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

MANAGEMENT OF DYSPHAGIA IN PATIENTS TREATED WITH CHEMOTHERAPY AND RADIATION THERAPY AS PART OF ORGAN PRESERVATION

DENNIS H. KRAUS, M.D. & RYAN C. BRANSKI, PH.D.

The management of patients with advanced squamous cell carcinoma of the upper aerodigestive tract has progressed considerably. In the past, surgery with or without radiation was the treatment of choice. However, during the past 20 years, the management philosophy has changed. Patients with advanced disease are now treated with a combination of chemotherapy and radiation therapy with the intent of "organ preservation." Emerging data suggest that these therapies yield improved quality of life. Although the organs of speech and swallowing are spared, these treatments do not guarantee preservation of organ function. Deficits in both speech and swallowing remain common. However, current strategies are yielding high levels of success in rehabilitating speech and swallowing disorders. Xerostomia, or dry mouth, is a major problem inherent in radiation therapy. Its occurrence is nearly universal in patients with oral and head and neck cancer having received radiation and may also contribute to swallowing problems in this population. Although a major problem, it is beyond the scope of this article.

Although swallowing function may be normal prior to treatment, a patient typically develops a severe sore throat during treatment, making it extremely difficult to swallow. However, once radiation therapy has begun, and it is determined that a feeding tube is necessary, the patient may need to discontinue therapy for several days or more while sores heal and the feeding tube is inserted. During this time, it is likely that the tumor will grow. Furthermore, it is

believed that discontinuity of radiation treatment is associated with worse tumor control and survival. As an alternative, a feeding tube is typically placed prophylactically. This measure assures that the patient will be able to maintain both nutrition and hydration during his/her treatment, should swallowing difficulties arise. Malnutrition and/or weight loss during the course of treatment has been associated with poor outcomes. To that end, it is extremely rare that a patient does not receive a feeding tube prior to therapy.

In addition, patients whose airways are in peril may require a tracheostomy prior to treatment. Although the tracheostomy may provide a viable airway for the patient, the tube also provides a considerable challenge for the radiation oncologist to tailor radiation treatments. Given these challenges, tracheostomy is only utilized when there is evidence that the patient's airway may be compromised, and the tracheostomy may be necessary to prevent any potential life-endangering events. However, in the absence of significant airway compromise, every effort is made to avoid tracheostomy.

As noted previously, swallowing disorders (also referred to as dysphagia) are common during the course of radiation treatment. Patients may develop severe burns of the lining of the mouth and throat, commonly called mucositis. The pain can be quite severe, potentially requiring narcotics for pain relief. In addition, patients are typically unable to maintain adequate nutrition and hydration. The duration of mucositis may vary from patient to patient. Typically, mucositis lasts anywhere from 3-4 weeks to several months after the completion of radiation therapy. During that time, patients' swallowing function should be evaluated by a member of the speech and swallowing team. Early detection of dysphagia allows for the development of a rehabilitation strategy to potentially avoid long-term swallowing deficits.

Placement of a feeding tube may also lead to swallowing disorders. Some have theorized that the placement of the feeding tube may decrease patient motivation to swallow during treatment. This type of disuse of the swallowing mechanism can potentially result in major long-term swallowing deficits. First, it can lead to scarring or fibrosis of the muscles essential for swallowing. Second, stricture, or the narrowing of the swallowing passage, may occur. Strictures are thought to be due to sloughing of the inner lining of the throat yielding fusion of the esophagus. A stricture may be so severe that there is a complete blockage of the junction between the throat and esophagus. In severe cases, food placed in the mouth may not be allowed to pass into the esophagus and, ultimately, into the stomach.

The evaluation of patients with dysphagia following organ preservation treatments poses a considerable challenge. Ultimately, recurrence or persistence of cancer must be ruled out as the source of swallowing deficits. To that end, PET/CT provides improved ability

See DYSPHAGIA on next page



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Nancy E. Leupold, MS

WEBMASTER

Barry Sebastian

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IN THIS ISSUE

Clinical Trials.....	3
A Time for Sharing.....	4
Deepening Your Spiritual Resources.....	6
SPOHNC Happenings.....	7

COMING IN NOVEMBER, 2005
A Patient's Guide to Tongue Cancer
Louis B. Harrison, MD & Peter Han, MD

DYSPHAGIA continued from page 1

to identify recurrence over traditional cross-sectional imaging via CT and/or MRI. The increased sensitivity to tumor activity associated with PET scanning permits the determination of dysphagia associated with recurrence, versus dysphagia as a consequence of treatment.

