

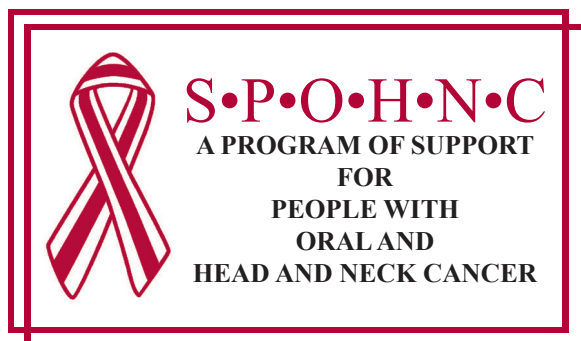
NEWS FROM S·P·O·H·N·C



VOL. 31 NO. 1

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

SEPTEMBER 2021



Adding Dental Coverage to Medicare Could Be Crucial For Oral, Head and Neck Cancer Patients and Survivors

Wey-Wey Kwok, JD

The Center for Medicare Advocacy (CMA) is a non-profit, public interest law organization headquartered in Connecticut and Washington, D.C., that works to advance access to comprehensive Medicare coverage, health equity, and quality health care for older people and disabled adults. Founded in 1986, CMA focuses on the medical care needs of people with long-term and chronic conditions. Our work includes legal assistance, advocacy, education, analysis, policy initiatives, and litigation of importance to Medicare beneficiaries nationwide. Our systemic advocacy efforts are based on the experiences of those who contact the Center each day with their concerns.



Dental Needs of Medicare Beneficiaries with Oral, Head, and Neck Cancer

CMA regularly hears from Medicare beneficiaries who are facing dental and oral complications as a result of oral, and head and neck cancer (OHNC) treatment. Some people, particularly those who have undergone primary radiation therapy, or in association with surgical treatment, face complications that often prove very challenging. These complications or side effects include oral pain, dysfunction and infections, and significant related damage to the teeth, mucous membranes and soft tissues, bone, salivary

glands and oral blood supply. These changes can deeply affect the individual's comfort, ability to chew and swallow, which in turn affect overall level of nutrition, and consequently general health and quality of life.

Prevention and management of dental and oral complications are crucial for oral, head, and neck cancer patients and survivors. There are many, though, who have difficulty affording and accessing the medically essential oral and dental care. CMA often gets calls from people seeking clarity on what dental services Medicare will and will not pay for in their situation, whether dental professionals (e.g., oral-maxillofacial surgeons, prosthodontists, general dentists) requiring up front payment for the services they need, and whether their claims are worth appealing to Medicare.

Medicare's Dental Coverage Gap

Dental/oral health benefits are not a part of the Traditional Medicare program. A provision in the Medicare statute prohibits payment for "services in connection with the care, treatment, filling, removal or replacement of teeth or structures directly supporting the teeth." The federal agency has long interpreted this language to bar coverage for nearly all dental work, including preventive and diagnostic services such as exams, x-rays, and cleanings, as well as restorative procedures like fillings, extractions, periodontal care, root canals, crowns, bridges, dentures, and implants.

While many private Medicare Advantage (MA) plans offer dental benefits, those benefits may be limited in scope of services, coverage amount, and provider network. Persons who are considering enrolling in an MA plan should seek out and evaluate the details of the plan's dental benefits.

Extremely Limited Coverage for "Medically Necessary" Dental Procedures

Medicare beneficiaries are often shocked to learn that Medicare typically will not even cover care to address dental problems that are caused by a medical condition or treatment, or that *could well jeopardize* their medical condition or treatment. For example, it will not cover care for rampant tooth decay and gum disease resulting from radiation, chemotherapy, or prescribed medications or diseases that affect the functioning of the salivary glands. Nor will Medicare pay for dental care that someone must have to obtain clearance for a critical medical procedure, such as heart surgery, organ transplant, or treatment for leukemia.

What Medicare Will Cover

Medicare's current dental policy generally limits coverage to the following procedures:

- Surgery related to the jaw and orofacial structures (e.g., skull, palate, tongue, salivary glands, sinuses, etc.), such as to repair a fracture or remove a tumor

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- Extractions needed to prepare the jaw for radiation treatment of cancer
- Inpatient oral examination prior to kidney transplant
- Dental items and services provided in connection with a primary covered service that the dentist is performing. For example, if the dentist must extract a tooth as a part of repairing a fracture or removing a tumor, then the entire procedure will be covered, including the extraction which normally would not be covered.

Tips for Beneficiaries

Beneficiaries who need the above-mentioned covered services should make sure to seek care from a provider who is enrolled in Medicare. Beneficiaries have a right to appeal denials of coverage. They can initiate an appeal by following the directions on the Medicare Summary Notice that reflects the coverage denial. The first two levels of appeal are paper reviews performed by contractors. At the third stage, conducted by an administrative law judge (ALJ), the beneficiary can choose to present supporting arguments and testimony at a telephonic hearing. At each of these stages, the beneficiary can submit additional evidence, such as supporting letters from their physicians. Two additional levels of appeal are available, assuming that the amount in controversy requirements are met.

