

NEWS FROM S•P•O•H•N•C



VOL. 28 NO. 1

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

SEPTEMBER 2018



Three Dimensional Printing for Head and Neck Cancer Surgery:

Monika E. Freiser, MD, MPH

Introduction

Three dimensional (3D) printing is the concept of creating a real-life three-dimensional object from a virtual model created on a computer. An individual model can be designed on the computer and based, for example, on an actual patient's CT scan, and then printed using a variety of materials such as plastic or silicone. Because the models can be designed based on actual patient scans,



there is a huge potential for their use in medicine. There are many uses for 3D printing that are currently being explored in head and neck surgery. In this article we will provide an overview of 3D printing and ways it may impact oral and head and neck cancer patients.

Background

While the earliest versions of 3D printing were first developed in the early 1980s, it is only over the past decade that 3D printing has become more widely available and is regularly making its way into operating rooms. It is also over the past decade that 3D printing has become available and widespread at the consumer level, such that any person could go online and buy one for use in their home. The capabilities, accuracy and reliability of the printers vary widely, as do the prices, ranging from about \$50 for the most entry-level printer to over \$300,000 for industrial-grade printers. Most materials thus far have not been tested or approved by governing agencies such as the FDA for medical use, but there are several materials that can be sterilized and brought into the surgical field, and there have been some materials that have or are

undergoing FDA review for implantation approval. Most likely, the uses of 3D printing in medicine and surgery will continue to expand over the next couple of decades, and the technology will become available to more and more physicians.

The process of designing a model from a patient's scan, optimizing it for printing, and printing the model itself is a skill that has to be learned. In many cases, it is not the surgeon who prints the model, but it is an associated 3D printing lab or company who will do it after speaking with the surgeon. These labs or companies often have radiologists, engineers and other specialists who master the skill of printing and understand how to maximize the success of the print.

Most practicing surgeons will not have had exposure to 3D printing during training given how it is only now making its way into the operating room, and having 3D printed models is certainly not essential for delivering excellent care to a patient. However, as its uses and availability continue to expand, we hypothesize that more and more surgeons will begin to use the technology.

3D Printing in Head and Neck Surgery

Already a number of uses in head and neck surgery are being explored, and we will discuss these uses now. This is not an exhaustive list, but it represents several of the current uses described in the literature to date.

- **Case Preparation:** This is where a model is created of the patient's tumor and the surrounding structures and the surgeon can use this to help plan the surgery. The tumor could be printed in red and the surrounding structures in white, for example, and then the surgeon can clearly see its relationship in three dimensions. They may use the model to help them decide the surgical approach and to take measurements ahead of time.
- **Intraoperative reference:** Models that can be sterilized are printed and brought into the operating room and used to help guide reconstruction. In head and neck surgery, it is common to need to place metal plates to help reconstruct structures where the tumor used to be. 3D printed models can be used as templates to bend the plates into a shape that closely matches the patient's natural anatomy. For example, if the bony floor of the eye socket had to be removed during surgery, the 3D model can be used to bend the plate that forms the new floor such that it closely resembles the contour of the patient's original orbital floor.
- **Surgical Planning:** This is where the surgeon can plan ahead of time which cuts they will make and cutting guides can be 3D printed to be used intraoperatively. For example, when a

3D PRINTING continued on page 2

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patient has a tumor that is invading the mandible (jaw bone), the surgeon will plan on cutting out that part of the mandible during the surgery. To reconstruct the mandible defect, the surgeon may plan on taking a piece of bone elsewhere in the body, such as the fibula bone in the leg and place into the defect. With virtual surgical planning, the surgeon can decide where they will cut the mandible in advance and a cutting guide can be printed that they use in surgery. An exactly matching series of cutting guides can be designed to be used on the fibula bone, so that the fibula bone is shaped and placed into the defect in such a way that tries to preserve the patient's natural anatomy. Since the cuts were planned in advance and cutting guides pre-made, the operative time may be quicker.