In addition, diagnostic tests to determine the nature and severity of swallowing deficits are necessary. The modified barium swallow allows for visualization of swallowing mechanics to determine the cause of dysphagia. An esophagram allows for visualization of strictures or narrowing of the esophagus that may be the cause of swallowing problems. In addition, FEES (Flexible Endoscopic Evaluation of Swallowing) and FEEST (Flexible Endoscopic Evaluation of Swallowing with Sensory Testing) are more commonly performed and provide increased insight into the function of the structures involved in swallowing. Beyond determining the nature of the swallowing disorder, these tests can also be used to determine the effectiveness of specific interventions designed to improve swallowing function. Furthermore, these tests provide complementary information, so that patients may require multiple tests to determine the nature of dysphagia.

In the case of severe dysphagia associated with stricture or narrowing of the pharynx, endoscopic dilation of the pharynx may be a viable treatment option. Traditionally, this type of procedure was performed in the operating room with the patient under general anesthesia. Using x-ray visualization to assure patient safety, it is now possible to place a small guidewire through the mouth and into the pharynx and esophagus. Dilators are then placed over the guidewire. Larger dilators are used in a serial fashion to stretch the pharynx in hopes of improving swallow function. Although effective, this procedure can only be used when patients have enough mouth opening to place the guidewire. In cases of complete obstruction, it may not be possible to safely pass the guidewire due to increased risk of perforating the esophagus, potentially leading to life-threatening infection of the chest known as mediastinitis.

In such cases, a procedure referred to as antegrade and retrograde esophagoscopy may be indicated to re-establish swallowing. Similar to endoscopic dilation, this procedure is performed under x-ray guidance. An esophagoscopy is performed through the mouth to determine the level of obstruction. Typically, the obstruction is located at the level of the collarbone. Simultaneously, a gastroenterologist performs an endoscopy through the feeding tube. This procedure allows for the flexible endoscope to be passed up through the stomach and into the esophagus. In many cases, using the two scopes allows for visualization of narrow, paper-thin strictures potentially obstructing the upper esophagus. Using endoscopic instruments, it is then possible to open the stricture and dilate the pharynx. Patients may then undergo serial dilations on a weekly basis for a number of weeks or even months. Using this technique, many patients who were previously dependent upon the feeding tube are now able to eat. However, this technique is not successful in all patients. In addition, the procedure itself presents potential risks including injury to the esophagus leading to mediastinitis. In patients in whom this technique has not proven

DYSPHAGIA continued on page 3

successful, there are limited options. Some institutions have reported replacing the pharynx and upper esophagus with a jejunal free-flap with preservation of the larynx or voice box. Another potential treatment option is to remove the entire larynx and pharynx which is known as a laryngopharyngectomy. The area is then reconstructed with a jejunal free-flap. Although this procedure may enable patients to eat again, it sacrifices the patient's ability to speak. There are numerous techniques currently utilized to regain oral communication, but the choice to proceed with such a drastic procedure is a personal choice. The patient, in consultation with his physician, must come to understand exactly what the procedure entails, while the physician must understand the patient's desires and expectations. In some instances, patients may elect to preserve their ability to have normal speech and sacrifice their ability to swallow.

This article intended to provide an overview of the management of post-chemotherapy and/or post-radiation swallowing disorders. Obviously, there are nuances from patient to patient. Moreover, centers will differ in their management as well. However, it is the hope of the authors that patients will recognize that dysphagia after chemotherapy and radiation as a part of organ preservation is not necessarily permanent. There are numerous rehabilitation strategies available to address swallowing disorders and the associated quality of life issues.

