

ESOPHAGEAL DILATATION IN THE HEAD AND NECK CANCER PATIENT

WILLIAM J. RAVICH, M.D.

How do you know that someone has a swallowing problem?

The most obvious sign that a patient has a swallowing problem is the sense of food or liquid sticking on the way down from the mouth to the stomach. Another common symptom is coughing during or immediately after swallowing. Patients may regurgitate food or liquid back to the throat or mouth after swallowing or after the meal is over. Other symptoms may include food, liquid or saliva coming out of the mouth because of difficulty sealing the lips or through the nose due to failure to close off the passage between the pharynx and nose during swallowing. Occasionally patients do not recognize that they are having swallowing problems. They may present with bouts of bronchitis or pneumonia due to recurrent episodes of saliva, liquid or food entering their airway.

What is an esophageal stricture?

In its most general sense, an esophageal stricture refers to any fixed condition within the esophagus wall that narrows the channel. A stricture may be due to inflammation and scarring. Examples of inflammatory strictures are strictures due to reflux esophagitis, radiation strictures, or strictures that occur after surgical resection (anastomotic strictures). Some patients have very short band-like strictures that are referred to as webs or rings. Malignant tumors also may produce strictures (malignant strictures).

What are the typical symptoms caused by a stricture?

Typically, strictures cause difficulty swallowing solid food.

The patient feels the food stick in the neck or chest. Often, the food will pass after a few seconds delay. However, the food may stay for longer periods. Patients may find that they have to drink fluids to “wash” the food down. They may find that they need to get the food to come back up by gagging in order to clear the channel and end the episode. Of interest, patients are not always accurate about the location of the stricture. It is fairly common for a patient with a stricture in the lower part of the esophagus, to feel the food stick in the throat.

How do you know that a stricture is present?

The diagnosis can be suspected from the description of symptoms (see above), but tests are required to definitely make the diagnosis. Barium studies are usually the best way to diagnose the presence of stricture, its location, and its features in preparation for treatment. Although the diagnosis can also be made by endoscopic examination, endoscopy can sometimes miss a stricture that only mildly narrows the channel. Nonetheless, endoscopy is still important in determining the cause, and in the treatment of, esophageal strictures and to rule out recurrent or a second primary cancer.

How do you treat a stricture?

A stricture creates symptoms by narrowing the swallowing channel. Therefore, treatment aims at increasing the size of the channel. The approach depends on the nature of the stricture. Strictures due to benign conditions are usually dilated (stretched) most often at the time of an endoscopy. There are a number of different types of dilators that may be used for this purpose. Some are a series of flexible plastic or rubber tubes of increasing size that can be passed into the mouth and through the pharynx (throat) and esophagus. Others are balloons on thin catheters that can be passed through an endoscope. When the balloon is placed within the stricture, it can be inflated, thus expanding the stricture. The choice of dilator depends on the specific type and appearance of the stricture, and on the preference and experience of the physician performing the procedure.

Does dilatation need to be repeated and if so, how often?

How long the effects of dilatation will last will vary according to the nature and cause of the stricture. Benign strictures, in the absence of ongoing inflammation, may respond to a single dilation. When inflammation is present, the response may be short in duration and frequent dilatation may likely to be necessary. Malignant strictures may respond poorly to dilatation and dilatation may be performed primarily to assist with the evaluation in preparation for other forms of treatment.

DILATATION continued on page 2



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
Maria DeMarco Begley, Esq.
Karrie Zampini, LCSW

MEDICAL ADVISORY BOARD

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

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 ©2006-2007

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

Maximizing Rehabilitative Efforts for Dysphagia.....	4
Through the Eyes of a Caregiver.....	5
A Time For Sharing.....	8
Local Chapters of SPOHNC.....	10

COMING IN MAY 2007

“Medicare Coverage of Dental Care Following
Radiation/Chemotherapy Treatment”
Sally Hart, JD, with Jamie Wyman

DILATATION continued from page 1

What other forms of treatment do you mean?

If removing the tumor surgically is likely to cure the condition, this would be the treatment of choice. When curative surgery is not an option, stent placement (insertion of a rigid tube that remains within the stricture to keep it open), laser therapy, radiation, chemotherapy or palliative surgery (surgery intended to improve symptoms rather than cure the tumor) may be useful either individually or in some combination.

If inflammation diminishes the effectiveness of dilation, does treating the inflammation improve that dilation’s effectiveness?

Absolutely. Decreasing the inflammation improves the response in two ways. The channel size in an inflammatory stricture is a result of both swelling from active inflammation and scarring from fibrosis that represents the body’s response to inflammation. Therefore if the inflammation resolves, the swelling decreases fairly quickly and the rate of scarring is likely to gradually decrease. Because the fibrotic response to inflammation decreases only slowly, the benefit in terms of the frequency of repeat dilations may not be fully realized for a year or more.

Can you give some examples of how inflammation can be treated?

The most common cause of an inflammatory stricture is one produced by gastroesophageal reflux disease (often referred to as GERD). While dilation will help symptoms, they are likely to recur and require treatment unless the reflux can be effectively treated. The availability of medications that decrease the production of stomach acid has dramatically improved the effectiveness of dilation for reflux-induced strictures. Another type of inflammatory stricture can be produced by certain medications, usually given in pill form that can cause inflammation if they stick in the esophagus for a prolonged period. Examples include any tetracycline type antibiotic, iron, potassium, non-steroidal anti-inflammatory drugs (NSAIDs) including aspirin, and alendronate (Fosamax). The treatment of drug-induced esophagitis is to stop taking the drug or, when possible, to take it in liquid or crushed form with a good deal of water and when sitting up so that it is less likely to stick. Strictures may also result from infections involving the lining of the esophagus produced by viruses or yeast. These infections are particularly likely in patients with weakened immune systems, as occurs in patients who are receiving chemotherapy.

How many times can a stricture be dilated?

There is no absolute limit to the number of dilatations that can be performed on a single patient. However dilation does involve a small risk, especially of perforation, so it is desirable to do whatever can be done to decrease the number of dilatations required. This is why treating the inflammation is important (see above).

When do you know that it is time to be dilated again?

In general, dilatation is repeated when symptoms of food

DILATION continued on page 3

DILATATION continued from page 2

sticking recur. When symptoms do recur, the first step is to consider whether the event resulted from some change in behavior, such as eating tough solids, eating too quickly, or not paying as much attention as usual to cutting and chewing. Under these circumstances, the appropriate action is to be more careful. However if symptoms keep recurring without an obvious reason and under circumstances in which food had been going down without difficulty, it is time to arrange for a repeat dilatation. In the meantime, it might be advisable to be particularly careful and perhaps exclude foods that are beginning to cause trouble.

Is there any diet for patients with esophageal strictures?

Obviously, it is desirable to avoid severe episodes of food sticking, often referred to as food impaction. During food impaction, the food remains in the esophagus for prolonged periods of time during which time the food may prevent even liquids or saliva from passing. This is not only uncomfortable, but may require emergency endoscopy to extract the food. Avoiding tough and difficult to chew solids may be helpful. Cutting food into very small pieces and putting small amounts in the mouth at a time should help. Carefully chewing solid foods is most important. Although difficulty swallowing in a patient with a stricture most often occurs with harder and difficult to chew foods, some patients have particular problems with foods that are soft, such as bread and pasta. This is because these particular foods, although soft, often go down as large balls that may swell when mixed with saliva and water.