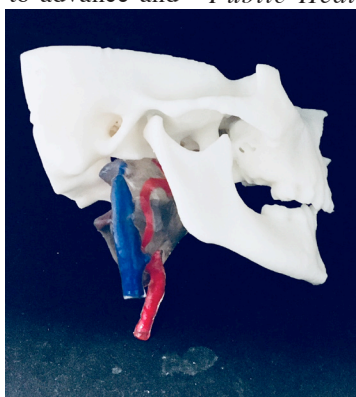
- **Patient Education:** A surgeon could print a sample or a patient-specific model and use it to describe to the patient what is going to happen during the surgery. It may be more informative if the patient can see on a model what their tumor looks like and what nearby structures are likely to be removed, than to just hear about the plan or look at the CT scan.
- **Training:** 3D models can be used to help train the next generation of head and neck cancer surgeons. The 3D models can be as simple as practice tying a knot on a model of a vein to practicing a specific surgery on a model.
- **Prosthetic Design:** Some head and neck cancer patients have needs for prosthetics after surgery in order to help restore function and quality of life. For example, a patient with a palatal tumor who had part of their hard palate removed may get a custom designed prosthetic to fill in where the palate used to be and allow them to eat food without it escaping into their nose. In certain situations, 3D modeling can be helpful to design a prosthetic or even to print a prosthetic.
- **Implantation:** A number of academic institutions and companies are working on inventing ways to create 3D printable implantables, and as time goes on, more of this technology will likely become available for patient use. Most of the technology is still in the research phase. Some implantable prints are meant to stay in the body for life, while others are designed to dissolve over time. Some serve as scaffolds for stem cells to grow, and others serve as stents to hold structures in place. One example that has been used in patients already and is undergoing FDA approval is that of 3D printed tracheal stents. There are some babies born with a condition known as tracheobronchomalacia in which they are at high risk of death from airway collapse, with limited options on how to help them. A group in Michigan has worked on a 3D printed stent that can be implanted into the patient's trachea to stent open the airway and keep it from collapsing. The stent is bioresorbable so that the patient does not need a second surgery to remove the stent at a later date. This has already saved several patients' lives and is an example of the incredible potential of 3D printing.

3D PRINTING continued on page 3

3D PRINTING continued from page 2**Conclusion**

In conclusion, there are many applications of 3D printing that may benefit head and neck cancer patients, some of which are available now and others which are still being explored. It is still too early to expect every surgeon to use 3D printing, and evidence is still being collected regarding its impact on patient care as compared to the standard of care in which models are not used. As the technology continues to advance and be studied, we expect that 3D printing will continue to make its way into the operating room and help oral and head and neck cancer patients in new and improved ways.

Figure 1: Here is a 3D printed model from a patient with a tumor at the base of the skull. The normal bone is printed in white and the tumor is printed in clear



material. The carotid artery is painted red and the internal jugular vein is painted blue so that their relationship to the tumor can be clearly visualized.

Editors Note: Dr. Monika Freiser is a Resident in Otolaryngology-Head and Neck Surgery at the University of Pittsburgh Medical Center. She obtained her medical degree at the University of Miami Miller School of Medicine and her Masters in Public Health at the Harvard School

of Public Health. During her residency she has been very involved with 3D printing research along with her mentors, Dr. Noel Jabbour and Dr. Andrew McCall at the University of Pittsburgh. Dr. Eugene Myers, MD, FACS, FRCS Hon is the previous chairman of the Department of Otolaryngology-Head and Neck Surgery at the University of Pittsburgh and

is a renowned head and neck cancer surgeon who dedicated his career to helping oral, head and neck cancer patients and training the next generation of head and neck surgeons. He is on the Board of Directors for SPOHNC. He was the impetus behind and the primary reviewer of this article.



photo courtesy of PJ Jordan, caregiver and NSVN Volunteer

Those who contemplate the beauty of the earth find reserves of strength that will endure as long as life lasts.

~Rachel Carson

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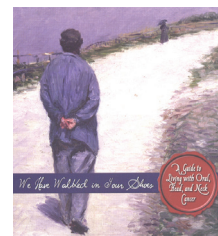
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CHAPTER NEWS

SPOHNC Chapter Support Group - Penn State Hershey, PA



In a special meeting on Sunday, June 24th, we honored our caregivers who so selflessly supported us during our journey through treatment.

Stories were shared by both caregivers and their loved ones: stories of dedication, of sacrifice, and of husbands, wives, and family, driven by love, finding the strength to care for us when they themselves were overwhelmed and exhausted. There were both laughter and tears as we each took turns reminiscing. More than ever, we understood just how much these people sacrificed to see

us through, putting their own needs and lives on hold and rarely complaining. What a world of difference they made, even in our



darkest hour, to know there was someone who was there for us every step of the way. We want you to know how very much we appreciate each and every one of you.

~ Patrice Saurmann, RN, BSN
SPOHNC Penn State Hershey,
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SPOHNC is Celebrating YOU!

We missed a very important summer birthday, celebrated by one of our favorites, from Dallas – Happy Belated Birthday to Survivor and SPOHNC, Dallas, TX area Chapter Facilitator, Jack Mitchell! Jack celebrated his birthday on August 30th.