MA plans are also required by law to cover these services, and a plan enrollee can appeal if the plan denies prior authorization. The enrollee should make sure to seek care from a provider who can be paid by the plan. If a dentist or dental specialist has opted out of Medicare enrollment, neither they nor their patients can be reimbursed by a MA plan or traditional Medicare.

Efforts to Expand Medicare Dental Coverage

CMA has long felt that Medicare's dental policy is unduly restrictive. The policy essentially disallows payment for any work performed on the teeth and supporting structures, regardless of the medical reasons why the individual may need the procedures. Only in extremely limited circumstances will Medicare make an exception to allow payment for normally non-covered dental services. The following is a link to the text of the dental policy (See Section 150, which is on page 137): <https://www.cms.gov/Regulations-and-Guidance/Guidance/Manuals/downloads/bp102c15.pdf>.

Over a decade ago, beneficiaries were sometimes able to win coverage for their dental claims at the ALJ (administrative law judge) appeal stage. Since then, however, such victories are highly rare, and the agency has successfully sought to overturn any favorable ALJ decisions granting coverage of dental treatments. This has proven very frustrating for beneficiaries. CMA's attempts to appeal these denials to the federal courts were ultimately unfruitful, as the courts have upheld the agency's restrictive dental policy.

For the past several years, CMA has been working to seek policy and/or statutory change to establish better dental coverage in Medicare. The organization has been working in broad coalition to try to get the agency to expand its definition of what is coverable "medically necessary" dental care. It has also been working to get Congress to pass legislation that would add a comprehensive dental benefit to Medicare Part B.

MEDICARE continued on page 3

MEDICARE continued from page 2**What You Can Do to Support****Adding a Dental Benefit to Medicare**

At the present time, there is real interest and activity in Congress around addressing the vital need for dental coverage in Medicare. The proposal to add a dental benefit to the program is being considered as part of the infrastructure and budget reconciliation package that Congress is negotiating this summer.

Legislators are finally starting to understand what the public has known all along – that oral health is a key part of overall health. Recent Morning Consult and YouGov polling shows that 8 out of 10 adults support including dental coverage in Medicare, and that the proposal is highly popular among U.S. voters across the political spectrum.

Because the current moment presents a truly rare opportunity to legislate a meaningful dental benefit in Medicare, it is a crucial time for people to contact and urge their federal lawmakers to make this important improvement to the program for current and future generations of Medicare beneficiaries. If Congress misses this chance, it could be a very long time before we will see another opportunity.

The following link allows you to

send an automatic email to your members of Congress asking them to support adding a comprehensive dental benefit to Medicare: <https://secure.everyaction.com/pa3W02ObtUqwRFH6-stqoQ2>.

If you prefer to call or write a letter to your elected representatives, you can obtain the contact information for your U.S. Senators on the “Find Your Senators” pull-down menu on the following site: <https://www.senate.gov/>. You can obtain the contact information for your U.S. Representative by typing in your zip code at the following webpage: <https://www.house.gov/representatives/find-your-representative>.

How to Share Your Story

CMA encourages Medicare beneficiaries to share their oral health stories with us at OralHealth@MedicareAdvocacy.org. They should also indicate if they would be willing to speak to the press or to policy makers. Sometimes reporters ask CMA for beneficiary stories when they are writing an article that highlights how Medicare’s restrictive dental policy harms beneficiaries. These articles can really help the public and policy makers understand the human impact of not having dental coverage in Medicare.

People can also share their oral health

experience at the Families USA story bank through this link: <https://familiesusa.org/share-your-story/>. The story bank is used in ongoing advocacy efforts to expand dental coverage as well.

Contacting the Center

Anyone can contact CMA to obtain information and assistance with our many factsheets and self-help packets, available for free on our extensive website. Please note that CMA is only funded to provide direct legal assistance for people from Connecticut. We do have certain substantive priorities and can sometimes provide limited assistance to people outside of Connecticut with those concerns – including, for example, advancing Medicare coverage for oral health care. Our phone number is (860) 456-7790 and our website is: www.medicareadvocacy.org.

References:

¹ 42 U.S.C. § 1395y(a)(12).

² Note: Pursuant to a local coverage determination (LCD) issued by the Medicare regional contractor Palmetto GBA, that processes claims submitted by providers in Alabama, Georgia, Tennessee, North Carolina, South Carolina, Virginia and West Virginia, coverage is available in those states for the insertion of metallic implants when “used to assist in or enhance the retention of a dental prosthetic as a result of a covered service.” [L34574]. <https://www.cms.gov/medicare-coverage-database/details/lcd-details.aspx?LCDId=34574>

³ For more detailed information on Medicare’s dental coverage policy, refer to the Medicare Benefits Policy Manual Chapter 15, §§ 150 [Dental Services], 150.1 [Treatment of Temporomandibular Joint (TMJ) Syndrome], and 120-C [Prosthetic Devices – Dentures].

