putting your keys down in the same spot when you get home, writing down the location of your parking spot at the mall all help to minimize the scramble to find something, and help to reduce distress. Planning an alternative route when you travel someplace new, either by car or public transportation (have a *Plan B*) also helps reduce lateness and feeling foolish or keeping people waiting. Letting your friends or family in on your strategy reduces isolation and makes it a bit less burdensome.

Medications

To the prudent layperson, taking a second medication to counteract the effects of the first may seem illogical. But such a strategy becomes advisable and even sensible when the original medication is life-saving. This is how we make choices in the world of modern cancer treatment.

A variety of medicines have been tried to counteract fatigue and cognitive impairment through a mechanism that's called "off-label use." Once a medication is approved by the Food & Drug Administration for use for a certain condition, it becomes the prerogative of the prescribing physician or nurse practitioner to advise its use in other illnesses for which it was not formally tested. However, when there is reason to believe that it can help an individual (single case reports or letters in professional journals, tips from colleagues, seeing it done by a more experienced clinician or "expert"), a physician may prescribe the drug "off-label." With the balance of "benefit" vs. "risk", a decision can be made to try a medication in a way outside of its formally accepted use. Unfortunately, the insurance company or prescription plan reimbursement for a medication used in such an off-label use may not be possible.

For fatigue, off-label use of antidepressants and stimulant drugs has been used successfully. Recent and remote experience with these medications reminds us to be circumspect about their use. People in their 50s and older remember the "diet doctor scams" in the 1950s and 1960s when stimulant medications (amphetamines like dextroamphetamine, Dexedrine) were prescribed to reduce appetite and weight, but resulted in dependence and withdrawal when stopped. More recently, stimulants have been FDA approved for "attention deficit disorder with hyperactivity" (ADD) in children and young adults whose motor capabilities are out of synch with their speedy brains, and consequently these individuals have trouble concentrating and sitting still. Countless educators have spoken out against the widespread use of stimulants like methylphenidate (Ritalin) when class size is too large to provide individualized instruction. But for individuals with ADD, these drugs are quite effective.

Application of these uses to cancer is a prime example of off-label use. Commonly, patients who have moderate to severe pain with cancer are treated with opioid (narcotic) analgesics, which can

CHEMOTHERAPY continued on page 3

CHEMOTHERAPY continued from page 2
be effective but quite sedating. Use of stimulants to counteract the sedating aspect of the pain medications has helped countless patients with cancer receive adequate treatment for pain. As long as someone is free of a pre-existing substance abuse problem that predated their cancer, or a heart rhythm that would not tolerate a faster heart rate (by about 10 beats per minute), this is a safe, tolerable and creative way to use one drug to balance out the effects of the other.

With such a model, we have made the next jump to using stimulants for fatigue and cognitive changes from cancer, chemotherapy or hormonal changes building on the success of the stimulant-opioid combination. It is thought that stimulants help counteract the fatigue, and overcome the cognitive impairment via a yet to be understood mechanism. Newer antidepressant medications, which have been used as adjuncts in ADD have been similarly used in an off-label way to counteract the fatigue

and cognitive impairment, even though the individual does not have serious depression.

In an effort to advance the science and move beyond the off-label use, groups of cancer centers have pooled their efforts and available patients to look at this issue more critically and successfully. At 21 centers in the USA, a study was created and approved by each center's institutional review board (IRB) to test an FDA approved stimulant, dexamethylphenidate (Focalin®) for fatigue and cognitive impairment. It differs from methylphenidate (Ritalin ®) in that it stays active for most of the day without having to take an afternoon dose that may interfere with nighttime sleep.

In addition, newer strategies are aiming directly at reducing the cytokines (proteins released by cancer cells) responsible for fatigue and cognitive impairment, rather than compensate for, or cover-over, the symptom itself. Such medications will be put through

clinical trials to prove their safety and effectiveness.