Jack has been a friend of SPOHNC since his diagnosis many years ago. He is an asset to our SPOHNC family, giving of himself to facilitate and organize our Dallas, TX area Chapters since 2002. Loving hubby, fun dad and grandpa, Jack loves to spend time with family both near and far. Also an avid hunter and fisherman, Jack knows much about wildlife and appreciates the beauty of nature and takes the time to enjoy it.

Jack was instrumental in facilitating the continuation of the Rick Agee Skate for SPOHNC event, following the passing of our dear friend Rick in 2015. He also coordinated a beautiful dedication of a park space, tree and bench in memory of Rick, who had been

a longtime friend of SPOHNC. SPOHNC Executive Director, Mary Ann Caputo, and Survivor and SPOHNC Founder, Nancy Leupold, have traveled to Texas for quite a few of the SPOHNC events facilitated by Jack, and they have both been the lucky recipients of some good ole' down home Texas hospitality, when staying with Jack and his lovely wife, MaryEllen.

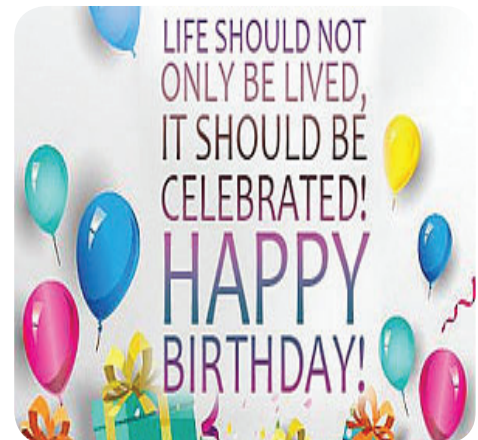
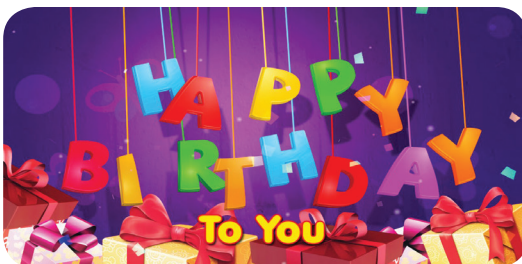
Jack – we wish you a great year of health and happiness, and we hope you had a terrific birthday!!

Never one to call attention to herself, there is another amazing Facilitator of a SPOHNC Chapter who recently had cause to celebrate. Happy Birthday Amy Beilman, SPOHNC's Palm Coast, FL Chapter Co-Facilitator. Amy celebrated her birthday on September 9th!

We're pretty sure Amy (caregiver) and Lewis (Survivor) had a great day for the big occasion – probably celebrating by doing something special with friends, or maybe even quietly celebrating at home with their

4-legged baby – Hero. He's pretty special too – but that's how it is when you have an awesome "Dad" and "Mom."

Amy is energetic, positive and such a pleasure and a joy to know. When Amy and Lewis became friends of SPOHNC, we knew it was going to bloom into something amazing – and we were right. Thank you to both of you for ALL that you do – and Happy Birthday Amy! We wish you a year full of love and laughter and above all, good health!



HEAD AND NECK CANCER NEWS

Marijuana Use Tied to Less Pain/Anxiety in Head and Neck Cancer

August 10, 2018 - Patients with newly diagnosed head and neck cancer who used marijuana had strikingly less pain and anxiety than their matched counterparts who did not use the drug, a prospective cohort study found.

Marijuana use was also associated with a more robust appetite and a greater sense of well-being than nonuse, the observational research indicates.

"The issue with head and neck cancer that makes it unique is that it really does affect some very basic functions, like speaking, swallowing, facial appearance, and a patient's ability to breathe, so it can interfere with basic functions of communication, eating, and really our sense of self when it changes the way your face looks," Michael Gupta, MD, McMaster University, Hamilton, Ontario, Canada, told *Medscape Medical News*.

Gupta said that a randomized controlled trial is now needed in this setting. He also believes that, in the meantime, cannabinoids could become part of standard care in treating these patients' anxiety and pain.

The new study was published online August 2 in *JAMA Otolaryngology — Head and Neck Cancer*.

For the study, researchers identified 74 patients with head and neck cancer who were using marijuana at the time of their diagnosis.

These patients were then matched to

74 other head and neck cancer patients who were not using marijuana at the time of diagnosis. The mean age of both groups was 62.3 years. More than 80% of both groups of patients were male.

Sixty-four percent of the patients who used marijuana had oropharyngeal cancer. Virtually all of these cases were p16 positive.

Similar proportions of patients who did not use marijuana had p16-positive disease, and the groups were well-matched for tumor site, T and N stage, and the treatment modalities they underwent.

Both the Edmonton Symptom Assessment System (ESAS) and the EuroQOL-5D (EQ5D) were used to assess quality of life (QOL). Importantly, most of the baseline QOL assessments were performed prior to the patients' receiving cancer treatment, Gupta said.

