Depression Among Survivors of Head and Neck Cancer

Allen M. Chen, MD

Introduction

Advances in the diagnosis and treatment of head and neck cancer over the last several decades have resulted in more patients surviving for longer periods of time. While physicians are encouraged by these statistics showing that head and neck cancer is as curable as ever, attention has increasingly focused on “survivorship” issues—those related to long-term functioning and quality of life. Although the benefit of aggressive treatment often utilizing multiple modalities including surgery, radiation therapy, and/or chemotherapy, is indisputable with respect to survival, the potentially detrimental effects on oral and physical health have become increasingly recognized as more patients are presumably cured.

Treatment-related side effects such as swallowing difficulty, neck stiffness, chronic dry mouth, speech impediments, and nerve irritation can persist for years and have a negative impact on well-being, defined as the subjective perception of one’s life. Indeed, it has long been hypothesized that patients with head and neck cancer, some of whom have a history of significant tobacco and alcohol use, suffer from disproportionate emotional distress due to the possibility of physical disfigurement from disease progression and/or treatment, as well as from impairment of such basic human functions as eating, speaking, and breathing.

Depression in Head and Neck Cancer Patients

Studies have convincingly shown that survivors of head and neck cancer are at dramatically higher risk for developing symptoms of depression. While the reasons are speculative, this is of particular relevance since depression not only adversely affects quality of life but its symptoms are also quite treatable. A recent study published by the David Geffen School of Medicine at the University of California, Los Angeles (Chen AM, Daly ME, Vazquez E, Courquin J, Luu Q, Donald PJ, Farwell DG. JAMA Otolaryngology Head Neck Surg. 2013 Sep;139(9):885-9) showed that the prevalence of self-reported depression among survivors returning for follow-up was 17 percent during the first year, 15 percent in the second year, and 13 percent the following year. By comparison, only about 6.7 percent of U.S. adults suffer from major depression in any given year, according to the National Institute of Mental Health. The fact that none of the patients in the study had a pre-existing diagnosis of mental health problems thereby suggests that the diagnosis of head and neck cancer and/or side effects of subsequent treatment were likely the primary etiologies for their psychosocial symptoms. Others have similarly suggested rates of depression ranging from 8 to 44% at various time points after head and neck cancer treatment, with the wide range likely due to the variability in screening instruments and patient characteristics across studies. Even more striking, data has shown that the suicide rate among patients with head and neck cancer is more than four times greater compared to that of the general population.

Risk Factors

The reasons why some head and neck cancer patients get depression and others don’t are poorly understood. For some, simply having a diagnosis of cancer is enough to trigger a cascade of negative emotions that never completely subside despite being rendered cancer-free with treatment. For these patients, the fear of the unknown, particularly with continued follow-up visits, leads to a heightened tension, which can unfortunately become chronic. For others, the lingering side effects of cancer and/or its treatment take a toll. For instance, many patients continue to experience a lack of normalcy with regard to functions, which were once taken for granted including swallowing, speaking, chewing, and/or sleeping. Physical reminders of cancer including surgical scars and defects including the presence of a tracheostomy and/or gastrostomy-tube can also have a profoundly detrimental effect on well-being. For instance, surgical neck dissection is often associated with poor shoulder function and impaired neck mobility, which can profoundly affect quality of life. It is also well known that chronic pain, particularly if poorly managed, is a leading risk factor for depression.

The effect of cancer and/or its treatment on long-term social functioning is an increasingly studied topic for researchers. It is becoming clear that patients with head and neck cancer are at risk for social isolation. Side effects of treatment including physical deformities, speech impediments, and dietary restrictions are often

DEPRESSION continued on page 2
DEPRESSION continued from page 1

visible sources of embarrassment and can lead to patients withdrawing from friends and family. Other factors such as the inability to attend social functions, the effect of illness on employment, and restrictions on activities are now thought to contribute to well-being for cancer survivors.

Symptoms of Depression

The symptoms of depression can be variable and may have even existed for long periods of time prior to diagnosis. Although a universal definition does not exist, depression is often characterized by a pervasive and persistent low mood, which is accompanied by low self-esteem and by a loss of interest or pleasure in normally enjoyable activities. Patients may experience feelings of sadness or unhappiness; irritability or frustration, even over seemingly simple matters; insomnia or excessive sleeping; reduced sex drive; changes in appetite with weight gain or loss; agitation or restlessness; troubled concentration and/or slowed thinking; loss of energy; and feelings of worthlessness or guilt. Patients with unexplained physical problems such as back pain, headaches, or fatigue should also be considered for depression.