Next Steps

Fatigue & “chemobrain” are significant sequelae of cancer and its treatment, These symptoms need to be recognized and addressed. Studies that enroll different groups of patients will help confirm that these impairments exist, and how they can be controlled. For now, just knowing that fatigue and cognitive impairment exist has been a relief to many cancer survivors. Patients and families living with these unexpected side effects are more and more vocalizing their distress, and looking for a way to live better lives. It is hoped that further research into the area can help make that possible.

Editor's Note: Stewart B. Fleishman, MD is Director of Cancer Supportive Services at the Continuum Cancer Centers of New York: Beth Israel & St. Luke's-Roosevelt.

A GIFT FOR THE HOLIDAYS

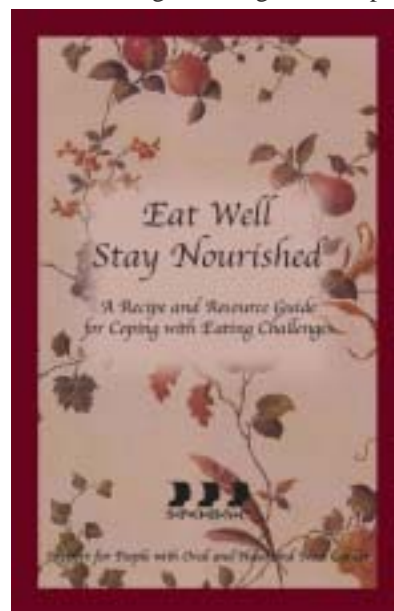
Throughout the last decade, SPOHNC's newsletter published recipes, suggestions, and “tips” written by cancer survivors to help those experiencing eating challenges occurring after treatments for oral and head and neck cancers. While difficulties with eating may vary from person to person, the common thread for oral and head and neck cancer survivors is that most confront some changes in eating habits either permanently or temporarily. Consequently, survivors are compelled to seek strategies and solutions to meet these changing needs.

The idea for a new resource cookbook evolved because SPOHNC members wanted useful information in an easy to follow format. This cookbook offers recipes and suggestions to meet the varying challenges of pureeing foods, preparing soft mechanical foods, adding spices to foods, selecting high and low caloric foods, and low fat/high fat foods. Nutritional information follows each recipe allowing the reader to determine which recipes are appropriate and nourishing.

The experiences of cancer survivors change throughout each phase of recovery and survivorship. The reader will be the

judge of which foods and recipes are best when to use them. Discovering and developing a “new normal” in eating requires patience, flexibility, and hard work.

SPOHNC's new publication, “Eat Well – Stay Nourished, A Recipe and Resource Guide for Eating Challenges” is a perfect



holiday gift for survivors and caregivers.

Holiday time is the ideal time to share this new resource with others enabling them to create opportunities for new, satisfying and joyful culinary experiences. This full color, hard cover cookbook with colorful dividers and a black spiral binding with the title in white will be easy to find on a bookshelf.

The book contains twenty four special pages including articles on the “Challenge of Eating” and “Nutritional Aspects” followed by three testimonials by survivors in which they relate how they met the challenge of eating. Just prior to the beginning of the recipes, there are several pages of “Tips From the Pros”, a section in which many survivors have contributed their personal experiences in meeting challenges that they faced.

The recipes, all of which include nutritional information, were contributed by survivors, caregivers, friends, family, and healthcare professionals. This section of 158 pages includes more than 270 recipes that are divided into the following categories: appetizers and beverages; soups; vegetables, main dishes, desserts, and “other things.” This book concludes with resources for other

HOLIDAY continued on page 7

A TIME FOR SHARING *It's About Attitude.*

Cancer can be beaten; If you catch it in time; If you are given the right medical care from professionals with the highest skills; And if you adopt the right attitudes.

My wife and I had just started a two day drive to Wyoming where we planned on riding horses for 14 days, when a casual rub of my neck altered our world. I felt an internal lump at the side of my neck that I had not noticed before. A very small alarm bell went off and I called my family doctor from the car and made an appointment to see him upon my return.