Significant Differences

On the basis of EQ5D scores, the researchers detected no significant differences between the two groups in terms of patients' mobility, self-care, or their ability to carry out usual activities.

However, the mean score in the anxiety/depression domain of the EQ5D was significantly lower for the marijuana users than for the patients who did not use marijuana, at 1.34 vs 2.08.

There were also significant differences in EQ5D scores in the pain/discomfort

domains for the two groups, at 1.53 for marijuana users vs 1.82 for those who did not use the drug.

Results remained significant for both domains when the data were subjected to an additional robust statistical analysis (Wilcoxon rank sum test), report the study authors.

"All domains of the ESAS showed improved QOL for the marijuana user group," the investigators state.

For example, scores for pain on the ESAS were significantly lower for cannabis users, at a mean of 1.85, than for the non-cannabis users, at 2.72.

This was also true for anxiety. The mean score in the anxiety domain was significantly lower for cannabis users than for nonusers, at 0.77 vs 5.30.

In addition, the ESAS mean depression score was significantly lower for marijuana users, at 0.72, than for nonusers, at 3.19.

In the domain of general well-being, cannabis users scored significantly higher compared to those who did not use cannabis, at 4.05 vs 2.12.

According to results from the additional statistical model, results for all domains, including pain, depression, anxiety, and general well-being, were significantly better for those who used marijuana compared to those who did not, the investigators write.

"There are lots of benefits to marijuana that seem to fit very nicely in the head and neck population," Gupta noted.

"Marijuana also helps with appetite," he said. "If you have your oropharynx radiated, frankly, you don't feel like eating very much, you lose your taste, so I think we are going to see marijuana as a big part of what we use helping people cope going forward," Gupta suggested.

The authors have disclosed no relevant financial relationships.

JAMA Otolaryngol Head Neck Surg.
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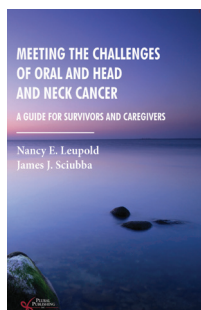
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HEAD AND NECK CANCER NEWS

Cetuximab with radiation found to be inferior to standard treatment in HPV-positive oropharyngeal cancer

Tuesday, August 14, 2018 - An interim analysis of data from a randomized clinical trial of patients with human papillomavirus (HPV)-positive oropharyngeal cancer found that treatment with radiation therapy and cetuximab is associated with worse overall and progression-free survival compared to the current standard treatment with radiation and cisplatin. The trial was designed to see if cetuximab with radiation would be less toxic than cisplatin with radiation without compromising survival for patients with the disease.

The phase 3 trial, which closed enrollment in 2015, was funded by the National Cancer Institute (NCI), part of the National Institutes of Health, and led by NRG Oncology, part of NCI's National Clinical Trials Network. The data monitoring committee overseeing the trial recommended releasing the data after an interim data analysis showed that cetuximab with radiation was associated with inferior overall and progression-free survival, compared to cisplatin and radiation. The U.S. Food and Drug Administration has previously approved cetuximab with radiation for patients with head and neck cancer, including oropharyngeal cancer. Cetuximab with radiation is an accepted standard of care, especially for patients who cannot tolerate cisplatin.

"The goal of this trial was to find an alternative to cisplatin that would be as effective at controlling the cancer, but with fewer side effects," said Andy Trotti, M.D., of the Moffitt Cancer Center in Tampa, Florida, a lead investigator of the trial. "We were surprised by the loss of tumor control with cetuximab."

There has been a lot of recent interest in the cancer clinical research community in evaluating the "de-escalation" of therapies for cancers that have a good prognosis, such as HPV-positive cancer of the oropharynx (the part of the throat at the back of the mouth, including the soft palate, the base of the tongue, and the tonsils). The goal is to improve patients' quality of life and reduce long-term toxic effects without compromising treatment efficacy. HPV-positive oropharyngeal cancer is frequently diagnosed in individuals in their 50s and

60s, and is associated with high survival rates, providing the incentive for this trial. Moreover, the incidence of this type of cancer has increased rapidly in recent years in the United States.

"Clinical trials designed to test less toxic treatment strategies for patients without compromising clinical benefit are a very important area of interest for NCI and the cancer research community," said Shakun Malik, M.D., of NCI's Division of Cancer Treatment and Diagnosis.

This trial's primary objective was to determine whether the substitution of cetuximab for cisplatin with radiation would result in comparable overall survival while reducing toxic side effects with improved long-term quality of life. The trial enrolled 849 patients with HPV-positive oropharyngeal cancer who were randomly assigned to receive either cetuximab or cisplatin with radiation. The study had three planned interim analyses.