⁴ Currently, oral appliances for treating obstructive sleep apnea are covered by Medicare as durable medical equipment pursuant to local coverage determinations.

Editors Note: Wey-Wey Kwok has been an attorney with the Center for Medicare Advocacy since 2002. In addition to her litigation and policy work, she also specializes in hospice coverage, and represents Medicare beneficiaries in appealing coverage denials of home health and skilled nursing facility care. She is an active member of the New York Bar.

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In Memoriam

Donald Lewis

SPOHNC was deeply saddened to learn of the passing of one of its Greenville, SC SPOHNC Chapter support group attendees. SPOHNC Chapter Facilitators, Bill and Linda Clyne, shared the sad news of the passing of Don Lewis with SPOHNC.

Don was an avid hunter and fisherman and loved to spend time at the coast with his family. He was a loving husband, father, and self proclaimed amateur chef, and always had a good dad joke. Don had a passion for irrigation, and was owner and operator of RainShine Irrigation and Landscape Lighting.

SPOHNC Chapter Facilitator, Linda Clyne, shared these beautiful words about Don, in an email to SPOHNC and to her support group as well.

"Don Lewis and his devoted wife, Sarah, have been a part of our local SPOHNC group since April 2016, but he began his battle with adenoid cystic carcinoma in



2005 - long before our group began meeting (and even before Sarah became his devoted wife!). Although in the course of his cancer

journey he endured multiple surgeries and setbacks, he never gave in to the temptation to feel sorry for himself.

I distinctly remember a phrase he often used when telling his story. For every curveball cancer threw him, Don did what he had to do and then "turned the page." He regrouped, refocused and went about living his best life. His humor, optimism and indomitable spirit shined a bright light that encouraged every new patient who came to our meetings.

But there comes a time in every earthly, human biography - no matter how inspiring - when we come to the last page of the last chapter and there are no more pages to

turn. For the many people who cheered Don through every twist and turn of his story, that book closed yesterday.

It's an "ending" that makes me weep, but when the tears subside I will sit quietly and revisit the best parts - of which there are many - in my memory....

When people come to their first meeting of SPOHNC they are asked to complete a short survey so we can get to know them a little better. When asked "What can our group do to best support you?" Don's answer turned the question around in a way that perfectly reflected the character of this man we came to know and dearly love: "Not sure. Would really like to help others."

Mission accomplished, Don. You are now perfect and complete."

SPOHNC shares in the sadness felt by the Greenville, SC SPOHNC Chapter on the loss of their dear friend, Don. We will keep the group, Don's loving wife, Sarah, and his family and friends in our thoughts and prayers, today and every day.

HEAD AND NECK CANCER NEWS

Lobaplatin-Based Regimen May Be 'Promising' Alternative for Nasopharyngeal Carcinoma

July 30, 2021 - Sucharita Mistry, PhD - The 5-year progression-free survival rates were similar between the treatment arms. Lobaplatin-based treatment is as effective as, but less toxic than, cisplatin-based therapy for patients with locoregional advanced nasopharyngeal carcinoma (NPC), according to a phase 3 trial published in *The Lancet Oncology*.

Cisplatin-based induction plus concurrent chemoradiotherapy is the current standard treatment for patients with stage II-IVB NPC, according to National Comprehensive Cancer Network Guidelines. However, cisplatin is associated with significant toxic side effects, according to the study authors.

They noted that lobaplatin is a third-generation platinum drug that previously showed encouraging antitumor activity against several cancers, with fewer toxic effects than cisplatin.

Based on these results, the authors conducted a randomized, phase 3 trial to compare lobaplatin-based therapy and cisplatin-based treatment in patients with

stage III-IVB NPC.

The study enrolled 502 patients. They were randomly assigned 1:1 to receive induction with lobaplatin plus fluorouracil (n=252) or cisplatin plus fluorouracil (n=250), both followed by concurrent chemoradiotherapy (either lobaplatin- or cisplatin-based).

The median follow-up duration for the intention-to-treat population was 75.3 months. In this group, the 5-year progression-free survival (PFS) rate was 75.0% for the lobaplatin arm and 75.5% for the cisplatin arm (hazard ratio [HR], 0.98; 95% CI, 0.69-1.39; log-rank $P = .92$). The difference between the arms was 0.5% (95% CI, -7.1 to 8.1; $P_{\text{noninferiority}} = .0070$).

In the per-protocol population, the 5-year PFS rate was 74.8% in the lobaplatin arm and 76.4% in the cisplatin arm (HR, 1.04; 95% CI, 0.73-1.49; log-rank $P = .83$). The difference between the arms was 1.6% (95% CI, -6.1 to 9.3; $P_{\text{noninferiority}} = .016$).