Editor's Note: Dennis H. Kraus, M.D., is Director of the Speech, Swallowing, and Rehabilitation Center and Attending Head and Neck Surgeon at Memorial Sloan-Kettering Cancer Center. He is also a professor of otorhinolaryngology at the Weill College of Medicine at Cornell University. Dr. Kraus' primary interests are the management of head and neck cancers, skull base surgery, and rehabilitation of the speech and swallowing mechanism. He has authored over 100 peer-reviewed articles and has written numerous book chapters and other publications.

Ryan C. Branski, Ph.D, is on staff at the Speech, Swallowing, and Rehabilitation Center as an Assistant Attending Speech and Swallowing Scientist. In addition, Dr. Branski is an Assistant Professor of Speech-Language Pathology and Otorhinolaryngology at the Weill College of Medicine, Cornell University. Dr. Branski's primary interest is the development of novel treatments for speech and swallowing deficits associated with head and neck cancers. Together, Drs. Branski and Kraus run an active clinical practice as well as clinical and basic science programs.

INTROGEN THERAPEUTICS' CLINICAL TRIALS

Introgen Therapeutics, Inc., a biopharmaceutical company specializing in the discovery, development and commercialization of targeted molecular therapies, is currently conducting two phase III clinical trials for patients with recurrent squamous cell cancer of the head and neck. ADVEXIN, Introgen's lead cancer treatment, uses the administration of the p53 tumor suppressor gene to reduce the size of tumor growth and destroy cancer cells. By using an adenovirus as a vector, the p53 gene is directly transferred into the tumor cells. Currently, patients who meet the requirements are being treated and tested throughout the United States and Europe.

The first head and neck cancer study, known as T301, compares the survival rate of patients who receive the ADVEXIN gene therapy with those who receive methotrexate, a standard chemotherapy.

Patients with recurrent or progressive head and neck cancer are entered into the study groups randomly and must be 18 years of age or older. Additionally, patients must have failed a chemotherapy treatment of platinum or taxane at least one time and reach a minimum of 5,000 cGy with a standard radiotherapy.

The second randomized clinical study, called T302, compares patients who received two standard chemotherapies, cisplatin and fluorouracil, with or without the ADVEXIN gene therapy. To participate in this study, a patient must be 18 years of age or older, be eligible for four courses of chemotherapy, have received a minimum of 5,000 cGy radiation and have undergone surgery.

A patient may be disqualified from both studies if a similar gene therapy has been performed or if specific organ or tissue transplantation has occurred. The tumor should not be larger than 7.5 cm, chemotherapy must not be performed four weeks prior to the use of ADVEXIN and non-topical corticosteroids may not be given in excess of 6 months.

To view a complete list of participation requirements, please visit the National Cancer Institute website, www.cancer.gov. If you are interested in receiving information directly from Introgen, please call its toll-free number, 1-866-631-INGN (4646), visit the website, www.introgen.com, or send an e-mail to clinicaltrials@introgen.com.

INOVIO'S MEDPULSER SYSTEM

Inovio Biomedical Corporation of San Diego, CA, is developing new strategies to treat cancer. The lead product is an investigational device referred to as the MedPulser System. The MedPulser System has been tested with an anti-cancer drug, bleomycin sulfate, to treat recurring solid tumors of the head and neck regions and various skin cancers. The MedPulser System is being used in the following manner: Bleomycin is first injected into the tumor and the surrounding tissue. Then, the MedPulser System is used to deliver a series of electrical pulses into the cancer tissue called "electroporation". Electroporation causes temporary small openings in the cell walls of cancer cells, which allow bleomycin sulfate to enter the cancer cells.

Inovio is currently conducting two pivotal international, multicenter, randomized, controlled, Phase III clinical trials in patients with head and neck cancer. The protocols are evaluating the efficacy and safety of the MedPulser System in conjunction with bleomycin sulfate administered intratumorally under an Investigational New Drug application that has been reviewed and accepted by the US Food and Drug Administration. Both studies are actively enrolling patients at this time. The primary objective of these two studies is to compare the MedPulser System to standard surgical treatment in ability to preserve patient functional status (e.g., intelligible speech, ability to swallow, normal diet). The company plans to seek FDA approval for this device in combination with bleomycin sulfate when current ongoing studies are completed.

In addition, Inovio is conducting clinical studies in head and neck and cutaneous cancer in Europe to seek market approval.