Contrary to public belief, depression is not a normal part of the treatment process for head and neck cancer patients. Unfortunately, depression is very likely to go undiagnosed in this population, particularly among older adults. As a result, many adults with depression feel reluctant to seek help when they’re feeling down. Furthermore, in elderly patients, depression often goes undiagnosed because symptoms— for instance, fatigue, loss of appetite, sleep problems, or loss of interest in previously enjoyable activities— may seem to be caused by other illnesses or blamed on other processes. Additionally, elderly adults with depression may have less obvious symptoms. They may feel dissatisfied with life in general, bored, helpless or worthless. They may always want to stay at home, rather than going out to socialize or doing new things.

Screening and Diagnosis

Unlike for many other medical conditions, there is no standard way of diagnosing depression. The diagnosis of major depressive disorder is based on the patient’s self-reported experiences, behavior reported by relatives or friends, and clinical evaluation including the use of mental status and/or psychiatric examination. There is no laboratory test for major depression, although physicians generally request tests for physical conditions that may cause similar symptoms. Many medical conditions and medications can cause symptoms of depression, including sadness, fatigue, and the loss of pleasure. Hypothyroidism, or underactive thyroid, is a particularly common reason for depressive symptoms, especially after radiation therapy. Older adults, or anyone who takes many different medications each day, are at risk for drug interactions that cause symptoms of depression.

Although various self-reported questionnaires have been proposed to help screen for depression, there is no universally accepted tool. Notably, these suffer from the problems inherent in any self-reporting inventory in that scores can be easily exaggerated or minimized. Patients need to be aware that depression is relatively common after head and neck cancer and encourage to seek help if they have symptoms.
DEPRESSION continued from page 2

Importance of Treatment

Despite the common belief that depression is not life threatening, its symptoms should never be ignored. This is because the consequences of untreated depression can be severe. Several reports have demonstrated that the incidence of suicide in cancer patients is dramatically higher than among the general population. From a therapeutic standpoint, untreated depression has been demonstrated to affect compliance to treatment and follow-up, wound healing, appetite, and contribute to prolonged hospital stays. The effects of depression on such functions as sleep, energy, and motivation have also been well described. By intensifying weight loss and fatigue, depression also has the potential to exacerbate treatment-related side effects leading to a vicious cycle, which may not only worsen depression and increase disability, but also impact cancer control.

Compounding this predicament is the fact that mental health services are severely underutilized among patients with cancer. Study after study has consistently shown that although many patients have symptoms of depression after cancer treatment, only a tiny minority ever are referred for professional counseling or are started on anti-depressant medication. Even when patients are referred for counseling, compliance with treatment recommendations has historically been low. Whatever the reasons-- insurance or financial barriers, lack of a primary care physician, lack of patient interest, poor follow-through on recommendations, and/or the fear of the social stigma of mental illness-- a sorely unmet need for psychosocial services among head and neck cancer survivors exists. This is unfortunate because depression, when appropriately diagnosed, is highly treatable.

Treatment Options

Just as no two people are affected the exact same way by depression, there is no “one size fits all” treatment that cures depression. What works for one person might not work for another. In this sense, depression remains a challenge to treat and often requires a combination of different modalities. The best way to treat depression is for patients and their physicians to become as best informed as possible about the treatment options, and then individually tailor them to optimize care.

Counseling

Although there are many types of mental health workers, one of the most important things to consider when choosing a therapist is to ensure that this professional has a thorough understanding of cancer treatment and is familiar with details of the oncologic history including side effects that have developed. Ideally, the mental health specialist should work closely with the oncology team.

Group support

Listening to peers going through the same struggles can validate one’s experiences and help build self-esteem. Often group members are at different points in managing their depression, so it might be valuable to obtain advice from others who have already worked through challenging problems. As well as offering inspiration and ideas, attending group therapy can also help increase social activities and network. The importance of validating and legitimizing one’s feelings through interaction with others cannot be understated.

Anti-depressant medication

At least 40 drugs have been approved by the Food and Drug Administration and are available by prescription for the treatment of depression. Since potential side effects, as well as interactions with other medications a patient might be taking concomitantly, vary significantly, it is important that the use of anti-depressants be individualized after a thorough review of the patient’s history and current level of functioning. This is especially important because dry mouth, which many patients with previous head and neck cancer suffer from, is a common side effect of many anti-depressants.