Grade 1 to 2 adverse events (AEs) that were significantly more common in the cisplatin arm than in the lobaplatin arm were

nausea (75% vs 42%; $P < .0001$), vomiting (60% vs 21%; $P < .0001$), nephrotoxicity (37% vs 21%; $P < .0001$), and weight loss (66% vs 32%; $P < .0001$).

The rate of grade 3-4 AEs was 73% in the cisplatin arm and 63% in the lobaplatin arm. The most common grade 3-4 AEs (in the cisplatin and lobaplatin arms, respectively) were mucositis (40% vs 41%), leucopenia (23% vs 16%), and neutropenia (24% vs 10%).

There were no serious AEs or treatment-related deaths reported during the study.

"The results of our trial indicate that lobaplatin-based induction chemotherapy plus concurrent chemoradiotherapy might be a promising alternative regimen to cisplatin-based treatment in patients with locoregional, advanced nasopharyngeal carcinoma," the study authors wrote.

"Future studies to enhance the potency of lobaplatin (eg, combination with other chemotherapy drugs, targeted therapy, or immunotherapy) are required to better understand its efficacy."

###

***Eat Well Stay Nourished
A Recipe
and Resource Guide
for Coping
With Eating Challenges***

*compiled by
Nancy E. Leupold, Founder;
in memoriam*



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

Compiled and Edited by Nancy E. Leupold, Founder; in memoriam

Zucchini Ratatouille - from Volume One

6 small zucchini, cubed
½ onion, chopped
2 large potatoes, peeled and cubed
1 small can tomato sauce
Olive oil
Salt and pepper



Parboil potatoes and drain. Saute onion and zucchini in olive oil. Add potatoes to zucchini and onion. When all is softened, add a small can of tomato sauce and salt and pepper to taste. Simmer for 30 minutes. Yields 15 (6 oz) servings. *70 calories per serving.*

~ Kathy P., NJ

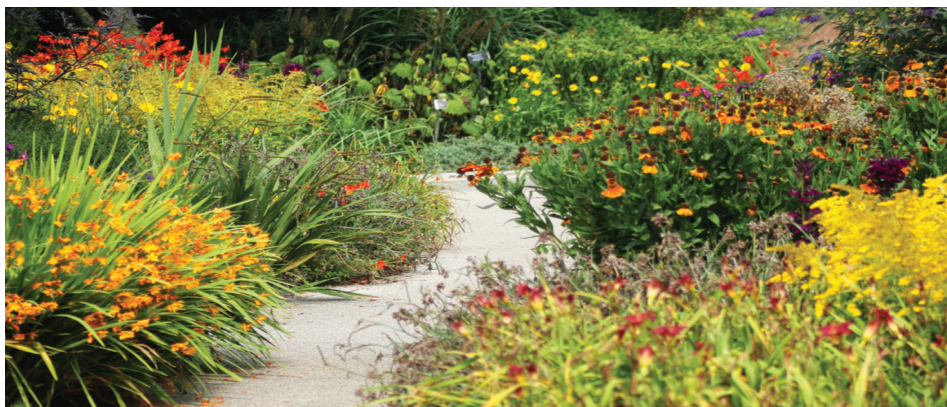
Flounder Florentine - from Volume Two

3 pkg. frozen chopped spinach
2 Tbsp. butter or margarine
¼ tsp. salt
Dash of pepper
½ c. grated Cheddar cheese
1 c. milk
1 lb. filet of flounder
1 to 2 Tbsp. flour



Cook spinach and drain well. Place in a 10 x 14 shallow baking dish that has been sprayed with Pam. Set aside. In a saucepan, melt butter; blend in flour and salt and pepper. Gradually add milk, stirring until smooth. Add cheese. When cheese is melted, pour over spinach. Place fish fillets on top. Sprinkle with paprika or lemon butter sauce. Bake 30 minutes at 375 degrees. Serves 4. *301 calories per serving.*

~ Nancy Leupold, *in memoriam*



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HEAD AND NECK CANCER NEWS

Personalized 3D-printed shields protect healthy tissue during radiotherapy

16 Jun 2021 - One of the primary goals of radiation therapy is to deliver a large radiation dose to cancer cells whilst minimizing normal tissue toxicity. However, most cancer patients undergoing such treatments are likely to experience some side effects caused by irradiation of healthy tissue. The extent of this damage is dependent on the treatment location, with the most common toxicities involving the oral cavity and gastrointestinal tract.

Materials with a high atomic number (Z), often known as radiation-attenuating materials, can be used to shield normal tissue from radiation. However, integrating such materials into current patient treatment protocols has proven difficult due to the inability to rapidly create personalized shielding devices.