Attitude #1 – Heed your body. You're the owner, pay attention to what it's trying to tell you.

Over the next two weeks the lump grew. There was no discomfort of any kind, but the growth was steady. The alarm bell got louder. I think that the body knows when something is wrong, no matter how subtle the symptoms are. I think part of that was my past history with skin cancer, including a melanoma on my chest that had been dug out with a backhoe, as evidenced by the scar that was left.

My doctor's appointment was the day after our return from the highlands of Wyoming. I walked into his office with a rolling gait, courtesy of a broad-backed horse named Buttons, and a stomach full of butterflies the size of crop dusters. My doctor felt my neck once, left the examining room to call an Ears, Nose, Throat (ENT) specialist, and got me in that afternoon. His sense of urgency set off my alarm bells to a full peal.

The next 3 weeks were a flurry of activity and dropped balls. We live in a small community in western Nevada, and the doctors, while good with the normal day-to-day health challenges, were not necessarily up to speed on the latest protocols for suspected cancer. And I, for my part, did not ask enough questions or do enough research – which in the age of Google is inexcusable.

Attitude #2 – Take charge of your own information gathering. Many doctors may have some outdated information because they don't have time to do extensive research for every possible ailment.

Several needle biopsies by the local ENT

came back "inconclusive." The response, I found out later, should have been more needle biopsies, but the ENT recommended surgery to pull out whatever was in there and send it to the lab. That sounded like the kind of aggressive approach that I felt was appropriate. Both of us were wrong. Prior to surgery a series of CT scans were done in a futile attempt to locate the primary cancer source, and look for any additional abnormalities or suspected tumors. The scans were all clear. The outpatient surgery was done, and three lymph nodes were sent off to the lab for testing. A week later, at 5:00 on a Tuesday afternoon, the doctor calls and wants to see me right away. I already knew what the lab results were by the tone of his voice, but we had to find out the details of the monster they found.

Squamous Cell Carcinoma. The recommendation of the ENT was a radical neck dissection, followed by chemo and/or radiation. In the intervening 7 days, from the surgery to this office visit, I had finally gotten into research mode and had been buried deep into the bowels of the internet, mining information and accepted treatment protocols. I told the ENT that I was going to get a second opinion from outside of the area, and I did not want to go through the surgery door just yet.

Attitude #3 – Always get a second opinion. The more brains applied to your problem, the better the chance of you making the right decision.

The Vanderbilt University Medical Center in Nashville, Tennessee was where I went to get that all important second opinion. I was assigned to a team of doctors: an ENT, a medical oncologist and a radiation oncologist.

My first visit was a preview of what was to come from these good people. The examining room was filled to overflowing with my wife, myself, the A-Team, plus various nurses and interns. I never felt so cared for – or probed – in my life. I had prepared a list of questions and concerns and I started rattling them off. Every question, every concern, was answered in detail, and non-solicited information was also offered in an effort to make sure that I was fully informed of all possible treatments, side effects, duration of treatments, survival rates and everything else under the sun that could possibly occur to me.

Attitude #4 – Ask questions, and then more questions. Knowledge is power. That power allows you to participate in your own cure.

A PET scan was done in another attempt at locating the primary cancer. Again, nothing was found. My medical team recommended that surgical biopsies be performed in the throat in an attempt to locate the source of the cancer. This seemed logical and certainly followed the accepted protocol that I had discovered in my research. This time I was correct in agreeing to another surgical procedure. My ENT removed tissue from 6 separate sites. I awoke with a King Kong sore throat and a strong feeling that they had not found anything, which was confirmed two days later by the Vanderbilt lab. They called this condition, occult primary, which occurs in about 5% of head and neck cancers. The diagnosis of occult primary precluded a radical neck dissection, since there was nothing to remove, but the prospect of chemo and radiation now loomed darkly on the horizon.

