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Multidisciplinary Care of the Head and Neck Cancer Patient

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Multidisciplinary Care of the Head and Neck Cancer Patient

Springer

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Preface

Head and neck oncology requires a well-orchestrated ensemble of subdisciplines that collectively enhance patient care. The wealth of fields that intersect within head and neck cancer is extraordinary compared to most disease sites. When in synchrony, the multidisciplinary approach can confer a dramatic improvement in patient experience, quality of life, and survival. The challenge for the busy provider is to embrace the team approach, supporting patient access to the most up-to-date science and technology.

The multidisciplinary approach allows for the cross cultivation of knowledge, performance improvement opportunities, and system-wide operational efficiencies. The surgeon learns about radiation contouring, the radiation oncologist learns about drug therapies, and the medical oncologist learns about surgical considerations. Just as important is the integration of necessary supportive services and rehabilitative care that often makes the difference in whether a treatment plan is properly executed or falls short. The team input broadens our scope, tailors our approach, and raises the bar on what should be considered the standard of care.

From the beginning, the head and neck teams at City of Hope and Cedars-Sinai have been built with this interdisciplinary concept in mind. Our mutual philosophy has been to provide multifaceted treatment driven by guidelines and patient goals of care rather than personal experience or institutional dogma. This volume is intended to help educate the reader about the integrated facets of head and neck care, with a spotlight on ancillary disciplines. It should be clear that the passion and skill that they provide are crucial to the care of the patient, both during treatment and afterward in survivorship.

A cancer diagnosis can be overwhelming. Head and neck cancer patients are particularly vulnerable as the cancer itself and the treatments prescribed can impact self-image, mental and physical stamina, and daily functions. Although each patient's experience with diagnosis, treatment, and recovery may be different, there are common challenges in the head and neck cancer journey, as illustrated in our patient perspective. This journey and others humanize the efforts described in the

Head and Neck Cancer Program, City of Hope National Medical Center, Duarte, CA, USA

Head and Neck Cancer Program, Cedars-Sinai Medical Center, Los Angeles, CA, USA following chapters in ways beyond the written word. We hope that you will enjoy reading this book as much as we have enjoyed assembling it.

Los Angeles, USA Allen S. Ho
Duarte, USA Ellie Maghami

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Head and Neck Cancer—The Patient Perspective

1

Sally Lapiduss and Francesca Bartoccini

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Abstract

The following chapter details diagnosis, treatment, and aftermath from a head and neck cancer patient's point of view. It illustrates the potential daily challenges of undergoing treatment while coping with the diagnosis of cancer. The toxicities of treatment and recovery from them are described to better inform treating physicians, as well as counsel future patients on the preparation needed for a successful outcome. We acknowledge each patient has a unique story to tell. This is one patient's story.

Keywords

Survivorship · Head and neck cancer · Patient perspective
Chemoradiation toxicity · Quality of life

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1.1 Introduction

In the hopes of giving doctors and other caregivers some insight into what their throat cancer patients go through, I have tried to record the facts of my case, the treatments I went through, and the emotional toll it took on my family and me. Since my recovery, several people about to embark on the same treatment asked me to please "tell them EVERYTHING!" They wanted to know what might and did go wrong for me. I realized knowing the possibilities helps patients be less fearful when things the doctors may not have mentioned start happening. Obviously, it's impossible to know EVERYTHING, and each patient is different, but having some idea of what to expect is intellectually and emotionally very helpful.

Doctors know the treatments they have prescribed for their patients, and the many possible outcomes. They may see us once a day (radiation oncologist) or once a week (medical oncologist), or even once every several weeks (supervising surgeon) as we go through the protocols. During that time, however, they may lose sight of the myriad things that go on the other 23 hours of their patient's day. Having lived through this ordeal and come out the other side 100% cancer free, I feel lucky and grateful, and I am happy to share my thoughts about the experience with you all.