James Byrne and colleagues at Brigham and Women's Hospital, Dana-Farber Cancer Institute, Massachusetts General Hospital and MIT have addressed this need. The team has developed 3D-printed radiation shields, based on patient CT scans, incorporating radiation-attenuating materials to reduce the toxicity to healthy tissue.

Producing personalized 3D-printed shielding

Before a patient undergoes radiotherapy, they undergo CT scans to provide anatomical information that is used to plan their treatment. Byrne and his colleagues utilize these CT images to design personalized radio-protective devices, which they produce through 3D printing.

To determine the most appropriate shielding materials for the device, the researchers tested various elements and alloys, including liquids, with a high Z number. They characterized these materials by measuring their relative mass attenuation coefficients. From this, the team determined that elemental materials demonstrated greater radiation shielding than alloys or composites, and that mercury largely outperformed all other liquids. They then incorporated the high-Z materials into the personalized 3D-printed devices. The devices were made such that the shielding material could be removed to reduce

artefacts during CT imaging and replaced prior to treatment.

To evaluate the device's ability to shield healthy tissue from radiation, the team treated 14 rats with single-dose irradiation, half with and half without radio-protective devices in place, and examined the incidence of toxicities such as oral mucositis and proctitis.

The group also simulated clinical radiation treatments by modelling the radio-protective devices in the treatment planning software. The dose distributions with and without shielding were compared to evaluate the dosimetric impact of the device. The researchers simulated treatments of prostate and head-and-neck cancer patients, selecting the appropriate positioning of the device based on the regions of increased radiation exposure.

Evaluation of radio-protective devices

Histopathological analysis revealed that only one of seven rats with radio-protective devices in place during treatment suffered ulceration on the surface of the tongue. In contrast, all seven control rats, with no device in place, experienced extensive ulcerations on the tongue surface.

The clinical simulations identified that using radio-protective devices during

prostate cancer treatment could reduce the dose to healthy tissue by 15% without reducing the dose delivered to the tumour. For the head-and-neck cancer treatment, the dose absorbed by inner-cheek tissue was reduced by 30%.

The results clearly show that the radio-protective devices may improve patient comfort throughout the course of treatment. "Our results support the feasibility of personalized devices for reduction of radiation dose and associated side effects" claims Byrne.

Future clinical implementation

The benefits of using 3D-printed radio-protective devices in the clinic are clear. "This personalized approach could be applicable to a variety of cancers that respond to radiation therapy," says Byrne. The researchers acknowledge that full clinical translation of 3D-printed shielding devices will require further development. "Given the small sample size of our dosimetric studies, further investigation in larger cohorts is needed to validate these approaches," they say.

The researchers publish their findings in *Advanced Science*.

###

Don't Miss Any News!



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Also remember if you have moved, or changed your email address or phone number, be sure to contact SPOHNC at 1-800-377-0928, or email us at info@spohnc.org to let us know.



*photo courtesy of PJ Jordan,
NSVN Volunteer
and
AMAZING photographer*

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CHAPTER NEWS

Play Ball!!

SPOHNC's Syosset, NY Chapter support group was busy again in August! The previously held picnic was so much fun, that Co-Facilitators Frank Marcovitz and Alice Steiner decide to try another outdoor event – and boy were they glad they did!

The Long Island Ducks are members of the Atlantic League of Professional Baseball and provide affordable family fun and entertainment for all of Long Island. The Duck's Stadium is conveniently and centrally located on Long Island and is a popular spot for groups to gather safely, outdoors, for a day or night of fun and entertainment. Frank is a frequent visitor to the Ducks games, so he thought it would be a fun night out for the group - and it was a home run!

Game night weather was perfect, and the Marcovitz family, along with the Folchetti family, Alice and SPOHNC Executive Director, Mary Ann Caputo and her husband Larry, along with yours truly, attended the

game. It was such a fun night! The Ducks vs. the Gastonia Honey Hunters (from NC) proved to be an exciting game,



as the Ducks took the lead early in the game and kept the pace going. On field activities and games between innings were fun for the kids including a potato sack race, a

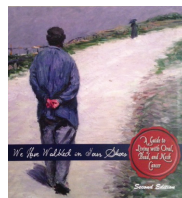
bounce house, and Quacker Jack kept the crowd going with his energetic personality and antics. For us in the stands representing SPOHNC, the Folchetti kids (young and “not so young”) kept us all laughing with antics of their own. What fun!! Mary Ann's husband, Larry, answered a Ducks trivia question

live, on camera, and was gifted a gift certificate for a Ferry ride to Bridgeport for his correct answer. Way to go Larry! SPOHNC was even acknowledged on the scoreboard during the 4th inning!!

It was such a fun night and so good to be with everyone in a safe outdoor space, just enjoying some good old fashioned all American baseball fun! Thank you Frank, for your terrific idea. We understand that plans are already in the works for the next outdoor gathering...stay tuned!!!!