Alternative treatments

Alternative and complementary treatments for depression may include vitamin and herbal supplements, acupuncture, and relaxation techniques, such as mindfulness meditation, yoga, or Tai chi. The jury is still out on how effective these alternative treatments work in treating depression. While many supplements are widely available over the counter, in many cases their efficacy has not been scientifically proven. Another concern is that many natural and herbal supplements can interfere with prescription drugs including traditional anti-depressants if they are taken at once. Acupuncture, the technique of using fine needles on specific points on the body for therapeutic purposes, is increasingly being investigated as a treatment for depression, with some research studies showing promising results.

Lifestyle changes

The importance of lifestyle changes should not be underestimated in the management of depression. Regular exercise, well-balanced nutrition, and adequate sleep have all been shown to be as effective as treating depression as medication. Building strong social networks and keeping in contact with friends and family have also been demonstrated to improve quality of life among cancer survivors. Participating in classes/groups and/or volunteer work can also have a beneficial effect on well-being. Lastly, efforts to reduce ongoing stress, whether from work or relationships, should be undertaken. Relaxation techniques may be useful to reduce stress and boost feelings of contentment and well-being.

Conclusions

Studies are increasingly showing that survivors of head and neck cancer are at risk for developing depression. While the reasons for this are varied, patients and their loved ones should be aware of its symptoms and encouraged to seek help when necessary. Similarly, physicians should be regularly discussing the psychosocial impact of head and neck cancer and its treatment with patients, particularly as more patients are living longer.

Editors Note: Dr. Allen Chen is an Associate Professor, Vice Chair of Education, and Residency Training Program Director at the David Geffen School of Medicine at UCLA. He earned his medical degree from Yale University and completed residency training at the University of Texas-MD Anderson Cancer Center and the University of California, San Francisco. Dr. Chen has published more than 100 original peer-reviewed articles and has an international reputation in the treatment of head and neck cancer.

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IN MEMORIUM...Karl J. Leupold

SPOHNC is deeply saddened to share the news of the recent passing of Karl Leupold, husband of our Founder and President, Nancy, on December 9, 2013. Karl was a dedicated husband, who supported Nancy in countless ways, when she began SPOHNC in 1991. He continued to be a great presence within the organization for many years, attending and supporting SPOHNC conferences and events across the country, with Nancy. He was a much appreciated partner in her vision to create and go forward with this organization - a very silent but strong influence in her quest.

Karl was a proud graduate of Duke University, served in the U.S. Marine Corp, and was an engineer and Assistant Superintendent for Con Edison. He was a Town Engineer, Superintendent of Engineering and Deputy Commissioner of Public Works for the Town of Oyster Bay, in New York. He became Commissioner of Public Works for the Town of Oyster Bay in 1990, and remained in that position until his retirement in 2002. He was also a longtime member of the New York State Society of Professional Engineers, Nassau County Chapter, and was designated as “Engineer of the Year” in 1997. While fulfilling his Town and family responsibilities, as a proud father and grandfather, Karl also gave generously of his time and talents to many organizations, as President of the Locust Valley Rotary Club, a Scoutmaster, a member of the Board of Directors of the United Presbyterian Home and the Long Island Heart Council. He also served as a Sunday School teacher and an Elder in the Reformed Church of Locust Valley for many years. Karl was a true friend to SPOHNC and those who knew him, and will be missed by many.

Eat Well Stay Nourished
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(Available for purchase on our website at www.spohnc.org or by calling 1-800-377-0928)

Swedish Berry Pudding

4 c. berries (fresh or frozen strawberries, blueberries, raspberries, blackberries)
2 c. water
½ c. sugar (use slightly more if you like it sweeter rather than tart or use Splenda/other sweetener)
2 Tbsp. cornstarch
2 Tbsp. cold water
1 - 2 Tbsp. sugar (sprinkle on top to prevent a skin from forming)
Whipped cream (optional)

Bring berries to a boil with the water. Add sugar; stir until sugar is dissolved. In a small bowl, mix the cornstarch with cold water until it is syrupy. Add a tablespoon of the hot berry mixture into the cornstarch. Add it to the remaining hot berry mixture. Cook over medium heat, stirring constantly until it thickens. Remove from heat and pour into individual glass dishes or one large glass bowl. Sprinkle lightly with sugar to prevent a skin forming. Let cool. Serve with whipped cream.