What about avoiding acid foods or foods that increase acid production or reflux severity, should they be avoided?

The most important aspect of the medical treatment of reflux-induced strictures is to decrease the amount of acid produced by the stomach. Although dietary and life-style changes are still used in reflux therapy and are appropriate for patients with reflux-induced strictures, they are not as critical as they once were. More importantly, these dietary and life-style modifications will play little or no role in patients with other causes of strictures.

Shouldn't dilating a stricture make reflux worse?

Strictures are not particularly effective barriers against reflux until they become so tight that they must be treated anyway. In practice, you dilate the stricture as required by symptoms and treat the reflux with medications directed at gastric acid secretion.

Is there anything special about dealing with esophageal strictures and their treatment in patients who have head and neck cancer?

Yes and no! In most ways the concepts described above hold true for all esophageal strictures. However, there are some aspects of strictures in patients with cancer of the head and neck that distinguish them from strictures that occur in other patients. First, because radiation is used so often for the treatment of head and neck cancers, radiation strictures are common. Radiation strictures tend to be composed of particular fibrotic tissue that is often more resistant to stretching. For this reason, dilatation often must be done in stages (stretching the stricture a little bit at a time) and quite often the ultimate extent of dilatation (the diameter to which the stricture is stretched) may need to be smaller because of concerns that being too aggressive may lead to an unacceptable high of perforation. The extent to which the physician is willing to dilate is often a matter of feel, the sense of resistance to dilatation noted by the physician at the time of the procedure. Second, because of the effect of tumor involvement, surgically related injury, and radiation on the strength of the throat muscles that are involved in swallowing, difficulty swallowing in head and neck cancer patients with strictures is more likely to be multi-factorial (due to more than one single cause) than when the only problem is the stricture itself. Treatment therefore may need to be directed not only to dilating the stricture, but also to improving the function of the pharyngeal muscles. This may require the combined efforts of an otolaryngologist and a swallowing therapist as well as a gastroenterologist.

Editor's Note: William J. Ravich, M.D. is Associate Professor of Medicine at The Johns Hopkins University School of Medicine, Baltimore, Maryland

MAXIMIZING REHABILITATIVE EFFORTS FOR DYSPHAGIA

DIANE SAULLE, M.A., CCC-SLP DOROTHY VILLANO, M.A., CCC-SLP

Management of a patient diagnosed with head and neck cancer requires a multidisciplinary approach including head and neck specialists, nurses, radiation oncologists, dentists, nutritionists, plastic surgeons, and speech pathologists. It is of great importance that the patient becomes a good medical consumer, play an active role in his or her own recovery, and become a significant member of that team.

Surgical reconstruction impacts the swallow function resulting in anatomical and sensory changes, reduced range of motion, and wound healing difficulties. Radiation therapy (RT) and chemotherapy also effects the swallow function and can cause xerostomia, fibrosis, mucositis, lymphedema, trismus, nausea, fatigue, and stricture, all of which render the patient at risk, not

only for dysphagia, but for malnutrition and dehydration as well.

Historically, patients with dysphagia resulting from surgery, RT and/or chemotherapy tried to manage eating on their own. However, not all patients were successful in maintaining appropriate nutrition and hydration and often suffered emotionally and socially. In our experience, these patients were referred several months post treatments and surgery, when deficits in swallowing were most pronounced due to muscle disuse, atrophy, and significant tissue fibrosis.

Dysphagia therapy, traditionally, has not been approached from a preventative perspective. Exercises to maintain range, strength and mobility of muscle and, thereby, limit atrophy and fibrosis of oral, laryngeal and pharyngeal muscles were generally not offered

DYSPHAGIA continued on page 3

DISPHAGIA continued from page 3

to patients upon initial diagnosis. Current research, however, indicates the significance of early referrals for therapy, prior to starting radiation therapy, chemotherapy and/or surgery. Oral motor and swallowing exercises are important to maintain range and strength of oral-pharyngeal musculature, which is, essentially, based upon the “use it or lose it” principle. The goals of swallowing therapy are to prevent malnutrition and dehydration, reduce risk of aspiration, re-establish a safe and efficient swallow for oral intake, and provide patient education and counseling.

Traditional swallowing therapy techniques for patients diagnosed with head and neck cancer have always included the Effortful Swallow, the Supraglottic Swallow, the Super-Supraglottic Swallow, the Mendelsohn Maneuver, the Shaker Maneuver, and the Masako Maneuver. Extensive data exists regarding the efficacy of swallow maneuvers. Maneuvers are designed to alter the physiology of the swallow. The Effortful Swallow improves tongue-based retraction and pressure generation. The Supraglottic Swallow closes the vocal folds before and during the swallow. The Mendelsohn Maneuver enhances and prolongs laryngeal elevation and anterior movement to improve laryngeal elevation and cricopharyngeal (the upper esophageal sphincter) opening. The Masako Maneuver improves strength of muscle contraction for tongue base to posterior pharyngeal wall contact. The Shaker Maneuver is another way to open the upper esophageal sphincter by having the patient lay flat on their back and, in a precise manner, slowly lift their chin to their chest. These swallowing exercises, in combination with positional maneuvers, have been the mainstay of dysphagia therapy. Frequently used positional maneuvers include:

- Head Turn or rotation to left or right side can eliminate the weakened or injured side of the pharynx from the food bolus path.
- Chin Tuck (placing the chin down wards toward the chest) can
 - 1) widen the valleculae to prevent the bolus from entering the airway.
 - 2) put the epiglottis in a more protective position.
 - 3) narrow the laryngeal entrance.

There are limitations, however, with regard to traditional therapy programs. Exercises are abstract in concept. There is

no way of knowing, objectively, that these exercises are being done correctly. Treatment is clinician driven and often treatment is discontinued prematurely, primarily due to patient frustration. However, there are new options available, within the therapeutic and rehabilitative process, to the patient who has experienced all of the ramifications of head and neck cancer. Patients should be proactive in seeking out therapy programs, which include current treatment options. The following treatment options should be considered:

- Surface Electromyography (SEMG): measures muscle contraction and can assist the patient to strengthen oral pharyngeal musculature and monitor progress via use of visual feedback, as the concept of exercising volitional control over the reflexive act of swallowing, is a difficult and abstract task. This is a computer-based program where electrodes, attached to lead wires, are placed on laryngeal/pharyngeal musculature to measure muscle strength and endurance during practice of swallowing maneuvers. The patient is provided with visual feedback regarding the change in his/her swallow from session to session.

- Neuromuscular Electrical Stimulation (NMES): utilizes electrical stimulation for muscle re-education. The use of neuromuscular Electrical Stimulation in conjunction with traditional swallowing exercises facilitates a more efficient recovery of the swallow function via muscle reeducation. This is a non-invasive therapy technique, which utilizes specially designed electrodes, which are placed on the neck to stimulate motor nerves in the throat while the patient practices swallowing exercises.