SPOHNC's most popular resource for newly diagnosed patients...

***We Have Walked In Your Shoes:
A Guide to Living With
Oral, Head and Neck Cancer -***
by Nancy E. Leupold &
James J. Sciubba, DMD, PhD



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in our country...but
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We All Need Happy News!!

A Time for Sharing... *A Few Twists and Turns*

We are all shaped by the encounters and the experiences that come into our lives on the roads we find ourselves traveling. As most of us begin our life's travels those early roads are usually laid out for us. Though, as time advances, we are often left to discover our own roads. No matter, fate sometimes decides for us the roads we find ourselves traveling and whom our encounters on those roads might be.

In the mid-Atlantic region, in early February 1986 we were in the grip of an icy winter. On a weekday morning I awoke with a sore throat, only to dismiss it as perhaps a cold coming on. Over a few days, the soreness became more intense, without so much as a mild fever. A family-practice doctor I saw at a military clinic near Washington, D.C., diagnosed the trouble as a viral infection that would run its course to clear itself. There wasn't much to do for it other than take Tylenol or aspirin for the discomfort and rinse my throat periodically with a heated saline solution. The pain persisted. I was referred to other doctors within the family-practice clinic and put on doses of oral penicillin, to no avail. In spite of frequent examinations by other physicians, no one seemed sure of what they were seeing in the right tonsil-fossa area of my throat, except for one young student intern, a junior officer, who's opinion was discounted. Twelve weeks would lapse before I was finally referred to the nearby hospital's ENT clinic. There I was to see an otolaryngologist, an air force major.

After just a few minutes of examination the doctor looked me straight in the eye to say insensitively, "You have cancer of the throat." Stunned, and searching for doubt, I asked how he could be so sure so quickly, without a more involved examination. "I know," he said bluntly, and apologized. "There's no doubt, what I'm seeing is squamous cell carcinoma in the cavity area behind your right tonsil. It may also involve your tongue. I can't be sure." He then offered to do the necessary surgery and other needed treatments locally, or, he said, he could refer me to Walter Reed Army Medical

Center, or to Bethesda Naval Hospital. I'd been away from active military service for a dozen years. A retired chief petty officer, I had served during the Korean war and was an in-country Vietnam veteran. With twenty-years of active navy service behind me, I opted for treatment at the naval hospital.

At Bethesda Naval, I spent almost a full week undergoing numerous tests. Several times I was hauled by gurney in and out of operating rooms for closer looks at my throat and lungs while sedated into the lullaby Land of Nod. While I slept the boundaries of the tumor were better established and tattooed. Other times, I was wide awake in clinics for



tests that were unable to occur while being unconscious. I was being observed by various doctors and dentists. The extent of radiation treatment necessary was going to become very damaging to all of my teeth, I was told, calling for removal of eight perfectly good molars prior to any radiation treatments. I was getting, I thought, much more attention than I deserved, and began to wonder why. In 1986 our oncoming digital world was just beginning to bloom as its edges, a much fuller glow of it was still years away. Generally, there were very few personal computers in daily use, there was no internet the likes of what we have today, and no iPhones, either, while Google was yet to become a word.

At the naval hospital, I was being seen primarily by a staff of five navy ENT doctors headed up by a navy medical corps captain, a four-striper, in charge of the clinic. During operating room procedures, the tumor had been discovered to have metastasized to the base of the tongue. In speaking to the surgery, a total glossectomy was proposed. Judgement among clinicians was that a complete removal of the tongue was necessary to assure my survival of the disease at hand. "Survival!? Survival to what?," I thought, being forever mute, unable to speak or articulate at all, only able to take sustenance via an external tube

installed into my stomach. Oh, but the tube would include a detachable funnel to better direct nourishment through the tube. Such a life wasn't my idea of survival. I felt trapped and condemned.

I was released from the hospital only to mourn to myself, and openly to my wife, over my plight before returning a week later for further involved tests and other evaluations by additional medical and dental specialists. Finally, a return date was set for treatment to begin, chemotherapy to be followed by surgery and radiation therapy. Upon being released again from the hospital the terrifying and terrible outcome awaiting gnawed at me. I needed treatment, and only with great reluctance could I resolve to the intended surgery. Could I come to live with all the complications a glossectomy would leave me with? I could barely stop questioning myself as I returned to work to discover a multitude of overwhelming support, and, of course, a flood of well-intended advice. For the prior six years I'd been employed on Capitol Hill, working under the Office of the Sargent at Arms of the United States Senate. My service at the senate is yet another story, suffice it to say that it turned out to be a culture I came to take pride in and enjoy, and have come to feel grateful to have been involved with. I had been offered work within the senate unexpectedly. A stroke of good fortune as it turned out. At the time, my employment was elsewhere, in the private sector not in government. The chance to work within the U.S. Congress was not service I'd been actively seeking. Initially, I had been tapped as a consultant.