Jane Zanca, New York
HEAD AND NECK CANCER NEWS

Screening Device Differentiates Between Normal and Unhealthy Cells

University of Surrey (UK) - A University of Surrey research team has developed an innovative device that can differentiate between normal and unhealthy cells. The team, led by Michael Hughes, Professor of Biomedical Engineering, has developed a device that analyses the electrical properties of cells - with hopes that it will enable the early detection of oral cancer and other medical conditions. The device is commercially available through its distributor Labtech, having been formally launched recently at the AES Electrophoresis Society.

The instrument - called the 3DEP - is the result of over a decade’s research by Professor Hughes and his colleagues Dr. Kai Hoettges and Dr. Fatima Labeed of the Department of Mechanical Engineering Sciences. The device works on the principle that when cells transition from a healthy to a diseased state, there is a change in their electrical properties. Using a technique known as dielectrophoresis (DEP), cells are scanned by the 3DEP to determine their electrical properties and differentiate between normal and cancerous ones. In addition to the reader, the team has developed an inexpensive chip (costing about £5), which contains the cells and is inserted into the reader. Applications of the 3DEP instrument are diverse, ranging from the detection of oral cancer to stem cell research and drug screening.

Explaining his motivation for developing the 3DEP, Professor Hughes said: “Platform technology is an overused phrase, but it means that this device can enable a wide range of important research. “We are currently involved in clinical trials to use the device to detect oral cancer in conjunction with the Eastman Dental Institute, the Royal Marsden and Bradford Royal Infirmary. Oral cancer is the sixth most common cancer worldwide; it is the most common cancer in India. Yet there is no cheap diagnostic approach to catch oral cancer at an early stage. With the 3DEP we are now making real progress.”

“We are also working with colleagues at the University of California to identify stem cells that can be used to repair damage in the brain. This research may help researchers find solutions to chronic neurological conditions such as Alzheimer’s disease, Parkinson’s disease and spinal cord injury. We are also working locally with collaborators in the University of Surrey’s Faculty of Health and Medical Sciences to study muscle and nerve electrophysiology and red blood cell chronobiology.”

The patented 3DEP system has been brought to market by DEPtech, which was set up in 2007 to commercialise the invention. It is available through Labtech (www.labtech.co.uk) and via the DEPtech website. The project has already generated over £1 million, which has been ploughed back into research.

IN MEMORIUM...Larry G. Menkhoff

It is with a sad heart and a tear that we share the passing of one of the original and very influential members of our SPOHNC, Dallas, Texas Chapter Support group. Larry Menkhoff passed away recently, after not only battling a recurrence of the cancer that so many have shared, but also the effects of a stroke he had a few years ago.

Larry was a very engaged member of his SPOHNC Chapter, filling in for facilitator Dan Stack when he needed to be out of town, and also researching and explaining issues brought up at meetings by fellow patients and survivors. Larry was always very meticulous with his information - his file filled with data about products, resources and support for oral, head and neck cancer patients and survivors. He was a true believer in giving hope and a sense of purpose to all that were his friend and fellow survivor. He was quick with a smile and also loved to share a laugh. Facilitator, Dan Stack, shared with us that he would often jokingly threaten to separate Larry from fellow survivors Brad Pate and Jim Holbrook for their light hearted banter with some group members as they would always sit close to each other.

Larry joined SPOHNC’s National Survivor Volunteer Network as a match volunteer in 2003. As a member of the NSVN, he was always ready to help anyone, as they travelled the journey that he knew so well.

Larry graduated from Tulsa Junior College and ultimately earned his Ph.D. at Embry-Riddle Aeronautical University. He was a veteran of the armed forces, having served his country honorably with the United States Air Force. He spent most of his working life with L-3 Communications as Manager of Operations. Larry also volunteered in several capacities including the Owasso Volunteer Fire Department, Owasso, OK Little League, and Owasso Rams Booster Club. He was a 32nd Degree Mason and had served as Worshipful Master in the Owasso Lodge, Kingsville Texas Lodge, and Bishop Texas Lodge.

Larry was married to his lovely wife, Linda for 46 beautiful years. They have 2 daughters, six grandsons, three great grandsons and four great granddaughters.