- Fiberoptic Endoscopic Evaluation of Swallowing With Sensory Testing (FEESST): Incorporation of FEESST, primarily recognized as a diagnostic tool, can be effectively utilized in therapy and provide visual feedback for both patient and therapist. FEESST is an evaluation tool that will allow for direct assessment of the motor and sensory aspects of the swallow. A flexible endoscope is placed through the nose into the endolarynx. The first part of the test assesses sensation in the larynx by eliciting an airway protective reflex. The second part of the test involves feeding various food consistencies and fluid densities (mixed with green food coloring)

to the patient and observing progression of food and fluid during the swallow.

- Modified Barium Swallow Study (MBS): allows a comprehensive radiographic assessment of all stages of swallowing. The patient sits in a chair and is given different food consistencies and fluid densities impregnated with barium. The clinician is able to assess structure and function of the oral and pharyngeal mechanisms and the upper esophageal. Although, primarily recognized as a diagnostic tool, it can be effectively utilized to provide information, which will direct therapeutic management.

- Esophageal Dilation: The impact of head and neck cancer surgery, radiation therapy, and/or chemotherapy on the swallow mechanism has been well documented. The impact of radiation therapy and chemotherapy on esophageal function has only, recently, been recognized. It is not uncommon that a patient will also experience changes to the esophagus which prevents its normal open / closure mechanism and motility. A patient can be referred to his/her physician to determine candidacy for a dilation through the mouth or through a gastrostomy tube. Retrograde esophageal dilatation of the esophagus (through a gastrostomy tube), in combination with traditional therapy and NMES, has afforded patients, with feeding tubes, the hope for improved swallow function and quality of life.

Results from therapy will not be realized immediately. It is important for both patients and families to understand that therapy is a process that takes time. The best rehabilitation occurs through good communication between patient and therapist, both before and after medical intervention. Patients must become good medical consumers and play an active role in their recovery process. They need to realize their responsibility to become as knowledgeable as possible regarding treatment alternatives and outcomes. A comprehensive therapy program will assist patients as they begin to look toward the future and accept the limitations imposed by the disease and /or its treatment.

Editor's Note: Diane Saulle, M.A., CCC-SLP is a Supervisor, Speech-Language Pathologist at the Hearing and Speech Center of North Shore-Long Island Jewish Health Care System. Dorothy Villano, M.A., CCC-SLP is a Senior Speech-Language Pathologist at the Hearing and Speech Center with 30 years experience. Both speech pathologists specialize in providing dysphagia rehabilitative services to individuals diagnosed with head and neck cancer.

Through the Eyes of a Caregiver by Kathleen Dicie due, R.N., M.S.N

"It takes strength to make your way through grief, to grab hold of life, and to let it pull you forward"....author unknown

The diagnosis of a life threatening disease such as cancer has the power to change a person's life in the blink of an eye. Suddenly the seemingly monumental problems in life are instantly reduced to microscopic issues. The diagnosis and all that follows, takes on a life of its own and becomes an all consuming affair. The questions that haunt us over and over; What do I do now? Where do I go for treatment? What are the best treatment options? and What are the survival statistics?

Many of you who are reading this now can identify with those moments. I am one who found myself in this totally unexpected situation when my husband, Robert, first noticed a small pea sized nodule on the left side of his neck in October 2002. What followed was a biopsy which was positive for squamous cell carcinoma, a radical neck dissection, chemotherapy and radiation, lots and lots of terribly awful and permanent side effects of the treatment.

What keeps the patient and the caregiver going through these life shattering events? You find that one must reach out and search for ways to cope and find strength to pull yourself up by the bootstraps to face each day. "God did not promise days without pain, laughter without sorrow, sun without rain, but He did promise strength for the day, comfort for the tears and light for the way."

Personally, for me I found my strength in my faith and my family and friends. It's through the tough times that you realize who the people are that you can depend on and those that really love you and will be there for you. Many people close to you will offer to assist you and others will be unable to cope with the situation and may run away from you. Remember that those offering to help may need direction from you. Think of tasks that you would find helpful and stress relievers for you, such as grocery shopping, running errands or simply sitting with the patient to provide you with needed respite.

At the time my husband was diagnosed I was already caring for and coordinating my mother's care. She had been diagnosed with multiple myeloma in 2001. As a nurse practitioner and the executive director of

a hospital based home hospice program I assumed that I could handle it all. That was truly easier said than done! My point being, no matter who we are or what our knowledge level, it is of great importance to realize how extremely valuable it is for everyone in this situation to have access to the available resources to carry us through, regardless of the expected outcome.

Although illness affects one person, it also affects all those people in the life of that one person. We know illness is a drain on the patient, but caring for a person who is ill, no matter how difficult the level of care may be, can also be an emotional, physical and psychological drain on the caregiver.

Everyone copes differently in trying situations. Some of us better than others and that is alright. There are no right or wrong rules to follow, but only to provide the best care possible for the patient while the caregiver maintains his/her own sanity and ability to cope with the situation at hand.

Patients living with a life threatening disease can be extremely angry and rightfully so! Who better for the patient to take out his/her frustration on but the person closest to him/her...the caregiver? Understand that these behaviors are not intentional to hurt the caregiver, but rather a way for the patient to express the feelings of "Why did this happen to me?" The patient knows that the caregiver loves him/her unconditionally or he/she would not be caring for the patient. As a result the patient has a certain sense of security that the caregiver will be there for him/her no matter what.

I speak from experience as I am sure that many of you can, too. My husband's fear when his illness worsened was often expressed in yelling and demanding behavior which in turn I sometimes interpreted as extremely hurtful towards me. It is important to try to talk about the issues as difficult as it may be for all concerned. When all else fails, call your best friend and let it all out.

The demands of being a caregiver can be very taxing both physically and emotionally. It is vital for the caregiver to take care of their own emotional and physical health

in order to maintain effectiveness as a caregiver. I can't stress this enough. Take time to care for yourself, remember to eat and sleep, take some free time away from the situation and most of all don't feel guilty about it. If possible try to off load some of your daily routine responsibilities on other family members and friends.

Children present in families who are coping with terminal illness can create even more sensitive situations depending on their age and place in the family. Some families are able to talk openly with each other regarding the illness and potentially about the death of a loved one. Others may never be able to reach that level of openness and sharing of feelings and emotions. If possible it is beneficial to include all the members of the family in the care giving process. This will help to keep everyone aware and informed of just what is really going on and in the long run helps to decrease the unknown and uncertainty of the situation at hand. Although children can be surprisingly strong and resilient, showing continuous displays of love, affection and maintenance of routines may help to decrease their confusion and fear.

Oftentime people in a life altering situation will feel the need to find comfort in ways other than physical means. A person's spirituality and faith can be a source of tremendous comfort, yet for others this may not be so. It is purely an individual preference since each person's needs and beliefs are unique.

In a crisis situation one must do what works best for them, but sometimes through the confusion of it all, you just might need to access resources to help assist with sorting it all out.

Despite the wonderful advances in medicine there are no guarantees in this life. It is important for folks to learn about the options and be well informed consumers before a catastrophic illness occurs. This can help keep your stress level in check if the need occurs for quick decision making. One exceptional available resource is hospice care. Dame Cicely Saunders founded the first hospice in 1968 in London. "You matter CAREGIVER continued on page 6

CAREGIVER continued from page 5

to the last moment of life, and we will do all we can, not only to help you die peacefully but to live until you die” was her philosophy of life that she shared with her patients and their caregivers.