The third and final interim analysis, done after a median follow-up of 4.5 years, found that overall survival on the cetuximab arm was significantly inferior to the cisplatin arm. Overall rates of serious (grade 3-5) adverse events were similar for patients in both groups. However, as the researchers expected, toxic side effects were different, with adverse events of renal toxicity, hearing loss, and bone marrow suppression more common in patients in the cisplatin arm, while body rash was more common in the cetuximab arm. All patients in this trial had completed therapy at the time of this analysis.

"This trial is the first randomized clinical trial specifically designed for patients with HPV-positive oropharyngeal cancer, and it establishes cisplatin with radiation as the standard of care," said Maura Gillison, M.D., Ph.D., of the University of Texas MD Anderson Cancer Center in Houston, the other lead investigator of the trial.

Full study details will be presented in the plenary session at the American Society for Radiation Oncology (ASTRO) Annual Meeting (link is external) in San Antonio, Texas, on Oct. 22 at 3:15 pm ET. Findings from the trial will later be published in a peer-reviewed journal.

For more information on the trial: <https://clinicaltrials.gov/ct2/show/NCT01302834>

About the National Cancer Institute (NCI): NCI leads the National Cancer Program and NIH's efforts to dramatically reduce the prevalence of cancer and improve the lives of cancer patients and their families, through research into prevention and cancer biology, the development of new interventions, and the training and mentoring of new researchers. For more information about cancer, please visit the NCI website at cancer.gov (link is external) or call NCI's Contact Center (formerly known as the Cancer Information Service) at 1-800-4-CANCER (1-800-422-6237).

About the National Institutes of Health (NIH): NIH, the nation's medical research agency, includes 27 Institutes and Centers and is a component of the U.S. Department of Health and Human Services. NIH is the primary federal agency conducting and supporting basic, clinical, and translational medical research, and is investigating the causes, treatments, and cures for both common and rare diseases. For more information about NIH and its programs, visit www.nih.gov.

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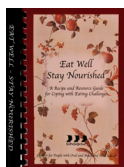
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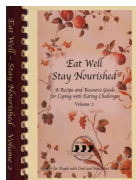


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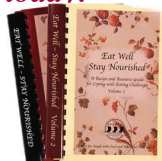
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Seasonal September Recipes from “Eat Well Stay Nourished A Recipe and Resource Guide For Coping With Eating Challenges”

Compiled and Edited by Nancy E. Leupold, Survivor, Founder & President Emeritus

Zucchini Casserole (from Volume 2)

- 3 c. cubed raw zucchini
- 1 ½ c. saltine cracker crumbs
- 3 eggs, beaten
- ½ c. butter or margarine, melted
- ½ tsp. salt
- 1 (4oz.) jar pimentos, diced
- 1 c. milk
- 2 c. grated cheddar cheese

Mix all ingredients together and pour into
casserole dish. Bake at 350 degrees for 30
to 40 minutes. Serve hot. Serves 6.

445 calories/serving.

~ Sister Mary Ryan, SPOHNC Terre Haute, IN Chapter Facilitator



Swedish Rice Pudding (from Volume 2)

- ¾ c. long grain white rice
(Carolina)
- 1 qt. whole milk
- 1 cinnamon stick
- 1pt. heavy cream
- 2 tsp. sugar
- 1 tsp. vanilla extract
- Ground cinnamon for garnish
(optional)

Combine rice and milk and cinnamon stick in the top of a double boiler. Cover and cook over simmering water for about 1 ½ hours or until thickened and rice is cooked. (Cooking time for rice varies. A sure test is to rub a grain between thumb and forefinger – if there is no hard kernel in the center, the rice is done.) Remove cinnamon stick and pour the finished rice into a bowl and cool. Place the heavy cream, sugar and vanilla in medium bowl and whip with a hand mixer on medium speed until soft peaks form. Chill. Fold into the finished rice mixture then into a serving dish and refrigerate until ready to serve. May be served with a raspberry sauce or fresh raspberries or sliced strawberries. Serves 8. 349 calories/serving.

~ Hannah S.



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TIME FOR SHARING...

“Not Finished Yet – My Personal Victory Over Throat Cancer”

Yeah, I know, the Personal Victory claim is really tempting fate, but hey, you have to think positive! Anyway, here is my story...

My Diagnosis

In November 2013, I was a fit and healthy 55-year-old, with no medical issues whatsoever apart from a persistent little lump under my jaw. I decided to visit a local ENT, who immediately suspected the worst. This innocent visit ballooned into a hurried series of CT Scans, Fine Needle Aspirations (FNA), and PET Scans, and signaled the start of the most unpleasant six months of my life.