For more information on Inovio, please call 1-877-MEDPULSER or 1-877-633-7857. For information on our studies visit www.inovio.com.

A TIME FOR SHARING My Journey

May 9, 2004 This is the day that I was diagnosed with cancer. The doctor placed me on disability the very next day. I had just turned 43. My whole world was turned upside down in a matter of seconds. Instead of flying to Miami to do a speaking engagement on May 10th I was in the hospital getting a biopsy of my throat and neck. What follows is a series of updates I sent out to my wonderful support group of family, friends and co-workers during my journey. We had all agreed that I was going to spend all my energy staying focused on getting back to health. My wonderful wife, Colette, took on the task of fielding all the calls in and out with the news to all, but after a week of that, it started to take its toll on her. Consequently, I set-up a distribution list on e-mail for us to update the support group. I wasn't sure if I would be able to be actively involved when the treatments started, but as you will see I was fortunate enough to keep up the correspondence. This became my way of dealing with my situation, and it became important to my healing.

Update 5.19.04 Hello all, I got the results back from my surgery on Tuesday; the biopsy was positive for squamous cell carcinoma which seems to be in my chest and neck. I will be going to Fox Chase Cancer Center within the week for multiple consultations concerning surgery and other treatment options. Keep the faith and pray. I will beat this challenge.

Update on 6.2.04 Hi all. Thanks so much for all your continued cards, medals, e-mails, phone calls and most of all your thoughts and prayers for Colette, Dante and myself. Colette and I went to visit two doctors at Fox Chase on Tuesday from 12:30 - 4:30 PM. Each has a great bedside manner and is the best in his field, so I have that going for me which is nice! Basically they confirmed the cancer in my neck is at the base of my tongue. They also told me that it was a really rare type of cancer for someone who never smoked or rarely drinks, (no comments from the peanut gallery). They are still trying to stage my cancer. So they will be sending me for a PET

scan that will highlight any inflamed spots in my body. They are unable to make a determination on the treatment for my neck until the thoracic surgeon does a biopsy of the lymph nodes in my chest. They are not sure if what they see on the films is squamous cell cancer or a different cancer or just infections. I vote for "just infections", so please say a prayer for that one. We are going back to Fox Chase today to meet with the thoracic surgeon for his evaluation. When the thoracic surgeon does the biopsy in my chest sometime next week, the surgical oncologist will do another biopsy on my neck to map out treatments. They did say that most likely the first course of action will be radiation and chemo. After they look at how the cancer reacts to the treatments, they will decide if a neck dissection is needed. But the BIG outstanding question is what's in my lungs?

They also said that I probably had this for only a few months, not years. They tried to put it in perspective by saying I was a person hit by lightning and if the chest shows positive for a different cancer in the neck, I was struck TWICE. Now, I know I have never tried to do anything average, but on this stuff I would be happy to have a below average name tag. Most likely the next update will happen after the news on the biopsies. I will leave you with this quote from Woodrow Wilson which I have tried to follow my entire life. My niece, Tina, sent it to me last week in a homemade card.

"The only use of an obstacle is to be overcome. All that an obstacle does with brave men is, not to frighten them, but to challenge them." - Woodrow Wilson

Update 06.16.04 Hi All, I received some good news and bad news from the doctors at Fox Chase today. The good news first: the results of my PET scan from Monday came back with the same results as the MRI and CAT scan of two weeks ago. The cancer has not spread to any other areas of my body. I have been scheduled to have two additional biopsies on July 1st at Fox Chase; one in the chest to see if the lymph nodes are the same as the neck or different. If it is the same they will start treatments

most likely the following week. If it is a different cancer in the chest they will need to see which area they will work on first since they can't treat both at the same time. The third option would be that the spot on my left lung could be benign and if that is the case during the biopsy on July 1st they will roll me over on my side and remove that spot from my lung.

Now for the bad news, for those of you who golf, you will appreciate this. They will not be doing any surgery on my neck until after the radiation and chemo, and if the treatment works, they may not need to operate. Most of you would say that was good news, but I was hoping that the surgery would help my golf handicap by 5 or 6 strokes since it would be harder to pick-up my head when I swing, with the missing neck muscles and all. All joking aside, I would consider the news today very positive news. I will leave you with a quote that I received from Barbara Flannery. Thanks again for all the support calls, e-mails, cards, prayers and gifts.