Because of the kind of cancer that had been detected, we knew that squamous cell carcinoma did not start in the lymph nodes, so the source had to be someplace else, most likely in the throat and neck area. We also knew that the source was not detectable via CT scan, PET scan or surgical biopsy. This meant that the source was small. The next step, the doctors explained to me, was to start radiation and chemo as soon as my throat healed. This would be a form of carpet bombing; the radiation would concentrate on the whole throat and neck area and the chemo would be for the rest of the body. I asked more questions and got very straight forward answers. I was going to have considerable pain in my throat and mouth, and be very sick by the time they finished with me. But I would start recovering within a month after the treatments ended. To me it was an issue of short term pain for long term gain. I never doubted that I was going to be cured. I never doubted that my medical team did not have my best interest at heart, and I never doubted that I had come to the right place. I was eager to proceed.

Attitude #5 – Positive, positive, positive. Never doubt that you are going to get better.

The plan of attack was laid out; 26

radiation treatments, Monday through Friday, and chemo every Monday. A fiberglass mesh mask was formed to my face and head to hold me in place during the radiation. My neck and throat were mapped out to try to save as many saliva glands and taste buds as possible, and I was introduced to the Trinitron Trilogy, a massive linear accelerator. This machine was so new and advanced that Vanderbilt had the only one operational in the United States at the time. The chemo would consist of Carboplatin and Paclitaxel. It was not anticipated that I would lose my hair, but it would get thinner.

So a routine started. Up at 6:00 AM every weekday morning for a drive of 30 minutes to the clinic. On Mondays I would first have 3 hours of chemo then I would walk to another part of the hospital and get my half hour of radiation. The rest of the week I did just radiation in the morning. What was at first dramatic, became routine, and routine melted into mundane. We humans are very adaptable to most any situation and this was no exception.

I made up my mind that I was going to maintain my sense of humor, as that was about the only thing that I would have control over for the next several months. I was always poking fun at my friends, family and most often myself, and I saw no reason to change. Luckily the staff sought out humor wherever they could find it, so we were the perfect match. A smile, a joke, a cheery good morning, always helped fend off the grimness of the treatments, the pain, and the shadow of fear that was always hovering close at hand. My fast recovery time I choose to put at the feet of my attitude and humor

Attitude #6 – Use humor to adapt to a bad situation. What have you got to lose?

While I had cancer, my family suffered from it. Never forget that as hard as the disease is on you, it is harder on your friends and loved ones because they are burdened with helplessness. As much as they might wish and pray to do so, they can't make you better. They

can't cure you. But they are the people, besides the medical types, that will get you through. Give them as much love, care and respect as you possibly can.

Attitude #7 – Focus on other people. It helps take your mind off of your own dilemma, and eases their burden.

Finally. Everyone is going to deal with cancer differently. Everyone approaches this disease from the perspective of their own experiences, so my formulas may not quite meet all needs. Use the attitudes that resonate, and add recovery attitudes that work for you. Get well and stay well. And.....

Attitude #8 – Never quit. Never, never give up.

Dave McNeill
Minden, NV

ImClone Systems Launches First-of-Its-Kind Registry for Head and Neck Cancer Patients

DENVER—(BUSINESS WIRE)—Oct. 17, 2005—ImClone Systems Incorporated (NASDAQ: IMCL) today announced the launch of a first-of-its-kind, independent national registry of patients with head and neck cancer known as LORHAN (Longitudinal Oncology Registry of Head And Neck carcinoma) at the 2005 American Society of Therapeutic Radiology and Oncology (ASTRO) Annual Meeting in Denver.

LORHAN will gather together detailed information, including treatment and supportive care choices as well as recurrence and survival outcomes, into a national database via a confidential Web-based system. The registry will then allow physicians participating in the registry to compare the treatment outcomes of their patients to a national database. LORHAN will also determine whether the results of treatment-changing clinical studies are being incorporated effectively into daily practice, and compare treatment practices in community and academic settings. An estimated 26,400 patients will be eligible to enter the system each year, of which approximately 1,000 are expected to be enrolled.