After Larry’s first diagnosis and recovery from oral, head and neck cancer, he quoted humorist Evan Esar “We can’t do much about the length of our lives, but we can do plenty about its width and depth” – which speaks volumes of Larry’s great personality and character. He made a lasting impact on those who were fortunate to know him. Brad Pate summed it up perfectly when he said Larry “gave of himself until he gave his all, then he gave some more.” He was a true servant leader, and will be missed by many.

March is Social Worker Appreciation Month

Is your Social Worker extraordinary? SPOHNC wants to know.

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We’ll feature outstanding social workers in the March issue of “News from SPOHNC”.

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“To love someone deeply gives you strength. Being loved by someone deeply gives you courage.”
~ Lao-Tzu

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A TIME FOR SHARING...A Family’s Journey

It was October, 2003. Both Bob and I were feeling well and we were planning a trip to Las Vegas and Sedona. Bob’s high school class was having an all school reunion and he was looking forward to seeing some old friends. A few weeks before we were to leave, Bob felt a lump in his neck. He went to see his internist who immediately sent him to see a surgeon. We both listened to the surgeon’s comments and came away with totally different feelings. The surgeon said the lymph node had to be removed, but that we should first enjoy our vacation. From different comments the surgeon made, Bob felt the lymph node was benign and I had that sinking feeling that it was malignant.

We had a wonderful time on our vacation, but when we came home we were not faced with good news. Bob had the outpatient surgery at Evanston Hospital and all went smoothly, but after the surgery when the doctor spoke to me he immediately said he thought the node was malignant which didn’t really surprise me. I spoke to both of my children and we decided to wait for the final pathology results before saying anything to Bob. I was extremely anxious the next four days waiting for results, which took longer than expected. I called the doctor’s office and they kept saying that the pathology report had not been completed. What was taking so long? Finally at 10 P.M. on Thursday evening, the doctor called and said to Bob, “It’s a cancer and we know it’s secondary so it’s somewhere else in your body. These are the tests that now must be done.” Apparently the doctor thought I had shared the news of a possible malignancy, so he couched nothing when speaking to Bob. When Bob got off the phone he could scarcely breathe and needed to go outside for some air. The doctor said it was a very rare tumor and the pathology was still being studied. We called our son who was doing a pediatric residency in Florida and he flew home to us in Chicago early the next morning. He went straight to the surgical hospital and spent several hours talking to the pathologist. They were still uncertain as to the pathology of the tumor, but eventually said it was an “interdigitating dendritic cell sarcoma”, which behaved more like a lymphoma and should be treated as such.

We didn’t know how to proceed, but Bob took several P.E.T scans and no cancer was evident anywhere else in his body. We were happy and perplexed at the same time. Our son e-mailed doctors all over the world and no one could come up with a definitive answer as to how to proceed. The slides were also sent to Massachusetts General Hospital for a diagnosis. They concurred with Evanston’s diagnosis.

We made appointments to see different oncologists at the major hospitals in Chicago. First we went to Evanston Hospital. Their oncologist had never heard of an “interdigitating dendritic cell sarcoma” and didn’t know how to treat it. He said he would speak with the other oncologists on the staff and then asked if he could xerox the huge folder of material that we had accumulated. He later called and told us that Bob should probably have some radiation. We then went to Northwestern and saw a lymphoma specialist, who also was not familiar with Bob’s type of tumor, but suggested the standard chemo treatment for lymphoma patients. After Northwestern we made our way to the University of Chicago. The oncologist there recommended the same treatment as Northwestern. Bob then came up with a wonderful idea. Since no test he had taken had shown cancer in his body he felt the best approach was watchful waiting. The oncologist said that would be acceptable if Bob took a bone marrow test. As long as the bone marrow test was clean, then they would proceed with watchful waiting and Bob would take P.E.T. scans every three months.

That procedure was followed for the next two years and all the P.E.T. scans were clean. Finally, Bob was told that he did not need any more P.E.T. scans, but should get a good physical exam yearly. Bob said, “If you have to have cancer this is the way to have it. I’m doing great.” Life had gone back to normal for us. Then in 2006..............our world again collapsed.

In 2005 Bob was diagnosed with sleep apnea and started wearing a special mask over his face while sleeping. He was not happy wearing it, but knew what was best for him. After about a year of wearing the mask, he felt some discomfort and numbness around his left nostril and up the left side of his face. He stopped wearing the mask expecting the discomfort to go away. Surprise! It got worse.