"I can be CHANGED by what happens to me. I refuse to be REDUCED by it."

-Maya Angelou

Update 07.04.04 Hello all. A lot has happened over the past 5 days. Thanks, again for the continued support with visits, calls, e-mails, cards and inspirational books. The best thing was coming home from my 3 day hospital stay late Saturday afternoon to an envelope filled with cards and notes from the my home office in NY. Timing was perfect. Thanks so much for taking the time. Bruce, I see we shop at the same store for cards. Also, I would like to say thanks to Mark, Jeff and Keith, long time friends whom I hadn't seen in years, for stopping by before my surgery last week. It was great catching up. OK enough of the mushy stuff! I had three procedures preformed on July 1st which took about 4 - 5 hours in the operating room. If anybody ever offers you an epidural TAKE IT, it was wonderful. The primary reason for the operation July 1st was to determine what stage my cancer was

along with seeing if the chest tumor was the same as the tumor at the base of my neck. They did frozen sections taken from my throat again and 4 lymph nodes running down my windpipe and sternum, while I was on the table. We will not have the final pathology reports until late next week but they didn't find any cancer in the chest, so they rolled me over on my side and performed a wedge dissection of my left lung removing the tumor and some additional lung which also came up benign. They said that I somehow contacted an air born fungus from the midwest region of the country. This was all great news to hear after coming out of surgery. But wait, it gets better. The tumor in my throat was a bit smaller than originally thought and they have placed me at a stage 4A cancer. In my case we can expect a cure with aggressive chemo and radiation daily possibly even twice a day for 7 straight weeks. Five weeks after the treatments stop, I will be seen by the surgical oncologist to see if a neck dissection is necessary. It is possible I might not need this if the lymph nodes in my neck react well to treatment. I will be having my final consults with the oncology doctors within the next week. I will need my chest and lungs to recover a bit before starting any treatments. So keep praying that the final pathology reports are the same. Hope everybody has a safe and Happy 4th of July. I will let Colette read this over since I'm on some pretty strong pain medication right now. Not only do I have a hole in my head, but now I have five in the side of my back. Take care while I leave you with this quote.

*"There are two days about which nobody should ever worry
And these are yesterday and tomorrow.
So with only today to cope with the burden becomes lighter,
For nobody ever stumbled under the burden of today.
It is only when they add yesterdays and tomorrows to the load they are carrying, that it becomes unbearable."*

---Helen Sterner Rice

Update 07.14.04 Hello all. Well lots more has been happening behind the scenes since the last update. I'm off the pain meds and feeling normal again. Monday July 12th I was able to meet with the radiation doctor and staff. They mapped out my neck and throat for treatments. Tuesday I was at Fox Chase for my post-op visit and to have my stitches removed. The pathology report on my chest came back negative for any cancer, so thanks for all the prayers. I then drove to Reading, PA to have my dentist do a dental evaluation and make fluoride trays that I will use each night to help protect my teeth, since I will most likely lose my saliva. Friday I will be back with the radiation team for a test run on treatments. We have decided to do a Clinical Trial RTOG-0129 for aggressive head and neck cancers. Monday I start both radiation at 7:30 AM and then drive to Fox Chase for a 6 hour chemo treatment. Then I will receive 3.5 weeks of radiation treatments daily at 7:30 AM. On August 9th I will receive another 6 hour chemo treatment at Fox Chase and start 2 radiation treatments daily for 2.5 weeks in the early morning and late afternoon. Right now I feel great and can't wait to get these treatments moving. They have told me I will be losing between 30-60 lbs during the next 2 to 3 months with limited ability to eat and the treatments accelerating my metabolic cycle. That's almost as much as I lost with the Atkins diet. If I had my choice I would rather do Atkins. Thanks so much for the continued support with prayers, calls, visits, e-mails and cards. We do appreciate your taking the time. Colette is hanging in strong and has been tolerating me being around the house so much. Dante is upset because we found out yesterday that the type of chemo I will be receiving doesn't affect the hair, and he was going to be shaving my head before treatments started. I know, let him shave it anyway! I don't have much to cut, sorry I'm partial to what I have. I will leave you all with My David Letterman TOP 10 list.