The hospice concept made its way to the United States shortly after it arrived in London and the dying process began moving away from the sterile hospital environment and back to the comfort of a person’s own home surrounded by loved ones. And while there is no doubt that this concept may be difficult and not for everyone, many who choose to be cared for by the professional interdisciplinary team of a hospice program generally find the experience to be a meaningful one. While hospice care brings the reality of the illness to the forefront, it also raises the possibility not the guarantee of death resulting from that illness.

I have come to realize that patients, caregivers, and even physicians often wait until the last moment when death is imminent to access hospice services. Many still believe the myth that if they sign onto a hospice program it is surely a death sentence. Who in their right mind would agree to this?

Throughout my career I have come to know that belief is not always entirely the case. It is important to think of hospice services as a support program. For patients and caregivers, this support program provides resources and information that can make the complex road through the health care maze a little bit easier to negotiate. Hospice care providers strive to assist patients and caregivers to maintain the highest quality of life while being cared for by loving family and friends in collaboration with knowledgeable and dedicated professionals. Exploring hospice is an option before the need for care becomes critical and can greatly reduce stress ahead of time. The sooner hospice is involved in a patient’s care, the more beneficial it is for both the patient and caregiver in providing support services such as; psychological and spiritual counseling, pain and symptom management, dealing with end of life issues, and planning for the future of loved ones who may be left behind after death.

In a perfect world, all of us would have clear ideas about what we would want for the end of our lives and how we

would want to spend our final days before we find ourselves faced with making that decision when diagnosed with a terminal illness. Even without illness it is important for everyone to consider making his/her wishes known and especially important for anyone with a potentially life threatening or terminal illness. This simple procedure can be accomplished by written instructions known as an “advance directive” or “living will”. This document will clearly spell out exactly what you want done in any situation and can be as specific as needed to include issues such as; pain control, mechanical ventilation, and insertion of a feeding tube. Expressing one’s wishes ahead of time allows each individual to make his/her own choice about the treatment he/she feels most comfortable with. In addition, it is crucial for the patient to choose a person they authorize to make important decisions regarding care in the event the patient becomes unable to do so. The social worker who is an integral member of the hospice interdisciplinary team can provide patients and caregivers with the resources needed to complete these documents.

Many times the continuation of active treatments can prolong a good quality of life for patients. However, other times a patient’s health status may continue to deteriorate and the benefits versus the side effects as they relate to quality of life need to be seriously evaluated when deciding whether or not to continue active treatments. If the negative side effects of continuing chemotherapy or radiation outweigh the benefits, the focus of care often turns from curative measures to palliative or “comfort” measures. Dame Cicely Saunders was quoted as having said, “How people die remains in the memories of those who live on”.

A year after my husband completed treatment for stage IV neck cancer with an unknown primary site, he developed a left lung tumor. A failed attempt at a lung resection indicated significant metastatic lymph node involvement. Despite my faith in God and the medical profession, my thirty years as a nurse provided me with the reality of a situation I did not want to face, let alone discuss with him. Throughout his bout with cancer he always remained optimistic and never discussed the possibility of dying from this disease although I knew he recognized

that possibility. After twenty years of marriage you get to know your partner well. Although I was aware Robert knew he was not getting better he took each day like a trooper and made the best of it despite his increased shortness of breath and inability to do much more than sit and rest. He was a headstrong and stoic man and I believe a part of him did not want to admit defeat for fear of upsetting me.

I was insistent upon getting the family together for Christmas 2004 because I knew it might be his last one with us and I was right. Robert and I spent New Year’s 2005 alone together. By this time he was unable to walk up the stairs anymore and we were sleeping on the sofa bed in our family room. At midnight I heard him say, “Happy New Year”. I lay there with my head turned away from him, tears rolling down my cheeks and pretended to be asleep because by now I was certain that without a miracle he would not be sharing the New Year with me too much longer.

On the morning of January 12th Robert told me he was tired and wanted to sleep. I lay down next to him and we held each other. As his breathing slowed and became less labored I called his name and as he woke up I asked him if he loved me. He replied, “Yes” and I said “I love you” and asked him to give me a hug. We hugged each other and somehow both knew this was our goodbye to this life as we knew it together. I listened as his breathing slowed and became calm and almost normal until it ceased within a few minutes. This is the memory I will remember for the rest of my life.

As a nurse I was aware when my husband was dying and at that time I forgot about being a nurse and concentrated on being a wife. At that instant I realized that my nursing training and years of caring for terminally ill patients could in no way prepare me for the grief that was to follow in the days and months ahead. In addition to my husband’s death, my mother also died in May 2003 during the time Robert was experiencing the absolute worst side effects from his chemotherapy and radiation treatments.

One day while sifting through articles about the grieving process I stumbled upon this quote, “no matter how bad your heart may be broken the world doesn’t stop for CAREGIVER continued on page 7

CAREGIVER continued from page 6
your grief". Truer words were never spoken. I had to return to my job, the bills had to be paid, the house had to be cared for.....the only difference was that now I had to do it alone. "Let me get through today and I shall not fear tomorrow".

Most people are familiar with Elizabeth Kubler-Ross's five stages of grief: denial, anger, bargaining, depression and acceptance. These stages are a framework of what one can expect to feel after a loss but each person's grieving is unique to them as it flows from the memories of a part of their life that has been taken away.

Experiencing the death of someone we love is never easy. The grief that follows is a painful, difficult, but necessary process. Emotions can range from overwhelming sadness to relief; from guilt to anger and fear. No two people react or manage their grief in the same way, but it is essential to the survival of those left behind to find healthy ways to manage grief in order to continue on with life.

Over the years I have come to believe that some of the best information for cancer patients and caregivers comes from survivors, those living with terminal illnesses and those of us who are mending our grief. Since my husband's death I have participated in three bereavement support groups offered cost free by Cancer Care and a local church. As a hospice director, being on the other side of the fence was a unique experience, but an invaluable one where I have been able to share my feelings and my grief with others who have been through the same as I.

As a nurse, who was also a caregiver, I found it necessary to appear strong, in control, and in charge. My faith sustained the better part of me and has been a great source of comfort to me in the days following Robert's death. It continues to carry me through the difficult moments. "It takes strength to make your way through grief, to grab hold of life and let it pull you forward". I don't remember where I read these words or who said them, but I have come to understand their true meaning.

Editor's Note: Kathleen Dickey, R.N., M.S.N. is the Administrator of a Community based Assisted Living Facility for Semi-Independent and Memory Impaired Residents. She is also an Adjunct Professor of Undergraduate Nursing and R.N. to B.S.N. Program in New Jersey.