The test results confirmed that I had stage 4 squamous cell throat cancer. The recommended plan of attack was TORS surgery, followed by a Radical Neck Dissection, topped off with some radiation therapy. For those keeping score, the initial clinical staging of my cancer was “T1, N2b, M0”, where “T1” referred to the size of the tumor; “N2b” implied that the cancer had spread to 2 or more lymph nodes; and “M0” implied that there was no distant spread.

Trans-Oral Robotic Surgery (TORS)

I was working in San Antonio, Texas, and lucky for me, my ENT Oncologist (Dr. Hales) specialized in Trans-Oral Robotic Surgery (TORS). On December 4, Dr. Hales used the robotic arms to remove my infected tonsil, as well as the entire left side of my throat; and a section from the base of my tongue. I spent a few relatively quiet days in hospital (on morphine, thank goodness!) before being released back into the wild. But when I left hospital – and my morphine drip – things turned ugly. In order to adequately describe the following few weeks, I would need to curse expansively, so all I will say is that for much of December 2013, I survived on doses of hydrocodone every four hours.

The Bleed

Ten days after my TORS surgery, I was watching TV one evening when my mouth suddenly started filling up with blood. I tried rinsing with salt water but the bleeding would not stop. (Note: the squeamish might want to move on to the next section...). When I started vomiting blood, my wife decided to drive me straight to the ER. By the time the on-call ENT doctor arrived, I had filled up so many barf-bags with blood that my blood levels must have been hovering below a quarter of a tank. Apparently, some scar tissue at the base of my tongue had torn and the doctor had to use a whole bunch of silver nitrate sticks to cauterize my tongue to stop the bleeding. (I can assure you this procedure was as unpleasant as it sounds!)



Radical Neck Dissection

On December 19, a few days after the bleed episode, I was wheeled into the operating room for my Radical Neck Dissection (RND). Basically, during an RND, the doctor will slice half of your neck open and remove as many lymph nodes as he deems necessary – in my case, the count was twenty-nine.

When I woke up, my head felt like it weighed a hundred pounds, my shoulder ached, a drainage tube poked out of my neck somewhere and I had a line of metal staples across my neck that would have made Dr. Frankenstein proud. The result of the RND was that two of the twenty-nine lymph nodes were cancerous, and one of them had been compromised. The actual term is “extra-capsular spread” and this is generally not the sort of thing you want to hear a few days before Christmas.

Radiation and Chemotherapy

Due to the “extra-capsular spread”, my staging was changed to “T2, N2b, M0, +ECS,” and my treatment had to be expanded to include chemotherapy. The new plan was thirty radiation sessions– five per week for six weeks – with a weekly chemotherapy session thrown in for good measure.

In the first week of January, I saw a dentist who built me a special mouthguard

that was designed to protect my teeth during the radiation sessions. I also visited the radiation clinic to have my “radiation simulation” where I was fitted for my radiation mask.

On January 13, 2014, I had my first radiation session. It only took 10-15 minutes, and as I drove back to work afterwards, I wondered what all the fuss was about. On the Friday of that first week, I had my first chemotherapy session.

By then, the five doses of radiation had turned my skin a pinkish color, but it was nothing worse than a sunburn. The chemo, however, knocked me around that first weekend. I was nauseous and very tired, and I suffered from constant indigestion (similar to acid reflux).

The symptoms all calmed down after a couple of days, and when I described the problems to my medical oncologist, he prescribed a selection of medications which virtually eliminated most of the side-effects of the chemotherapy over the next six weeks.

The radiation, however, was another issue altogether. After 10 sessions, the skin around my neck and chest was bright red and quite painful. After 20 session, the skin started to blister and was so painful and itchy that I could barely sleep at night. I tried all of the recommended creams and lotions but they didn’t appear to make much of a difference.

In late February 2014, I had managed to endure radiation session number 30, and I was presented with a certificate of completion by the wonderful radiation assistants. All of the scheduled radiation and chemotherapy sessions were officially over.

My Journal

Way back in November 2013 when the entire journey began, I started keeping a journal. I recorded the time and place of my appointments; the doctors I saw; my daily weight; the medications I had to take; and the pain level at the time. Eventually, I included my daily mental state and calorie intake.

During my treatment, I could see patterns over days and weeks as to when I became particularly nauseous or fatigued, or when I felt okay, or when I slept well or slept badly. I shared this information with

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my doctors, who could then make any necessary adjustments to my medications.

The journal was very useful when I moved from Texas to Florida and had to switch doctors, because I had a clear history of exactly what drugs and dosages I had tried, along with comments about their effectiveness.