Bob went from doctor to doctor, had numerous CT scans of the head and was told the same thing by every doctor; the scans were all negative. Bob was told he had facial neuropathy and medication was prescribed. This went on for almost a year as Bob was getting worse and the pain was getting more intense. One day, Bob met the surgeon who had removed the original lymph node in 2003. They discussed his new problem. Bob asked if the pain and numbness could be related to his original cancerous lymph node and the doctor said, “No.”

In March of 2007, Bob went to a new ENT physician and we finally got a few answers. He had Bob take a skull base CT scan and it showed an enlargement of the infra orbital nerve canal on the left side of his face. That nerve led to the brain. Now we could move a bit faster. We found a surgeon who was able to biopsy a piece of the enlarged nerve and they found the same cancer that had been found in the original lymph node four years earlier.

Now we had some big decisions to make. For assistance, we again called on our son. There were still so many unanswered questions, but we decided to go with the lymphoma doctor from Northwestern who said we had to think “outside the box” since this was such an unusual tumor. He finally came up with a plan and felt chemo should be started immediately. Our daughter, also in the medical field, said that even though the slides had been read by some of the leading pathologists, she wanted the slides sent to one more person. Having our children to help us through Bob’s cancer journey was truly a blessing. Our son and daughter were both able to use their expertise in the medical field, to help Bob access the best care and treatment possibilities.

Since Bob’s tumor had been originally diagnosed as a sarcoma, our daughter wanted the slides read by a sarcoma specialist. No one seemed to want to do the legwork and our continued on page 8
They had seen squamous cell tumors on a nerve, so they weren’t sure how to treat it. The doctors had never seen a melanoma growing on a nerve before. They concurred with the diagnosis.

The slides were sent to Sloan Kettering and they connected with one of those unusual desmoplastic melanomas that have produced lymph node metastasis before the primary was discovered.” The next day he left me a note saying, “I couldn’t call. It felt like I was calling a funeral home.”

Of course Bob knew he had no options. In the middle of September, he had the surgery in which 35 lymph nodes, the lining of the sinus and a large part of the cancerous nerve were removed. Toward the end of October, he started his hospital stays. The treatments were grueling, but Bob maintained a good attitude and was a model patient. He rarely complained and did what had to be done. He made many friends during treatment - everyone on his floor, 6 east, had a similar regimen for oral, head and neck cancer. It was 25 miles each way to the hospital, but I went to visit for a good part of every day.

On our anniversary the hospital baked a cake for us. The University of Chicago Hospital was not computerized at that time, so each time Bob checked in they asked the same questions as they did for his previous stay. Once when they asked to see his photo ID he said, “You mean there is someone out there looking to steal my identity so they can take my chemo and radiation?” Bob never lost his sense of humor and developed a good relationship with the nurses and other staff. On another occasion a floor nurse with a heavy accent was asking the same questions she asked each time he came to the hospital. He had trouble understanding her, and after one question he paused and said, “Yes, I guess I’m ready to die.” She replied, “I didn’t ask if you were ready to die; I asked if you were on a regular diet.” We both had a chuckle and were happy to respond.

It has been 5 years since Bob finished his treatment and all of his CT scans and MRIs have been negative. He has some residuals, such as total numbness on the left side of his face and much discomfort around his eye. We are thankful that all went as well as it did, but never a melanoma.

They were finally able to come up with a plan. Bob was to have surgery to map out a radiation plan and to remove as much of the nerve and tumor as possible. The treatment would consist of five days in the hospital with 24/7 chemo and one radiation treatment daily, then nine days at home over 14 weeks. When they started to tell Bob their plan of action he was sitting straight in a chair. By the time they finished, he was totally slumped down in his chair. His first words were, “I’m not going to do it.” So they told him to think about it and call them. The next day he left me a note saying, “I couldn’t call. It felt like I was calling a funeral home.”

On July 19, 2007 Bob had his first intravenous chemo treatment at Northwestern Hospital. When we arrived home there was a fax from the hospital and we were in shock when we read it. The report said, “I can understand why you think this is a sarcoma, but the mass strongly suggests that we are dealing with a desmoplastic melanoma with neurotropic features. This seems to represent one of those unusual desmoplastic melanomas that have produced lymph node metastasis before the primary was discovered.”

The son insisted that Bob start chemo immediately. We had already spent too much time looking for answers. I finally decided to send the slides to the specialist.

Bob had been misdiagnosed from the very beginning and we were now back to square one. We were ready to fly to Sloan Kettering, but thankfully, Sloan Kettering recommended a team of head and neck doctors at the University of Chicago.