Resources
The National Hospice and Palliative Care Organization
1700 Diagonal Road
Suite 300
Alexandria, VA 22314
1.800.658.8898
www.nhpco.org

Cancer Care National Office
275 Seventh Avenue
Floor 22
New York City, New York 10001
1.800.813.HOPE (4673)
www.cancercare.org

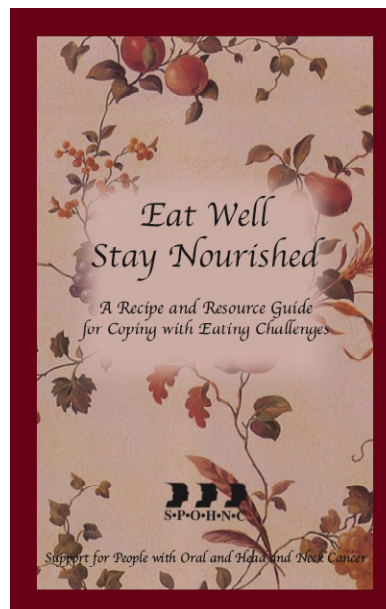
Coping with Cancer Magazine
P.O. Box 682268
Franklin, TN 37068
www.copingmag.com

Healing Thoughts Unity
1901 NW Blue Parkway
Unity Village, MO 64065
www.dailyword.org
Bereavement Magazine
P.O. Box 61
Montrose, CO 81402
1.888.60.4HOPE (4673)
www.bereavementmag.com

After Cancer- A Guide to Your New Life
Wendy Harpham, M.D. 1995, Harperperennial Library.

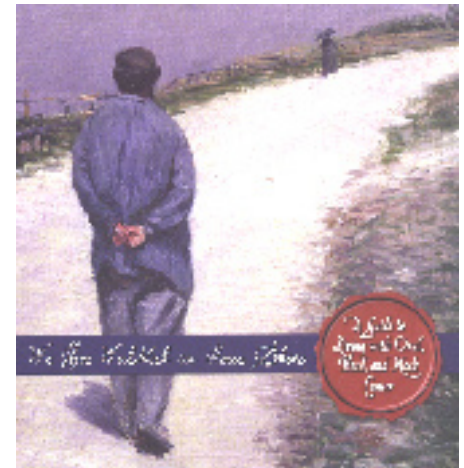
Happiness in a Storm: Facing Illness: Embracing Life as a Healthy Survivor, Wendy Harpham, M.D., 2005, W. W. Norton & Company.

The Circle of Life: The Heart's Journey Through the Seasons, Joyce Rupp and Macrina Wiederkehr, 2005, Ave Maria Press.



"Eat Well – Stay Nourished: a Recipe and Resource Guide for Coping with Eating Challenges"

To Order
Call 1-800-377-0928 or order online at
www.spohnc.org



"We Have Walked In Your Shoes, A Resource Guide to Living with Oral, Head and Neck Cancer"

This book contains basic information about oral and head and neck cancer and provides resources for patients and families facing a diagnosis of this type of cancer, its treatment, rehabilitation and recovery. It is not intended to replace any information and/or recommendations made by health care professionals. It is designed to help you get the answers you need. It summarizes the most common advice on living with oral and head and neck cancer, provides you with resources if you want more information and offers practical tips as well as weekly and monthly calendars to help you track your treatment. This book is free.

To order visit www.spohnc.org
For large orders, please call
1-800-377-0928.

(This book was made possible though the generous support of
Bristol-Myers Squibb & ImClone Systems)

Louis Frillmann, LaD
1928 - 2007

SPOHNC is deeply saddened by the loss of a kind man and dedicated member of the Board of Directors. Lou Frillmann will be remembered as a man of wisdom, humor and humility who brought experience and knowledge to SPOHNC. SPOHNC and its Board of Directors are indeed diminished by the passing of its dear friend, Lou.

A TIME FOR SHARING...The Road Back

Once home, I lay in bed for days. My body was so emaciated and riddled with the side effects of radiation, chemotherapy and surgery that I felt like there was nothing left in me. I had lost all interest in activities. Ron and another friend brought over some things my coworkers had made to keep my mind active. Elaine made me get out of bed and go downstairs to meet them. I just stared and don't recall making any sign or gesture. It was like my body was there, but my spirit had left me. I was lost within myself as I drifted thru the days.

All during my treatment I'd never thought about how hard recovery was going to be. For me, surgery was the end of it all. Now it really hit hard. Would I ever be able to eat regular food? Would I ever experience a good night's sleep? What kind of life was ahead for me? The doubts were floating about me. For the first time, I feared I might go under.

I began to search for motivation. Mt. Rainier, Washington popped into my mind. I had lived within 65 miles of it several times in my youth. On a clear day in Washington, the top of the mountain dominated the skyline. My parents would take me up there to get a closer look at its majesty. I set my goal. I vowed to regain enough health to take my family on a hike up to the glaciers of Mt. Rainier. They had never seen the beauty I'd known as a child. I wrote a note for the family about my idea and they were game. On that day, Tim, the Mountain Man, was born.

Ah, sweet motivation. With it, you can view trials with a zestful spirit. My mind leapt ahead to the day when I'd be up there with my family, standing tall and breathing the cool mountain air. It was so real that I could taste it. I was on my way back!

Gradually I began to come back. I still remember how glad I was to be able to walk 15 feet to the bathroom by myself. As Gabby Hayes used to say in the old western movies, "Jumpin' Geehosifatts!" Then I could walk down the steps to the family room. Eventually I could make it to one of my daughter's baseball games. My wife would drive us there and the short walk to the field was exhausting. I'd sit in a chair and mostly

stare. Elaine would tell me when Karen came up to bat. It was several months before I could walk around my block, but I did it!

Two years after cancer, my family and I made it to the glaciers of Mt. Rainier. We drove a car up to Paradise Lodge and then hiked a few miles to the glaciers. I barely made it. I was so ecstatic that I started a snowball fight with my family. Seconds later I sat down exhausted. I pondered on what to do next. I still had a long ways to go in my

I have made many hiking sticks from vine altered trees.



Each one takes many hours and is an effort to show the inner beauty. I give them to cancer patients. It helps them find the positives on their journey. For several patients it has had a profound effect, one even slept with his.

physical recovery. I did not want to go back to the overweight out-of-shape man I'd been. It was then that I decided to backpack the Appalachian Trail from Georgia to Maine. It was such an awesome idea. I could hardly believe what I was thinking. If I made it, I'd have recovered physically and gotten into the shape I was as a miler on the high school track team. I'd be a mountain man!

Then the enormity hit, 2,200 miles with

a heavy load on my back, a dropping right shoulder and no saliva. Heck, I couldn't even carry a heavy backpack a mile. All the while I would need to keep up my professional career because we had three children to put thru college. Yet, the thought motivated me. I set it as a life time goal. How long it took was not relevant.

Some thought I was crazy. Others knew it. I began training and kept building up to it. Part of the beauty for me was that it took the focus off what I couldn't do and put it on what I was going to do.

Finally, three years after cancer, I was ready to do a four-day trip. To better understand this, I have to tell you that while I had a lot of courage in business, at my core I am a coward when it comes to physical activities. I'm the kid who was always picked last in a game because I'm uncoordinated and slow. I'm the kid that was goaded on by the neighborhood kids to jump from one garage roof to another and landed on the picket fence in between. So, now it was time to start my dream, filled with all those doubts. I had my son Shawn videotape me as I walked off into the woods by myself. No one knew how scared I was. If they had, they would have stopped me. I just wanted the video for them in case I didn't make it back. It was my great fortune to meet two fellow trekkers and they helped me learn a lot. This was just the beginning of countless friendships on numerous trips.

Whenever I had off a couple of days, it would be back to the trail. Sometimes I'd hop on a bus right after work, ride it all night, reach the trail in the morning and begin hiking till the next bus stop and then home again. Other times, I would drive to the trail, backpack for several days and then head back to the car.