Weight Loss

During treatment for head and neck cancers, the simple act of eating can become extremely difficult for many patients, which can result in significant weight-loss. Just before I started my radiation and chemotherapy treatment, I was encouraged to have a PEG tube inserted into my stomach. However, I decided that I would force myself to eat as normally as possible. Despite my determination to “tough it out,” there were times when I could barely swallow. I managed to survive on milkshakes and Ensure, but I still lost a quarter of my body weight.

I was lucky because I was at least given a choice of having a PEG tube or not. Some people won’t have that option, and they’ll have to learn to feed themselves through the tube.

Lymphedema

With the loss of twenty-nine lymph nodes during my RND, it’s no surprise that I developed lymphedema a few months after my treatment. When I woke up each morning, my neck was usually quite swollen. My morning ritual was to drink copious amounts of water for my dry-mouth, then spend five to ten minutes massaging my neck to reduce the swelling. Three years later, the lymphedema is all but gone, but I still get cramps in my neck nearly every day.

Health Care

A truly unfortunate aspect of the cancer journey is the need to deal with your health care provider. You simply must understand what your coverage entails (copays, deductibles, out-of-pocket expense limits) and the enormous difference in charges between in-network and out-of-network procedures. I received over a hundred bills (some doubled-up or re-issued), and I had to use a spreadsheet to reconcile them with my health care provider.

Questions for doctors

All of my doctors tried to explain the sequence of events for my treatment, but since the terms were unfamiliar, I didn’t quite understand how everything would fall into place. Therefore,

I wrote down a list of questions before every doctor’s visit. Also, I most strongly recommend that you take someone with you to all of your appointments – it really helps to have a second set of ears with you. My sister Jenni usually came with me, and it was remarkable how many times she picked up on a doctor’s response that I had missed, or she asked a follow-up question that helped clarify something.

Don’t be afraid to ask your doctors lots of questions. You may find that he/she has already compiled a set of FAQs (frequently asked questions) on pamphlets or a website. If so, take the time to read these FAQs, and if necessary, ask your doctor for clarification.

My Heroes

People like to congratulate me on my “bravery” throughout my cancer battle. But I really didn’t do much at all – the real heroes in my little drama were all the people who looked after me and cared for me during this time. I was incredibly fortunate to be blessed with a wonderful team of doctors and therapists in San Antonio who worked together to ensure my survival and recovery:

Dr. Robert Spears was the ENT doctor who first suspected that I had cancer, and he scheduled the FNA and CT scan so he could confirm the diagnosis.

Dr. Nathan Hales was the ENT otolaryngologist who performed my two major surgeries - the TORS surgery and the radical neck dissection.

Dr. Raj Dahiya was my radiation oncologist, and he was responsible for determining the doses and duration of my radiation therapy.

Dr. Syed Raza was my medical oncologist. He determined what type of chemotherapy was best for me, and he monitored by bloodwork before each chemotherapy session.

Dr. Kyle Ash was my dentist who specializes in dealing with head and neck cancer patients.

Lori Henkener was my speech therapist who gave me exercises that helped regain swallowing function in my throat.

There were numerous other nurses and therapists who helped me during my

stays in hospital, my visits to the radiation center and the chemotherapy infusion room, and my physical therapy sessions.

Support during this ordeal

The love and care provided by my wife Janine and sister Jenni were absolutely crucial to my recovery. Apart from the much-needed TLC they gave me during this time, one of them would always join me at doctors’ appointments to provide a second set of ears. They helped me manage my medications, cajoled me into eating, and put up with my complaints. Jenni literally flew half-way around the world to help look after her little brother. I owe them both an enormous debt of gratitude.

A number of fellow cancer patients became friendly faces in the radiation waiting room and the chemotherapy infusion room. At the SPOHNC meetings, there was a wonderful feeling of community – a common bond of understanding.

When you receive the news that you have cancer, your emotions will likely be in a swirl as you try to understand what impact this will have on your life, your family, your loved ones and your job. Much of your anxiety will simply be the fear of the unknown. However, you don’t have to go through this ordeal by yourself – in fact, you may be surprised how many people will be willing to help. Take advantage of all the assistance that is available.

Allow yourself time to heal

I made a couple of mistakes during my treatment and recovery period, making life harder than it needed to be. One early mistake was underestimating the level of fatigue during radiation and chemotherapy - I tried to continue working as long as possible, but I really should have called a halt after my tenth session.

But my major mistake was not understanding the healing process after my radiation and chemotherapy treatment had finished. I failed to realize that I was “still cooking”, and that severe dry mouth and painful mouth ulcers were part of the territory. Instead of rushing back to work after a week, I should have spent at least three weeks at home relaxing, recovering strength, regaining weight, and working on my physical therapy and lymphedema control.