A good friend from another office within the senate complex put me in touch with a lawyer friend she knew...lots of lawyers on Capitol Hill. This fellow was a true gentleman, a man who had recently had oral surgery to remove a developing tumor from his right interior jaw, in an area of soft flesh between his lower gum line and mandible edge. It was, he said, an early-stage malignancy spotted during a dental check-up by a sharp-eyed dentist and resulted in prompt treatment. The otolaryngologist who performed his surgery, he told me, was a former army medical doctor, a retired colonel, and an ENT specialist who at the

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time had a practice in Baltimore, MD. A resident physician at the Greater Baltimore Medical Center, the doctor was a decorated combat surgeon by the name of Darrell A. Jaques. A thoroughly trained and experienced surgeon and otolaryngologist, whom it turned out I would end up owing a deep debt of gratitude to. This law guy could only laud Dr. Jaques, and all but demanded that I see Jaques ASAP for at least a second opinion. Within the hour, I called Jaques' office only to learn he was out of town on business without a known return date. I was asked about my illness and left contact details. With my return to Bethesda Naval nearing, I could only feel disappointment and fear, along with a deep sense of reluctance over my tongue being cut out.

Meanwhile, I was called to the hospital where I had first been diagnosed to see another doctor interested in my condition. Awaiting this guy, I saw a book on chemotherapy in his office and took it up to look for information on a drug I'd heard named at Bethesda Naval: cisplatinum-five. It was noted as a drug containing mostly platinum found to stop the growth of some cancerous tumors and was finding use in treating lymphoma and some internal borne cancers. Its use among some patients could be an unpleasant, debilitating experience, a hard to endure treatment I had observed among patients at Bethesda Naval. There was nothing indexed on treating the cancer I was dealing with. Later, when pressing doctors waiting to handle my intended chemotherapy, I learned that the cisplatinum-five was chemistry that would indeed shrink tumors like mine, thus a reason for tattooing the tumor's boundaries. However, about ninety days after using cisplatinum-five against squamous cell carcinoma, the tumor was known to reemerge in a much more virile state. Such chemotherapy in cases like mine would be an opening salvo to damage the tumor, surgery would then be the main attack, and would have to follow chemo quickly. The third action in the war I was caught up in would be a substantial radiation assault. Once radiation therapy began, I was told, it would rack up nearly 6,000 RADs of radiation; this coming after, in my case, some twenty-uninterrupted hours of surgery. Prior to my treatment beginning I declined chemotherapy, either before or following

surgery. I did so with the thought that I might later use chemo to buy a little added time if surgery and radiation failed to do the job. Understandably, the chemo docs were irate over my stand against chemotherapy. They threatened to forgo all my intended treatment only to relent in the face of my determination.

(Here, please allow me to note that my treatment occurred 35-years ago, it was cancer treatment in an era of pioneering medical efforts in the struggles with head and neck cancers. There wasn't a lot of history out there and what was there was not easily nor widely available. By today's standards it was treatment somewhat primitive. Nowadays, chemotherapy, for example, is no longer just a broadsided assault. The chemistries used are more tailored for the tumors they are being used against; surgery techniques with the use of new methods and devices have become more refined; and radiation therapy methods have been upgraded and revised. Cancers are also targeted more accurately with ever improving state-of-the-art equipment. Radiologists today say, "there are no more shotgun blasts," targets are now able to be more precisely aimed upon, resulting in much less damage to surrounding "good" tissue areas causing fewer long term side effects. Once my radiation treatments began, I became nauseated. A condition that worsened through thirty-three treatments, to result in my being hospitalized again during a Christmas Holiday, capping off a long year of battle in the war on cancer.)

Getting to my salvation by Dr. Jaques, Jaques unexpectedly had returned to Baltimore to learn of my need for care. After earlier calling my home and speaking with my wife, he reached me by telephone just past 6:30 a.m. at Bethesda Naval ENT clinic where I had come earlier in the morning. I was in the beginning processes of being admitted and was astonished to hear from Jaques. "Tell them to stop," he told me. "Don't check in. Come to Baltimore to see me right away for an evaluation." I explained that my check-in was underway, I felt committed. I could not just walk away. "Yes, you can," he told me. "It's your rainy day. Just tell them you're leaving and do it." After a moment of nervous pause, I agreed. Later in the day, meeting with Jaques for over three hours, with my wife in company,

was life changing.

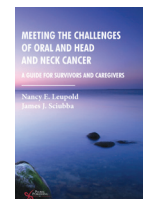
Following his examinations of my condition Jaques considered he could save half my tongue, or perhaps more. Furthermore, he did not intend to remove my right mandible, the lower jawbone below the maxilla area, to include the hinged joint at the cheek, near the ear. The surgery planned at the naval hospital involved removal of about half of the mandible to allow full access to the tumor site. Dr. Jaques, however, intended to split the mandible bone at the chin and swing the right mandible up and out of the way to reach the tumor site. Then, following surgery, he would reset the mandible and join it with pinning. It would be involved surgery, also calling for a muscle and skin flap taken from the upper abdomen and chest, termed a pectoralis major myocutaneous (PMMC) flap. Surgery was to occur at the Greater Baltimore Medical Center's Milton J. Dance, Jr. Head and Neck Center.