Bit by bit the trail was being done. I made a pole for my office and marked all the key points on the trail. Then I magic-marked each section that was done. When I'd get back from each trip, I couldn't wait to mark the pole. Each time was exhilarating. The pole was a constant motivator.

Six years after cancer, I did a long stretch

of backpacking in Virginia. Every night I'd ponder life. Gradually it started to appear more as a journey. While we need goals, sometimes what we learn along the way is more important than the destination. Later this would bring about a major change in my life.

On the Appalachian Trail, there are many doing a "thru hike", which is end to end in a single year. This is the origin of "thru" which I have used faithfully thru ought this text. It's a subculture and many are dealing with life altering issues or are at a turning point in their life. They keep in contact with each other by entering information in the logs at shelters. When another hiker catches up with you, they will frequently ask about other hikers that are ahead of them. Sometimes, a hiker will stop over for a day or two in a town to rest up while one of their friends catches up. It is like a slinky going down the stairs.

While I was only a "section hiker", they welcomed me since they saw me as a fellow journeyer. I'll never be able to offer enough thanks for the many awesome friendships. Because of them, the word journey is always in the background of my thoughts.

Then there are the "trail angels". Often when a hiker completes all 2,200 miles of the Appalachian Trail, they still want to keep in contact with the community. One of the ways is by becoming a trail angel. They can be found sitting by a road with drinks, energy bars, oranges, etc. Several groups will take a week of vacation each year and set up a feeding station. Hikers literally stuff themselves with hamburgers or spaghetti, for free. We always stop and have a good time sharing our tales. You meet as strangers and a few minutes to hours later you are friends. The comradeship from the shared experiences is such a treat. You feel deeply connected with your fellow journeyers. It warms your heart and fortifies you for what lies ahead. It is similar to what I experience when meeting fellow cancer patients/survivors.

A tradition of the Appalachian Trail is that people either give you a trail name or you pick one. It is often humorous but sometimes deep and meaningful. You know each other by your trail name but rarely by real name. In fact, we rarely use anyone's real name even when we know it. This is more intimate and is part of the comradeship. Some examples:

Heavy Food: He carried canned food.

Polka Dot: Dorothy was near 80 and hiked slowly. She selected this name and wore a polka dot hat.

Bleeder Guy: A hemophiliac that beat the odds by doing the whole trail.

Dog Bone: From the first few days on the trail he complained about his energy bars. He said they tasted terrible. Finally someone looked at the label on one. They were made for dogs!

Old Smokey: He'd been a trail-runner in the Smokey Mountains for the National Forest Services. He did it in his late 70s, which is amazing.

Duncannon Hustler: I was given this name in Duncannon, PA on another hike. Two hikers at a bar were playing everyone for the cost of the pool table. All night they kept winning. I kept refusing to play protesting that I was pathetic at pool, which was mostly true. Finally, around midnight, I said OK. I found a partner and we beat the two hot shots. They had been drinking heavily all night which, no doubt, was wearing down their senses. I was totally sober. When we won, they became upset and demanded a second game, then a third. Finally one moaned, "You are the **"Duncannon Hustler"**".

After meeting many trail angels, I began to wonder if I might help cancer patients on their journey the way my brothers had for me, sending tons of cards. At church I heard of a parishioner that had cancer. I'd never met Larry. He'd always gone to a different mass than Elaine and I attended; I didn't know what his interests were. My only connection was being a fellow journeyer. I began buying cards and sending them every other day. I didn't include a return address and only signed my first name. I didn't want Larry to feel like he had to thank me or even spend his precious energy on yet another relationship. It got so expensive that I began taking old cards and writing little encouragements in them. Eventually I realized that if he had wanted to get in touch with me, he would be frustrated. So, I included my full name and address on one card, noting that I was not trying to initiate contact. I did not hear from him and kept sending cards. Then one day Larry called. He had been across the country seeing cancer doctors. When he came home there was this big pile of cards. Larry thanked me and wanted to meet me. We became best

of friends after only a few brief meetings. Larry was saving his energy. I just kept working on the cards.

When Larry was too sick with cancer to attend mass, I got poster board and decorated it with blades of grass and daisies (made from pastel construction paper). It was set out in front of the church and everyone signed his or her name on a flower petal or blade of grass. Larry knew our spirits were with him.

Larry had always wanted to hike the entire Appalachian Trail and had done a small section in the Shenendoah National Forest in Virginia with his son. Larry gave me a picture of him on the trail. I carried it the rest of the way on the trail so that he could be there with me.

Along the way, I began to realize how cancer had led me to a better life. My best analogy is the transformation that happens to a small tree that is being strangled by a vine. It struggles to grow and gradually the bark grows around the vine and the tree develops twists in its trunk. The tree takes some interesting shapes and becomes a work of art. Such can be your journey through a hell. Like the tree, I am physically altered and you can see it. But, more importantly, it changed me inside. A severe trauma can cause psychological changes and if you keep looking for the positives it can lead to inner beauty. This analogy resonated with Larry and I gave him a vine altered hiking stick that I had made for him. It helped him so much that he had it displayed at his funeral.

To date, I have made many hiking sticks from vine altered trees. Each one takes many hours and is an effort to show the inner beauty. I give them to cancer patients. It helps them find the positives on their journey. For several patients it has had a profound effect, one even slept with his.

Ever since meeting Larry, helping others thru cancer has been a critical part of my life. While it effects me deeply when one does not beat cancer, I treasure being there for them. Viva the brotherhood!

Tim O'Neill
Wilmington DE

Editor's Note: The preceding story is excerpted from "Antelope Racing with the Duncannon Hustler – A Journey thru Cancer to a Better Life" an unpublished book by Tim O'Neill

LOCAL CHAPTERS OF SPOHNC FOCUS ON SPOHNC - BOSTON-MASSACHUSETTS

On November 14, 2000, 22 head and neck cancer survivors and their caregivers gathered at Massachusetts General Hospital for the first meeting of SPOHNC-BOSTON.

The group's birth resulted from a combination of frustration and good timing. As a two-year survivor of squamous cell carcinoma of the lateral tongue, I was frustrated that a large city like Boston offered no head and neck cancer support groups that met regularly.

The good timing came on two fronts: In early 2000, Massachusetts General Hospital Cancer Center's Network for Patients and Families was developing peer-led support groups. Having been a volunteer for the Network's peer support program for young survivors, I approached Network Director Sally Hooper, MSW, who encouraged me to start a peer-led support group for head and neck cancer survivors at Massachusetts General Hospital Cancer Center (MGH CC). She also provided a room (and pudding!) for meetings, along with a social worker to help co-facilitate. Meanwhile, SPOHNC founder, Nancy Leupold, was forming

local chapters nationwide. MGH CC met SPOHNC and SPOHNC BOSTON was born. The partnership of a nationally recognized education and advocacy organization with a local comprehensive Cancer Center allowed both organizations to address an unmet need.

I expected few people at the first meeting, but close to two-dozen survivors and their loved ones showed up, eager to meet others with a similar diagnosis and treatment. We went around the room, giving each person the chance to share their story. In some cases, it was the first time that survivors had gotten to meet a survivor with a similar diagnosis. Clearly there was a need for a group like SPOHNC-BOSTON.