The American Board of Internal Medicine (ABIM) has approved use of LORHAN for medical oncologists wishing to

satisfy a part of their re-certification related to practice performance. ABIM Certification is designed to assure the public that a medical specialist possesses the knowledge, experience, and skills requisite to the provision of high quality patient care.

"This registry is unique in that it is the first time that the overall management of head and neck cancer will be tracked across academic centers and community settings," said Eric K. Rowinsky, M.D., Senior Vice President and Chief Medical Officer of ImClone Systems. "Patient and physician confidentiality and the independence of this program are critical to the registry's success. Therefore, all patients will be referenced by an identification number only, no physician-to-physician data comparisons will be made and LORHAN will not be tied to any specific product."

"Advances in the treatment of head and neck carcinoma have come principally from randomized studies, but the degree to which these trials have changed clinical practice is largely unknown," said K. Kian Ang, M.D., Ph.D., Professor, Radiation Oncology, University of Texas M.D. Anderson Cancer Center, and Chairman of the LORHAN Advisory Board. "Detailed registries such as LORHAN can provide data on how patients are being treated and on the outcome of this

treatment, both in practice and in clinical trials. Ultimately, we expect that information like this will help improve consistency of patient treatment and outcomes."

"Disease-directed registries have been of significant benefit to patients in the more common tumor types such as breast and lung cancer, so LORHAN is a welcome addition to those of us in the head and neck community," said Dan Stack of Support for People with Oral and Head and Neck Cancer (SPOHNC), a patient-directed, self-help organization dedicated to raising awareness and meeting the needs of oral and head and neck cancer patients. "Treatment options in head and neck cancer are limited, but as new, more effective drugs and treatment methods are introduced, this registry will help ensure that physicians are educated about them."

LORHAN is guided by a prestigious advisory board chaired by Dr. Ang that includes: Walter Curran, M.D., Thomas Jefferson University Hospital, Paul Harari, M.D., University of Wisconsin, Madison, Barbara Murphy, M.D., Vanderbilt-Ingram Cancer Center, Stuart Wong, M.D., Medical College of Wisconsin, and Amy Chen, M.D., Emory University. The program is being supported by ImClone Systems and implemented by MedNet Solutions, Inc. of Minnetonka, Minnesota.

HO-HO-HO—UH, OH.

A MESSAGE FOR CAREGIVERS by MARYANN SCHACHT, LCSW, BCD

The holidays approach again. When illness is a houseguest, it may seem hard to feel festive and be “of good cheer.” But you and the person you care for can find new and more meaningful ways to enjoy this holiday season.

Many caregivers attempt to carry on as if the elephant of illness was not squatting in the living room. You pretend nothing has changed, but the big elephant keeps on trumpeting. You wake up exhausted and fall asleep dissatisfied. The person you’re caring for might not feel like celebrating this year.

Often caregivers and receivers adopt a stoic stance. Friends come by, pat you on the back, and admire the loving personas on display. Their attitudes reinforce the role-playing, so you stifle feelings and attempt to carry on. This is nonproductive behavior. You short-change yourself when you smile and chat about the weather. Covering up reality drains energy. Sharing can be restorative.

Ask for Help

It isn’t unusual (particularly this time of year) to find yourself face-to-face with the specter of envy.

“How come other folks have it so easy? How can they talk about fashions while I’m dealing with feeding tubes?” The kid in you cries out, “I want to go to the party.” You can do it.

Don’t be afraid to ask for help. Everyone feels better when they’re allowed to be useful. Give your family and friends the chance to help. Accept the gifts of caring. Relax that stiff upper lip. Consider this an ADGE (another darn growing experience.)