Top 10 reasons Chris is happy!

10. The Attention, Chris loves to be the center of attention!
9. No cancer found in the lungs or chest.
8. My stitches are out and I don't leak.
I've been told by my wife I'm full of hot air.

7. I'm more than halfway into this Challenge and that makes me that much closer to returning to work.
6. They told me I can be CURED with the treatments.
5. All the Ice Cream I can eat for the next 2 months.
4. I'm not going to lose my hair during chemo treatments.
3. Doctors said I can still ride in my convertible with the roof down during radiation treatments, yes with sun block!
2. I'm going to lose between 30 and 60 lbs without trying over the next couple of months.
1. My friends, family and faith! I feel like George Bailey in the movie "It's a Wonderful Life" the richest man alive.°

Update 7.27.04 Hi all, Well I'm a little more than a week into treatments and I feel pretty good. My first chemo treatment on 7.19 only presented minor side effects of a queasy stomach and numbing of my head thanks to some great breakthrough meds. I know many of you would say the numbing of the head is nothing new. The next 7 to 10 days the chemo will have my blood count at its lowest point, challenging my immune system, so I will stay away from kids and adults with colds. My daily radiation treatments are going well and I have some fatigue, but a 1 to 2 hour nap helps to pick me back up. Did I just admit to taking a nap during the day? I have had an insatiable appetite and still lost 2.5 lbs so they said today I should eat more fat and smaller meals every 2 hours. OK, I can do that. That's it for now, again thanks so much for all the prayers, cards, e-mails, calls and visits. My strength comes from your great support. I will leave you with this quote.

*"What lies behind us?
And what lies before us
Are tiny matters
Compared to what lies within us."*
---- Ralph Waldo Emerson

Christopher Urso
Toms River, NJ

To be continued in the November 2005 issue of "News From SPOHNC."

DEEPENING YOUR SPIRITUAL RESOURCES WHILE LIVING WITH CANCER

by Kava Schafer, M.Div

In Part I, Rev. Schaefer discusses what allows certain individuals to experience themselves as spiritually intact in the face of great adversity and challenge and what is it that promotes a sense of blessing and spiritual growth while facing situations that strive to fragment and pull us off center? She begins Part II discussing spirituality and head and neck cancer patients.

We can look at some of the core issues that face head and neck cancer patients and examine the spiritual correlates to the impact of treatment and the resulting recovery time. Cancer patients share a host of challenges, but it is commonly accepted that head and neck cancer patients can be especially vulnerable to specific life-altering challenges during treatment and recovery. If we isolate a few of these issues, we would find ourselves preoccupied by personal appearance changes, marked changes in the ability to take nutrition by conventional means, and increased difficulty in expressing ourselves in communication with others. Even in these three broad categories, it is easy to see in each one them a linkage to the world of relationships. If we focus in on personal appearance and communication, there are strong possibilities that these changes may deeply impact intimacy with others. A by-product of those difficulties may lead to a growing sense of self-consciousness which may cause one to lose confidence in one's ability to interact and be a vital part of family and community. These are just a few of the issues.

Behind every one of these concerns lie psychosocial dimensions that strongly influence patient coping; yet there is a spiritual dimension to each of these concerns. For instance, changes in personal appearance impact one's family relations, one's relationship with a spouse or partner, and of course, this change alters the way in which we move in the world among strangers. One core question might center on whether we will lose love because of these changes. If we do lose love or only fear that we will, how does that affect our ability to love our selves? I suppose this is what people refer to as low self-esteem, but it can possess even greater weight when we begin to question our value in the scheme of things, our place and value in the world, and our relationship to God. Do we experience ourselves as worthy of love?