The next day, while at Bethesda Naval to pick up several biopsy slides for Jaques I ran into the navy captain from the ENT clinic, as I was leaving, and he was entering. We spoke briefly. I offered my apology for leaving his care. He was annoyed with my decision. He doubted Jaques' approach

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would cure my cancer. As we parted, he advised that I should go to Baltimore to see ENT doctors at Johns Hopkins Hospital for their opinions. Once home, I phoned Hopkins ENT clinic and to my surprise got an early afternoon appointment that day to see the ENT clinic's leading doctor.

At Hopkins I learned several things. Jaques, among a fraternal order of ENT surgeons, was undoubtedly considered to be one of the best of the best, a highly skilled, and broadly experienced surgeon, able to think outside of constraints. Upon conclusion of two doctors' examinations, I was told that although neither doctor could be absolutely positive, both felt that careful, skilled surgery could likely save at least half of my tongue. It looked a good chance I could get through surgery with a hemi-glossectomy, it was a crapshoot they both ventured; a decision could only be clearly determined during surgery, when the area in question was fully exposed. Then, in a private conversation with the clinic's senior doctor, I was counseled at some length about care costs that would occur at the Greater Baltimore Medical Center, or at any other private hospital. I was cautioned that all the care I needed to receive would include a great deal more than surgery. In all likelihood the costs involved in my case would be bankrupting given that the only medical coverage I held was that which I had earned entitlement to from military care facilities. Though doubtful, I might possibly get some limited financial support, but I had no private health insurance to rely upon to cover costs at private hospitals. The cancer care I was needing could run well over a hundred thousand dollars, and likely much more, I was told. Being swamped with a glut of billing paperwork would be stressful, markedly undermining my ability to recover from all the care I would endure. More than likely, I would end up having to take a second mortgage on my home, and though my wife was employed what of funding my two daughter's educations, and all other expenses families have. While Dr. Jaques and I had touched on some aspects of care costs, the Hopkins' doctor presented a more lengthily, objective view of costs I would be faced with during care at Greater Baltimore Medical or any other hospital. He suggested I consider seeking care at Walter Reed Army Medical Center. Costs to me there would

be minimal, not bankrupting. As a former army surgeon himself, a retired colonel, the Hopkins' doctor knew the ENT staff at Walter Reed. He recommended a surgeon at Walter Reed whom he offered to put me in touch with, a young army major with a glowing reputation as a talented surgeon, someone whom he felt sure would be able to save part of my tongue if that was indeed a doable task. "Take a day to think it over," he said, "then, call me if you want to be seen at Walter Reed, I can set up an interview for you there at the ENT clinic."

Again, I was faced with a dilemma, that of turning away from another surgeon and another hospital. I felt heartsick at the thought of turning away from Dr. Jaques' care. He had pulled me away from an abyss of fear and depression to offer me an uplifting prospect of hope. A human being of the first order, Jaques had shown himself as a generous, caring, and empathetic physician. Walking away was no way to repay him, never mind that it remained my rainy day. I felt I owned him dearly. Without further detail here let me say that ultimately, I did not have Dr. Jaques do my surgery. Notwithstanding, he remains with me as the most notable encounter on my journey along the bleak road through cancer and cure, although there are many, many more than a few to whom I came to owe much to

for my care and recovery.

The upshot of my evaluation at Johns Hopkins was that I ended up taking treatment at the Walter Reed Hospital ENT Clinic where half my tongue was saved although I said goodbye to most of my right mandible which was removed. Given my navy background and my senate service along with senate visitors and the concerns I received from folk at the senate majority leader's office, doctors at Walter Reed weren't quite sure just who I was. I wasn't quite sure either, but what I came to know was that I was a member of the senate family of the day. And while at Walter Reed I did all I could to keep the docs and staff in the dark about my true status as a weightless, insignificant nobody of ignoble origins. I could go on here yarn spinning about nearly six months in and out of Walter Reed, but we're out of print space, and I can't promise any further purging of some of my darkest days would be any less boring than what has thus far been laid down here. Remember, don't take the first opinion and keep the faith on the roads you travel in spite of the darkness you many encounter. Every day holds the potential for sunshine.

~ David Joy

(to connect with David, please send your comments and questions to c.leonardis@spohnc.org for forwarding)



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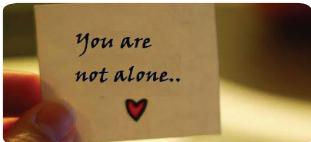


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