In the middle of August, 2007 we spent the day at the University of Chicago. We saw a surgeon, an oncologist and a radiation oncologist all on the same day. They told us they would discuss Bob’s case at the hospital’s tumor clinic and figure out a plan of action. None of the doctors had ever seen a melanoma growing on a nerve so they weren’t sure how to treat it. They had seen squamous cell tumors on a nerve, but never a melanoma.

When they started to tell Bob their plan of action he was sitting straight in a chair. By the time they finished, he was totally slumped down in his chair. His first words were, “I’m not going to do it.” So they told him to think about it and call them. The next day he left me a note saying, “I couldn’t call. It felt like I was calling a funeral home.”

Of course Bob knew he had no options. In the middle of September, he had the surgery in which 35 lymph nodes, the lining of the sinus and a large part of the cancerous nerve were removed. Toward the end of October, he started his hospital stays. The treatments were grueling, but Bob maintained a good attitude and was a model patient. He rarely complained and did what had to be done. He made many friends during treatment - everyone on his floor, 6 east, had a similar regimen for oral, head and neck cancer. It was 25 miles each way to the hospital, but I went to visit for a good part of every day.

On our anniversary the hospital baked a cake for us. The University of Chicago Hospital was not computerized at that time, so each time Bob checked in they asked the same questions as they did for his previous stay. Once when they asked to see his photo ID he said, “You mean there is someone out there looking to steal my identity so they can take my chemo and radiation?” Bob never lost his sense of humor and developed a good relationship with the nurses and other staff. On another occasion a floor nurse with a heavy accent was asking the same questions she asked each time he came to the hospital. He had trouble understanding her, and after one question he paused and said, “Yes, I guess I’m ready to die.” She replied, “I didn’t ask if you were ready to die; I asked if you were on a regular diet.” We both had a chuckle and were happy to respond.

It has been 5 years since Bob finished his treatment and all of his CT scans and MRIs have been negative. He has some residuals, such as total numbness on the left side of his face and much discomfort around his eye. We are thankful that all went as well as it did, but in the end, Bob is happy to wake up each morning and continue to live a normal and productive life.

Joanne Colen
greens716@comcast.net
<table>
<thead>
<tr>
<th>Chapter Location</th>
<th>Chapter Location</th>
<th>Chapter Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>ALABAMA-BIRMINGHAM</td>
<td>COLORADO-DENVER</td>
<td>FLORIDA-SARASOTA</td>
</tr>
<tr>
<td>ARIZONA-CHANDLER</td>
<td>COLORADO-PUEBLO</td>
<td>FLORIDA-THE VILLAGES</td>
</tr>
<tr>
<td>ARIZONA-PHOENIX/MESA</td>
<td>CONNECTICUT-NEW LONDON</td>
<td>GEORGIA-ATLANTA-EMORY</td>
</tr>
<tr>
<td>ARIZONA-PHOENIX</td>
<td>CONNECTICUT-NORWICH</td>
<td>GEORGIA-AUGUSTA</td>
</tr>
<tr>
<td>ARIZONA-SCOTTSDALE</td>
<td>DC-GEORGETOWN</td>
<td>GEORGIA-COLUMBUS</td>
</tr>
<tr>
<td>ARKANSAS-HOT SPRINGS</td>
<td>FLORIDA-BOCA RATON</td>
<td>IL-EVANSTON/HIGHLAND PARK</td>
</tr>
<tr>
<td>ARKANSAS-NORTHWEST</td>
<td>FLORIDA-FT MYERS</td>
<td>ILLINOIS-MAYWOOD</td>
</tr>
<tr>
<td>CALIFORNIA-LOS ANGELES-UCLA</td>
<td>FLORIDA-FTWALTONBEACH/NW FL</td>
<td>ILLINOIS-SPRINGFIELD</td>
</tr>
<tr>
<td>CALIFORNIA- NEWPORT BEACH</td>
<td>FLORIDA-GAINESVILLE</td>
<td>INDIANA-FORT WAYNE</td>
</tr>
<tr>
<td>CALIFORNIA-ORANGE-UCI</td>
<td>FLORIDA-JACKSONVILLE/FCO</td>
<td>INDIANA-INDY-NORTH</td>
</tr>
<tr>
<td>CALIFORNIA-SAN DIEGO</td>
<td>FLORIDA-JACKSONVILLE/UFS</td>
<td>INDIANA-INDY-WEST</td>
</tr>
<tr>
<td>CALIFORNIA-SOUTH SAN FRANCISCO</td>
<td>FLORIDA-LECANTO</td>
<td>INDIANA-SOUTH BEND</td>
</tr>
<tr>
<td>CALIFORNIA-SANTA MARIA</td>
<td>FLORIDA-MIAMI/UMS</td>
<td>INDIANA-TERRE HAUTE</td>
</tr>
<tr>
<td>CALIFORNIA-STANFORD</td>
<td>FLORIDA-NAPLES</td>
<td>IOWA-DES MOINES</td>
</tr>
<tr>
<td>CALIFORNIA-VENTURA</td>
<td>FLORIDA-OCALA</td>
<td>KANSAS-KANSAS CITY</td>
</tr>
<tr>
<td>COLORADO-COLORADO SPRINGS</td>
<td>FLORIDA-PALM COAST/NORTHEAST</td>
<td>KANSAS-TOPEKA</td>
</tr>
</tbody>
</table>