The same possibilities also apply to difficulties in communication with friends, family, etc. A sense of isolation may develop and one's world begins to narrow in ever deepening ways. Self-consciousness grows into the threat of alienation from others and then from one's own sense of self. When we become estranged from ourselves, it is conceivable that this might lead to a sense of estrangement from God. If we are having difficulty in being understood, there is the possibility that one might stop trying to communicate one's needs and desires to God as well. Such a situation constitutes spiritual distress. Our spirituality works for us, but also it can work against us if we are overwhelmed, and our religious or spiritual system of values, beliefs, and practices no longer possesses sufficient elasticity to support us during crisis. In my work, I often encounter spiritual distress in the form of anger at God. Why has a loving God let this happen to me? Where is God right now? Why haven't my prayers been answered? Often people will wrestle with guilt over life-style choices that they believe may have contributed to their illness. These are not always easy things to admit to a chaplain because it is not unusual to find guilt and shame entwined with the anger and the sense of self-judgment.

When permission is given to express this anger, often the blockage or estrangement breaks and communication is restored to God once again, which in itself may unblock the other life impasses. Spiritual distress has the power to choke the soul. A blocked spirit saps life vitality that is desperately needed to cope with the challenges of living with disease. This is another way to say that all of these dimensions are interconnected. I would advise anyone experiencing these symptoms of spiritual distress to seek help from a pastor or a chaplain. If the person is not religious, certainly look for guidance from someone skilled in recognizing these common complications of serious illness. I put additional stress here on the normalcy of these concerns. Even persons of great religious faith may find their faith not as life-enhancing as they had once experienced it in health.

Receiving a serious cancer diagnosis can generate a grieving process. Something will feel lost. We commonly think of the loss of our health as the first casualty, but often the losses collapse into one another like a nested Chinese box. A dream may die, plans may evaporate, the certainty about life and its fairness may disappear. Our whole world view may come crashing down. This gives us some idea as to why there are so many dimensions to a cancer diagnosis and all of the treatment that follows. When our understanding of the world shifts, we are left with the opportunity for the growth of a deeper perspective or we may find that we simply cannot accommodate to the changes in our lives. All of these changes that feel like losses need to be grieved even when hope for life returns and new dreams emerge. Connecting to our spirituality gives us the capacity to make meaning of what seem like unbearable choices and situations. Spirituality graces us with the gift of creative imagination. Illness leads to a slower pace of life, a space for reflection, which may never have been consciously sought during periods of health. The spirit is infinitely resilient. My patients tell me that being able to find some kind of meaning in their experience will enable them to persevere. And yet that implies that survival is the extent of the spiritual growth. If I left you with that impression, I would be remiss. Finding meaning transforms the situation and transforms us.

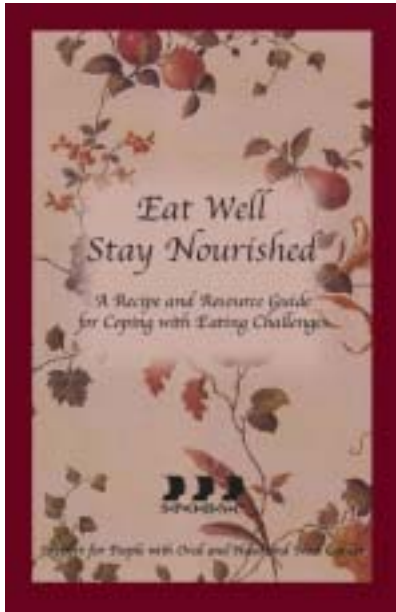
This is just a brief overview of a complex subject. I will end by sharing some of the wisdom that my patients often tell me. My patients have taught me how to live. I hear repeatedly that the struggle of illness has enabled people living with cancer to discover the true meaning of life for them. Maybe they had a glimmering of this while they were healthy or maybe not. Perhaps, they also practiced spirituality before or maybe not, but right across those lines of difference, people tell me that their illness has been a blessing to them in the sense that they now know what is truly important and what has the most meaning and value for them. In their coming to terms with human frailty and limits, a new compassion often is born. Inside the experience of vulnerability, a new strength may emerge. Repeatedly, I am told that Love is the source of this courage, strength and compassion. It is up to the individual to discover the source of that mysterious Love.

Editor's Note: Kava Schafer, M.Div is the primary staff chaplain on the Bone Marrow Transplant Unit at The Hospital of the University of Pennsylvania. Rev. Schafer specializes in providing pastoral care to oncology patients and their families.

SPOHNC HAPPENINGS

IT'S ARRIVED!

“Eat Well – Stay Nourished: A Recipe and Resource Guide for Eating Challenges”



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