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Connect with SPOHNC’s “group” on Facebook

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Give yourself time to heal. Your poor body will still be traumatized from the radiation and chemotherapy, and you need to be treated gently. You will probably be very eager for your life to “resume normal operations,” but if you push things too hard and too quickly, you will greatly increase the likelihood of setbacks in the following months.

Positive thoughts

As soon as I learned about my cancer, I started checking the statistics on the “5-Year Survival Rate” and became even more depressed – if that was even possible. Survival rates of 20% and less didn’t give me much cause for optimism. But I quickly decided that worrying about the worst-case scenario was a colossal waste of my imagination. Instead, I decided to take on this “challenge” in the most positive fashion I could. I saw the effect the diagnosis had on my wife and family, and I decided – for their sake as much as for mine – that I would portray the most positive attitude I could. Remarkably, I believe my positive thinking played a significant part in my eventual recovery.

Now, I’m not saying that positive thoughts alone will cure stage 4 throat

cancer, but in my case, it wasn’t going to help anyone if I spent all day whining about it! I had some bad days, and I had some very bad days, but I could always see an end to it (“this too shall pass”). Occasionally, I became frustrated when I felt I wasn’t recovering as quickly as I thought I should, but fortunately, I was able to recognize those negative emotions for what they were.

I realize that I am one of the lucky ones. I was diagnosed just in time; treated by a fantastic set of doctors; nursed back to health through the love and care of my wife Janine and my sister Jenni; and almost before I knew it, I was back to full health. However, too many people will not be as fortunate as me. They will also be treated by wonderful doctors, and cared for by cherished loved ones, but their path may be different to mine. I try to remind myself regularly to have an “attitude of gratitude” and to give thanks for my good fortune.

Final words

My diagnosis, treatment and recovery were enormously significant events in my life – events that really should be life-altering. For me, I’m making an effort to try to live a better life and not take things for granted.

My “bucket list” has become less of a wish-list and more of a set of definitive goals. I have made a conscious decision to try to make things happen. If an opportunity presents itself, I am much more likely now to take that opportunity and run with it.

A case in point is my journal. When Dr. Hales suggested I turn it into a book – with the idea that it might actually help someone – I decided to do it. And the achievement has given me the confidence to write a second book (purely fiction, this time), and I am half way through my third. All I needed was a little push (and stage 4 cancer...)

Thanks for sharing my story. For those of you who are either undergoing treatment now, or are about to start, I hope this article gives you some encouragement. The experience will not be fun, and there will certainly be some testing days ahead for you, but you just need to look at all the wonderful people at SPOHNC to know that you can get through this.

For more information about my full story and my publications, please e-mail me. My contact information is below, or check out MikeMcGrathBooks.com

~ Michael McGrath
mfsmcgrath@gmail.com

HEAD AND NECK CANCER NEWS

Patient Education Symposium At Stanford Health Care, Stanford University

On April 28th, 2018, Stanford Health Care sponsored its second annual Head and Neck Cancer Patient Education Symposium on the Stanford University campus. The event was once again well attended and had a format similar to last year’s inaugural program. After registration and breakfast, there was a keynote presentation by a throat cancer survivor, and that was followed by five technical presentations by physicians and other medical professionals involved with head and neck cancer patients. Those presentations included Clinical Trials, Living with Uncertainty in the Day and Age of Targeted Precision Medicine, Human Papilloma Virus, Genetics and Genomics: Why and What’s Next and lastly, Evaluation and Treatment of Swallowing Difficulties After Head and Neck Cancer. A brief Q & A followed each presentation. The morning was concluded with a Provider Panel that included some of the presenters of the above noted topics, a Radiation Oncologist, the

Stanford Head and Neck Cancer Support Group Facilitator and a dietician/nutrition specialist.

Following lunch, there were five more technical presentations that included The Role of Palliative Care, Nutrition After Treatment, Exercise for Head and Neck Cancer Patients and Survivors, Head and Neck Lymphedema and Skin Care During Radiation Therapy. Again, a short Q & A period followed each session. A Patient/Caregiver Panel of three survivors and a caregiver succeeded the presentations and the Symposium closed with the day’s second Provider Panel that again included some of the afternoon presenters, a Head and Neck Surgeon from the Stanford Medical Otolaryngology Clinic, a Dental Hygiene professional with both clinical and academic credentials and a Stanford Speech and Swallow Therapist.

~ Jerome Young,
Survivor & SPOHNC Member

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To find out how you can help a newly diagnosed patient, contact Chris at SPOHNC at 1-800-377-0928, x4 or email c.leonardis@spohnc.org.

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