Give Yourself a Break

If the person you care for wants to stay home when you want to go out, allow that choice graciously. You can give yourself permission to take care of yourself and make arrangements to leave him or her in competent hands. It is ok not to be the caregiver every minute and every hour of the day. A family member, neighbor, or other volunteer could enjoy the chance to watch an adventure film or play a game of cards. Shifts in routine can provide great relief. It is always important to take

breaks, especially during the holidays. You will come back refreshed after enjoying the goodies, the punch, and, above all, the conversation.

When you force yourself to stay home, you have to deal with the deprivation. If you aren’t clear about leaving, you have to confront guilt. When you’re stuck in indecision, feelings of helplessness multiply. “Ought” and “Should” are extremely powerful. Too many people let overbearing super-egos govern their actions. Think it through, talk it over together, and take care of both of you. You are both entitled to time away from each other. Much as you love each other, you do have your own life story.

The Gift of Honesty

It takes courage to be a caregiver and bravery to keep a relationship honest. When you acknowledge your feelings and choose either to act or not to act on them, you get to live in the moment. You take charge.

Trying to prove your competence too easily slips into becoming directive and demanding. Talk to your partner. Reach for the bond that exists between you. Let each other know you are in this together. You regain your power to choose every time you acknowledge reality.

You might decide to have your own private party. Focus on making it a beautiful party. Create a special bond through memory. Remember that nurturing means listening to what a patient wants, not insisting on what you want him or her to want.

A New Etiquette

The invitations pile up and the person you care for may want to go to some special events. Don’t let fears or uncertainty hold him back. Help her to make peace with the fact that it’s fine not to eat what everyone else piles on their plates. What people choose to eat doesn’t matter as much as the pleasure of their company. True friends will see him for who he really is and accept external changes. The patient is the same inside as she was before the illness. Cancer does not define anyone! Patients are who they are. The more comfortable you both become with that reality, the more others can grow to understand it. Worrying about what people are saying or

thinking about you puts unnecessary stones in your path. Kick those rocks away. Remember that whatever anyone else thinks is their problem, not yours

There’s More to Love than Food

The idea that conversation is richer when it happens at the table starts in childhood. So many holiday traditions revolve around food. A “good” hostess offers her guests canapés and a drink of some kind. A “good” guest says, “Thank you, this is delicious,” even when the hot chili explodes his taste buds. It is only natural that a “good” caregiver wants to use food as a way to say, “I love you.” When the patient doesn’t respond to that, your pushing food becomes an irritant rather than an expression of loving concern. Hard as it feels to accept, patients know what they need. He or she may not be able to eat the food you spend hours preparing. When he can’t swallow it, let him be. Let go. Let it be. It doesn’t spell failure if that wonderful chocolate shake enriched with an egg doesn’t taste good to her.

Remind yourself that it isn’t about the eating or drinking. It is about caring. People advise caregivers to plan small amounts of variegated colorful foods. A green bean, beet, and corn combination may have eye appeal, but the color scheme is irrelevant if someone can’t swallow it. Try arranging three small bowls of applesauce or custard on a pretty plate and color each one differently (green, red, and yellow.) Put a chocolate kiss on top of mashed potatoes. Pour a liquid meal into your prettiest goblet. The thought says, “You matter to me.” Whatever you can do to lighten up the situation will benefit both of you.

Explore the Other Senses

When the patient’s sense of smell remains strong, you might try filling a small container with cinnamon sticks or cloves. Talk about the holiday memories these smells trigger.

If smelling is problematic, decorate a tray or table with silk or velvet. Top it with autumn leaves or fir branches. Vary the textures you use to make the setting special. Touch is an often under-used sense.

What would the holidays be without
CAREGIVERS continued on page 7

CAREGIVERS continued from page 7
music? Play some of your favorite songs and see how everyone's spirits lift.

Whenever you act from that caring place, it will show. Your patient will receive it at some deep level even when you don't hear the words "thank you."