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<table>
<thead>
<tr>
<th>LOUISIANA-BATON ROUGE</th>
<th>NEBRASKA-OMAHA/NMC</th>
<th>NEW YORK-ROCHESTER</th>
</tr>
</thead>
<tbody>
<tr>
<td>MAINE-AUGUSTA/CENTRAL</td>
<td>NEW JERSEY-ENGLEWOOD</td>
<td>NEW YORK-STONY BROOK</td>
</tr>
<tr>
<td>MARYLAND-BALTIMORE-GBMC</td>
<td>NEW JERSEY-LONG BRANCH</td>
<td>NEW YORK-SYOSSET</td>
</tr>
<tr>
<td>MARYLAND-BALTIMORE-JHMI</td>
<td>NEW JERSEY-MORRISTOWN</td>
<td>NORTH CAROLINA-ASHVILLE</td>
</tr>
<tr>
<td>MARYLAND-LIBERTYTOWN</td>
<td>NEW JERSEY-PRINCETON, UMC</td>
<td>NORTH CAROLINA-DURHAM/CHAPEL HILL</td>
</tr>
<tr>
<td>MASSACHUSETTS-BOSTON</td>
<td>NEW JERSEY-SOMERVILLE</td>
<td>OHIO-CINCINNATI</td>
</tr>
<tr>
<td>MASSACHUSETTS-CAPE COD</td>
<td>NEW JERSEY-SPARTA</td>
<td>OHIO-CLEVELAND</td>
</tr>
<tr>
<td>MASSACHUSETTS MID-CAPE ON CAPE COD</td>
<td>NEW JERSEY-TOMS RIVER</td>
<td>OHIO-DAYTON</td>
</tr>
<tr>
<td>MASSACHUSETTS-DANVERS</td>
<td>NEW MEXICO-ALBUQUERQUE</td>
<td>OHIO-LIMA</td>
</tr>
<tr>
<td>MICHIGAN-ST. JOSEPH</td>
<td>NEW YORK-ALBANY</td>
<td>OKLAHOMA-TULSA</td>
</tr>
<tr>
<td>MINNESOTA-MINNEAPOLIS</td>
<td>NEW YORK-BUFFALO</td>
<td>OREGON-MEDFORD</td>
</tr>
<tr>
<td>MINNESOTA-ST. PAUL</td>
<td>NEW YORK-MANHATTAN/BI</td>
<td>PENNSYLVANIA-DUNMORE</td>
</tr>
<tr>
<td>MISSOURI-ST. LOUIS/SUCC</td>
<td>NEW YORK-MANHATTAN/MS</td>
<td>PENNSYLVANIA-HARRISBURG</td>
</tr>
<tr>
<td>MISSOURI-ST. LOUIS/DPC</td>
<td>NEW YORK-MANHATTAN/NYU</td>
<td>PENNSYLVANIA-LANCASTER</td>
</tr>
<tr>
<td>MONTANA-BOZEMAN</td>
<td>NEW YORK-MIDDLETOWN</td>
<td>PENNSYLVANIA-MONROEVILLE</td>
</tr>
<tr>
<td>NEBRASKA-OMAHA/MCC</td>
<td>NEW YORK-NEW HYDE PARK</td>
<td>PENNSYLVANIA-PHILADELPHIA/PMP</td>
</tr>
</tbody>
</table>
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