The participants at those early SPOHNC Boston meetings helped to set the format and topics of future meetings. In addition to peer support, people wanted information about common concerns. Since then the group has met monthly and most meetings have featured speakers on topics ranging from acupuncture, to speech therapy, pain management and esophageal dilation. Some speakers are professionals

who work at MGH, but we have also featured professionals from other organizations. Often I learn of potential speakers through my group members or from professionals who have worked with our group in the past and know of a colleague who would make a good speaker. And there is time at every meeting for group members to catch up on each other's progress.

In six years of leading SPOHNC-BOSTON I have seen remarkable courage and perseverance among those in our group. Sadly, we have lost members to this disease, but we also have many who are years out of treatment, doing well and continuing to inspire our newer members. And we are currently over 75 members strong!

A long road still lies ahead of us in educating health care professionals about the needs of head and neck cancer survivors and raising desperately needed research funding. But through SPOHNC-BOSTON, I have learned that a difficult journey is easier to endure when you share it with friends.

Valerie Hope Goldstein
Founder and Facilitator

ARIZONA-PHOENIX
Banner Desert Medical Center
3rd Wednesday: 5:30 PM
Keri Winchester, MS, CCC-SLP 480-512-5604
Keri.Winchester@bannerhealth.com

ARIZONA-SCOTTSDALE
Virginia G. Piper CA Center
3rd, Thursday: 6:30-8:30 PM
Bette Denlinger, MA, RN - 480-838-5194
betneldenlin@cs.com
Sally Kaszilek
skaszilek@yahoo.com

ARKANSAS-LITTLE ROCK
Baptist Health Medical Center
2nd Thursday: 7:00 PM
Cathy Peralta - 501-202-1703
cathy.peralta@baptist-health.org

ARKANSAS-NORTHWEST
NWA Cancer Support Home
3rd, Saturday: 10:00 AM-12:00
Jack Igleburger - 479-876-1051/586-4807
tmplnjak@cox.net

CALIFORNIA-LOS ANGELES-UCLA
UCLA Med. Pla., Rad/Onc Conf. Rm. B-265
1st Tuesday: 6:30-8:00 PM
Sabah Qasim, LCSW - 310-825-5707
sakmal@mednet.ucla.edu
Pam Hoff, LCSW-310-825-6134
phoff@mednet.ucla.edu

CALIFORNIA-ORANGE, UCI
Chao Family Comprehensive CA. Ctr.
1st, Monday: 6:30-8:00 PM
Jennifer Higgins, MSW - 714-456-5235
jhiggins@uci.edu

CALIFORNIA-PASO ROBLES
The Wellness Community
1st Tuesday: 6:00 PM
Kenda Kellawan - 805-238-4411
kenda.kellawan@wellnesscommunityhope.org

CALIFORNIA-SAN DIEGO
Valerie Targia - 760-751-2109
valtargia@yahoo.com

COLORADO-DENVER
Porter's Adventist Hospital
Last Thursday: 6:30-8:00 PM.
Virgil Holdridge - 303-798-3041
virgil126@juno.com
Jeanie Curry - 303-778-5832

DC-WASHINGTON
Lombardi Cancer Center.
3rd Monday: 12:15-1:45 PM
Joanne Assarsson, MSW, LICSW - 202-444-3755
assarssj@gunet.georgetown.edu

FLORIDA-BOCA RATON
Boca Raton Community Hospital.
1st Tuesday: 4:00-5:00 PM
Laura Moon, MSW - 561-955-5897
lmoon@brch.com

FLORIDA-ENGLEWOOD
Englewood Community Hospital
3rd, Thursday: 10:30-12:00 PM
Joseph Bauer - 941-474-0099

FLORIDA-GAINESVILLE
Winn Dixie Hope Lodge
2nd Monday: 6:00-7:00 PM
Carol Glavin, MSW, LCSW - 352-371-86
Cglavin@gru.net
No calls after 9:00 PM, please

FLORIDA-MIAMI
Baptist Hospital
1st Wednesday: 5:30 PM
Annie Garcia-Montes - 786-596-6951
anniegm@baptisthealth.net

FLORIDA-MIAMI
UM/Sylvester at Deerfield Beach, Ste.100
2nd, Tuesday: 1:30 PM-3:00 PM
Penny Fisher, MS, RN, CORLN = 305-243-4952
pfisher@med.miami.edu
Marty Mash
mashmarty@hotmail.com

FLORIDA-SARASOTA
The Wellness Community
2nd, Thursday: 5:30 PM
Joseph Bauer - 941-474-0099
John Kleinbaum, Ph.D.-941-921-5539
hope@wellness-swfl.org

GEORGIA-ATLANTA
St. Joseph's Hospital
2nd Monday: 6:30-8:00 PM
John Sandidge - 404-851-5585
jsandidge@sjha.org

GEORGIA-ATLANTA-Emory
Winship CA Institute (Bldg. G)
Last Monday: 6:30-7:30 PM
Arlene S. Kehir, RN - 404-778-2369
Arlene.Kehir@emoryhealthcare.org

ILLINOIS-CHICAGO
Duchossois Ctr. for Advanced Medicine
2nd Tuesday: 9:30-10:30 AM
Robyn Egan - 773-834-2470
regan@medicine.bsd.uchicago.edu

ILLINOIS-MAYWOOD

The Cardinal Bernardin Cancer Ctr.
3rd. Wednesday alternate mo.: 6:00-7:00 PM
Marilyn Myles - 708-327-2061
mmyles@lumc.edu

INDIANA-INDY NORTH
Marion County Public Library
Lawrence Branch
3rd. Tuesday: 7:00-9:00 PM
John Groves - 317-872-6674
Jgroves14@comcast.net

INDIANA-INDY SOUTH
St. Francis Education Center
1st. Thursday: 7:00 PM
Janice Leak, MSN, APRN-BC, AOCN
317-782-7604
Janice.Leak@ssfhs.org

KANSAS-KANSAS CITY
Univ. of Kansas Hospital
2nd & 4th Wednesdays: 4:00 - 5:00 PM
Mary Moody - 913-588-3630
mmoody@kumc.edu
Dorothy Austin, RN, OCN - 913-588-6576
daustin@kumc.edu

LOUISIANA-BATON ROUGE
American Cancer Society
2nd to last Tuesday: 6:30 PM
Krystal k. Sauceman, RN - 225-572-7943
KKS.BR@yahoo.com

MARYLAND-BALTIMORE-JHMI
Johns Hopkins - Greenspring Station
2nd. Wednesday: 7:00-8:30 PM
Kim Webster - 410-955-1176
Kwebst@jhmi.edu
Dwayne Arehart: 717-615-7464

MASSACHUSETTS-BOSTON
Massachusetts General Hospital,
One Tuesday each mo.: 6:30-8:00 PM
Valerie Hope Goldstein - 617-731-1703
Femval@aol.com

MICHIGAN-DETROIT
Henry Ford Hospital
Josephine Ford Cancer Ctr. Rm. 2038D
1st Wednesday: 11:30 AM
Amy Orwig, MSW - 313-916-7578
aorwig1@fhhs.org