Trust Yourself

Feelings and fears can become chronic when you avoid recognizing them. Trying to make a feeling disappear only gives it more power. Observe it, and it will change. Emotions and feelings go with being alive. Cherish them.

It seems as if everyone has advice to give you. They applaud the Mother Teresa in you

and ignore the Gauguin. Everyone must deal with both parts. You can want to run away and still hang in there. You can be sad without wailing. You can be insecure and still go about your business. You can be frightened and still marvel at the thunderstorm around you.

In his book, *The Four Things That Matter Most*, Dr. Ira Byock gives a simple list. "I forgive you." "Please forgive me." "Thank you." "I love you." Put these thoughts at the top of every to-do list you make during this busy season.

The job requirements of a caregiver are to listen, to keep on loving, and to let go. The loveliest thing you can do is to be a companion on a life journey. You cannot be in charge of anyone except

you. If you think it through honestly, whatever way you decide to handle the holiday situation will be the right way for you.

From this caregiver to all of you: Happy holidays. Give yourself the gift of enjoying each possible moment and celebrating your love.

Editor's Note: Maryann Schacht, MSW, has written A Caregiver's Challenge: Living, Loving, Letting Go for everyone who must provide care for a seriously ill loved one. Schacht draws on her personal experience and professional expertise to address how illness affects relationships as much as individuals. She transforms her own experience caring for her terminally ill husband into a survival guide for all caregivers.

For more information visit Ms. Schacht's website at www.caregivers-challenge.net.

HOLIDAY continued from page 5

cookbooks, web sites and "Tools of the Trade."

It is important to remember that each survivor is as unique as his or her experiences. Consequently, a recipe that is suitable for one person may not necessarily be appropriate for another. Only by trial and error will the survivor know what is best and what will meet his/her nutritional needs.

Hopefully, this recipe and resource book will provide nourishing and practical guidance tailored to accommodate changes in eating capacity.

From all of us at SPOHNC, Best Wishes for a Healthy and Peaceful Holiday Season and for all your victories yet to come.

*Karrie Zampini Robinson, LCSW
Fighting Chance, Sag Harbor, NY*

**Excitement Over
"Eat Well-Stay Nourished"**

Finally, a wonderful resource for our patients who are nutritionally challenged. This attractive and informative cookbook can be the mainstay for any patient undergoing treatment for head and neck cancer. "Eat Well-Stay Nourished" goes beyond smoothies and scrambled eggs.

The staff in our radiation department was impressed with the book and felt the need for each head and neck patient to have their own copy. Our department decided to buy the first 100 copies. Our plan is to give a copy to each patient after they are simulated for their radiation treatments. We also plan to share a copy with the in-patient nutritionist, our speech-swallowing pathologist, and our Cancer Resource Center.

Our plan for now is to just share this book with head and neck patients. Our long range goal is to attempt funding in order to be able to share this book with any patient with swallowing problems or patients who need to pack on a few pounds.

*Mary Ellyn Witt, RN
Radiation Oncology
University of Chicago Hospital*

*A gift has been received
IN HONOR OF
Trish Appelhans
by
Pam Reichert
Linda A Judson, Monique Price*

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

- \$25.00 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+

Call 1-800-377-0928

to become a member and make a contribution by credit card or order online at www.spoync.org

480-512-8040
 480-838-5194
 310-825-5707
 714-456-5235
 760-751-2109
 415-353-7982
 303-798-3041
 202-444-3755
 561-637-7216
 561-737-7733
 352-65-0680
 786-696-6951
 305-243-4952
 561-737-3699
 404-851-5585
 404-778-2369
 773-834-2470
 708-327-2061
 317-872-6674
 410-955-1176
 617-731-1703
 313-916-7578
 586-228-2309
 3814-251-6569
 704-355-7283
 402-559-4420
 973-886-3522
 Micki Naimoli
 Sherry Laniado, MSW, LCSW
 Anita Bryan
 Fran Tanzella, RN
 Jacquie Mojica
 Nancy Leupold
 Mark Tenzer
 Vicki Heinke, LISW
 Barbara Darcy, RN
 Marilyn Hudak, RN
 Dan Stack
 Jack Mitchell
 Pat Johnson
 Vikki Bravo
 Corrie Cook, LCSW
 Rachael Kammer, MS, CCC-SLP