MICHIGAN-TROY
Wilson Cancer Resource Center
4th Thursday: 6:30 PM
Suzanne Frantz, RN, CNOR - 586-228-2309
sfrantz@beaumont-hospitals.com

MINNESOTA-MINNEAPOLIS
The Lymphedema Center
4th Monday: 7:00-9:00 PM
Colleen M. Endrizzi - 952-545-0200
rivers3jvk@aol.com

MONTANA-BOZEMAN
Bozeman Deaconess Hospital
3rd Thursday: 12:00 Noon-1:00 PM
Doug Stiner - 406-586-0828
nancydoug@theglobal.net
Wendy Gwinner, LCSW--406-585-5070
wgwinner@bdh-boz.com

N. CAROLINA-CHARLOTTE
Blumenthal Cancer Center
2nd. & 4th Thursday: 1:30-3:00 PM
Meg Turner--704-355-7283
meg.Turner@carolinashhealthcare.org
Terri Painchaud - 704-364-7119
Trappi6@yahoo.com

NEBRASKA-OMAHA
Methodist Cancer Center
1st Friday: 3:00 PM.
Susan Stensland - 402-559-4420
sstensland@nebraskamed.com

NEBRASKA-OMAHA
Nebraska Medical Center
3rd Tuesday: 12:00 noon
Susan Stensland - 402-559-4420
sstensland@nebraskamed.com

NEW JERSEY, LONG BRANCH
Leon Hess Cancer Center
The Goldsmith Wellness Center
2nd Thursday: 7:00-8:00 PM
Becky Kopke, RN, BSN, OCN - 732-923-6473
BKopke@SBHCS.com
Anita M. Pfisterer, MSW, LSW - 732-923-6961
ampfisterer@aol.com

NEW JERSEY, MORRISTOWN
Morristown Memorial Hospital
3rd Wednesday: 1:30 PM
Howard Sakolsky - 973-586-3522
hesakolsky@aol.com

NEW JERSEY/PENNSYLVANIA
University of Pennsylvania Hospital
1st Wednesday: 9:30-11:00 AM
Micki Naimoli - 856-722-5574
Stefanie Washburn - 215-615-0536
Stefanie.washburn@uphs.upenn.edu

NEW JERSEY-TOMS RIVER
Community Medical Center
Last Thursday: 3:00 PM
Sherry Laniado, MSW, LCSW - 732-557-8
slaniado@sbhcs.com

NEW MEXICO-ALBUQUERQUE
Christ Unity Church
3rd Friday: 4:30-5:30 PM
Anita Bryan - 505-681-1971
anitabeach2@yahoo.com

NEW YORK-MANHATTAN
Beth Israel Head and Neck Institute
4th Tuesday: 1:30-3:30 PM
Jackie Mojica - 212-844-8775
jmojica@chnpnet.org

NEW YORK-ROCHESTER, NY
Strong Memorial Hospital
1st. Thursday: 4:00-5:30 PM
Sandra E. Sabatka, LMSW - 585-275-4631
Sandra_Sabatka@URMC.Rochester.edu

NEW YORK-Stony Brook
Ambulatory Care Pavillion
Adjacent to Stony Brook Hospital
1st. Wednesday: 7:30-9:00 PM
Dennis Staropoli - 631-682-7103
den.star@hotmail.com

NEW YORK-SYOSSET, NY
NSLIJ-Syosset Hospital
2nd Thursday: 7:30-9:00 PM
Nancy Leupold - 516-759-5333
nleupold@spohnc.org

NEW YORK-WESTCHESTER
White Plains Hospital Cancer Center
2nd Thursday: 7:00 PM
Mark Tenzer - 914-472-3397
tenzer1@optonline.net

OHIO-CLEVELAND
Cuyohoga County Public Library
2nd Saturday: 10:00 AM
Tom Wurz - 440-243-6220
TomRoe8@adelphia.net

OHIO-COLUMBUS
The James Cancer Hospital &
Solove Research Institute
1st. Monday: 3:30-5:30 PM
Vicki Heinke, LISW - 614-293-7042
Vicki.Heinke@osumc.edu

OKLAHOMA-TULSA
Hardesty Public Library
1st. Tuesday: 6:30 PM
Christine B. Griffin, RN - 918-261-8858
Beritgriffin@cox.net

PENNSYLVANIA-MECHANICSBURG
Health South Lab
Every 3rd. Month/3rd. Tues.: 6:30 PM
Joseph F. Brelsford - 714-774-8370
Jfbrelsford1@mmm.com

TEXAS-DALLAS
Baylor Irving-Coppell Medical Center
2nd Saturday: 10:00 AM
Dan Stack - 972-373-9599
danrstack@aol.com

TEXAS-DALLAS
Cvetko Ctr. at Sammons Cancer Ctr.
2nd Tuesday: 11:00 AM-12:30 PM
Jack Mitchell - 972-496-6561
jackmitchell5225@aol.com
Travis Maxwell - 214-820-2608
travism@BaylorHealth.edu

TEXAS-FORT WORTH
Moncrief Cancer Resources
2nd Wednesday: 3:30-5:00 PM
Valerie Oxford, MSSW
817-927-6364/838-4863
Valerie.Oxford@moncrief.com

TEXAS-HOUSTON/TOMBALL
Tomball Regional Hospital
2nd. Thursday: 12:00 noon-1:30 PM
Lynda Tustin, RN - 281-401-5900
ltustin@tomballhospital.org

VIRGINIA-CHARLOTTESVILLE
Dept. of Forestry Building, Suite 800
Last Thursday: 12:00 noon-1:00 PM
Vikki Bravo - 434-982-4091
vsb4n@virginia.edu

VIRGINIA-FAIRFAX
Inova Fairfax Hospital, Radiation/Oncology
2nd Wednesday: 5:30-7:00 PM
Corine Cook, LCSW - 703-776-2813
Corinne.cook@inova.com

WISCONSIN-MADISON
Univ. of Wisconsin Hospital
ENT Clinic Rm. G3/206
1st. Wednesday: 11:30-1:00 PM
Rachael Kammer, MS, CCC, SLP
608-263-4896
Kammer@surgery.wisc.edu

Call 1-800-377-0928
to become a member and make a contribution by credit card or order on line at www.spohnc.org

- ANNUAL MEMBERSHIP**
 \$25.00 individual \$30.00 family \$30.00 Foreign (US Currency)
- CONTRIBUTIONS**
 Booster, \$15+ Donor, \$50+ Sponsor, \$100+
 Patron, \$500+ Benefactor, \$1,000+ Founder, \$5,000+
 Leaders Circle, \$10,000+

Please Check: Survivor _____ Friend _____ Health Professional (Specialty) _____
City _____ State _____ Zip _____
Address _____
Address _____
Name _____ Phone (_____) _____

MEMBERSHIP APPLICATION
SUPPORT FOR PEOPLE WITH ORAL AND HEAD AND NECK CANCER, INC.
Membership includes subscription to eight issues of *News From SPOHNC*

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



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

Helping to Raise Awareness of
Oral and Head and Neck Cancer

AWARENESS RIBBONS



1-9 pins: \$6.50 each
10 or more pins: \$6.00 each
includes shipping and handling

AWARENESS WRISTBANDS



5 for \$10.50
includes shipping and
handling

www.spohnc.org
1-800-377-0928