480-512-8040
 480-838-5194
 310-825-5707
 714-456-5235
 760-751-2109
 415-353-7982
 303-798-3041
 202-444-3755
 561-637-7216
 561-737-7733
 352-65-0680
 786-696-6951
 305-243-4952
 561-737-3699
 404-851-5585
 404-778-2369
 773-834-2470
 708-327-2061
 317-872-6674
 410-955-1176
 617-731-1703
 313-916-7578
 586-228-2309
 3814-251-6569
 704-355-7283
 402-559-4420
 973-886-3522
 Susan Stensland
 Meg Turner
 Howard Sakolsky
 Carol Murphy, LCSW
 Suzanne Frantz, RN, CNOR
 Amy Orwig, MSW
 Valerie Goldstein
 Kim Webster
 John Groves
 Marilyn Myles
 Robyn Egan
 Arlene Kehir, RN
 John Sandidge
 Carmine Puleo
 Penny Fisher, MS, RN, CORLN
 Annie Garcia-Montes, LCSW
 Gail Adorno
 Lynn Edinoff, LCSW
 Darci McNally, LCSW
 Joanne Assarsson, MSW, LICSW
 Virgil Holdridge
 Michele Francis, LCSW
 Valerie D. Targia
 Jennifer Higgins, MSW
 Sabah Gasim, LCSW
 Bette Denlinger, MA, RN
 Kent Winchester, MS, CCC, SLP

ARIZONA-PHOENIX
 ARIZONA-SCOTTSDALE
 CALIFORNIA-LOS ANGELES-UCLA
 CALIFORNIA-ORANGE-UCI
 CALIFORNIA-SAN DIEGO
 CALIFORNIA-SAN FRANCISCO-UCSF
 COLORADO-DENVER
 DC-WASHINGTON-LCC
 FLORIDA-BOCA RATON
 FLORIDA-BOYNTON BEACH
 FLORIDA-GAINESVILLE
 FLORIDA-MIAMI
 FLORIDA-MIAMI-Mort Silverblatt Head and Neck
 ILLINOIS-CHICAGO
 ILLINOIS-MAYWOOD
 INDIANA-INDIANAPOLIS
 MARYLAND-BALTIMORE-JHMI
 MASSACHUSETTS-BOSTON
 MICHIGAN-DETROIT-HFHS
 MISSOURI-ST LOUIS (new)
 NORTH CAROLINA-CHARLOTTE
 NEBRASKA-OMAHA
 NEW JERSEY-MORRISTOWN
 NEW JERSEY-PENNSYLVANIA
 NEW JERSEY-TOMS RIVER
 NEW MEXICO-ALBUQUERQUE
 NEW YORK-LONG ISLAND EAST
 NEW YORK-MANHATTAN
 NEW YORK-SYOSSET
 NEW YORK-WESTCHESTER
 OHIO-COLUMBUS
 PENNSYLVANIA-HARRISBURG
 PENNSYLVANIA-PITTSBURGH-UPMC
 TEXAS-DALLAS
 TEXAS-DALLAS
 TEXAS-HOUSTON/TOMBALL
 VIRGINIA-CHARLOTTESVILLE
 VIRGINIA-FAIRFAX-Heads Up!
 WISCONSIN-MADISON

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

SPOHNC CHAPTER

COORDINATOR/FACILITATOR

PHONE



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

**Survivors, Family, Friends,
 Health care Professionals**

Save the Date and join us for

**SPOHNC's
 15th ANNIVERSARY
 A Conference and
 Celebration
 August 19-20 2006
 Marriott Laguardia Hotel
 NY**