1.2 Cancer Diagnosis

On Memorial Day weekend, 2015, I was diagnosed with a tumor on the base of my tongue. For months I had sometimes felt like a popcorn kernel was stuck under my tongue—but experienced no pain. Over time, I asked various doctors, including an ENT doctor, to examine me—but no one found anything. Finally, after my cat began draping himself around the front of my neck, sticking his snoot into my mouth, and even tapping with his paw at a spot on my neck, I became concerned. I pressed that spot, and felt a zap of pain that radiated up my neck. I called the doctor the next day.

My internist still saw and felt nothing, but given what I had described, (Sans the cat story) decided to send me for an MRI. That scan revealed the tumor. My internist immediately ordered a PET/CT and sent me to the head and neck surgeon, who also ordered a PET scan. The surgeon scoped my throat in his office, to visualize the tumor and try to get enough of the growth to make an exact diagnosis.

That was one of my first and more hellish medical experiences. Lots of gagging and lots of blood, but I got through it. Unfortunately, the clinic biopsy was non-diagnostic, so I underwent a formal biopsy under anesthesia in the hospital a week or so later. While still in recovery, the surgeon came to tell my wife that it was indeed cancer. A 2.9-cm midline base of tongue, (oropharyngeal) squamous, HPV-positive cell carcinoma, to be exact. Phew. That was a lot to digest (at least I didn't say "swallow!") and we went home quite shaken. Or my wife did, as I was still pretty dopey from the drugs. Once the doctor called to explain what all those medical words above mean, the whole “cancer adventure” began in earnest.

The diagnosis left me rather numb. I remember being slightly relieved that there was actually something there, and that they had found it. At least now there was something specific to do something about. I bless that cat for making me listen to my body and return to the doctor, and I bless that doctor for taking me seriously and moving forward toward a diagnosis. Most of us know our bodies well, and rather than ignore something and hope for it to go away, I’d now tell anyone who felt there was really something wrong, to persevere and keep looking for the answer.

The good news, I was told by literally every clinician I encountered in those first couple of weeks, was that I was very lucky because I had one of the “best” possible cancers, one with a 95 % cure rate. The bad news, they all hastened to add, was this was also the cancer with one of the worst treatments. They said that because “killing” the tumor involves radiating the head, neck, tongue, palate, teeth, gums, salivary glands, taste buds, etc. … it can be a hellish proposition. You can lose the ability to swallow and eat. The skin on your neck gets very burned, as does the tissue on the inside of your mouth and throat. Sometimes a person undergoing this treatment needs a feeding tube. Also, the chemo drug used to make the cells more susceptible to the radiation (cisplatin), may sometimes have a deleterious effect on one’s hearing. Yikes!

In anticipation of the treatment beginning, I met with a dental oncologist—(who knew?) who explained what some of the side effects (dry mouth, gum, tissue, enamel damage, etc.) could/would be. Again, a bit scary and daunting, but he and his nurse were helpful in trying to make me more comfortable as the weeks wore on. Much attention was paid to my not losing the ability to swallow, so I also began seeing a speech and swallow therapist. After an evaluation, she gave me a series of exercises to start and continue to do throughout and after my treatment. They proved to be invaluable.

I was also measured and fitted for a “mask” (Fig. 1.1), which covered the entire upper third of my body during my daily radiation treatments. I had to purchase upper and lower mouth guards to protect my teeth, gums, and dental work and visit my dentist to have a cleaning and to set up a dental baseline. My dentist is also a cancer survivor, so he was very empathetic and helpful.

Despite the fear of the treatment and the cancer itself, I think because I was given that positive prognosis immediately, I always felt the odds were on my side. It truly never entered my mind that I was going to be one of the five percent. I felt like I had to suit up and show up… and there was quite a lot to do to prepare for the treatment to come.

The surgeon explained he felt surgery was not the wise course to take as the position of the tumor, pretty much in the middle of the base of the tongue, meant it was between two major arteries and surgery would be too risky. Instead, he advised chemo and radiation as the most effective course of treatment.

Because I was over 65 years old, the chemo would be once a week, and it was a drug specifically targeted to make the tumor more susceptible to the radiation. The radiation would be Monday through Friday, for 7 weeks (which stretched into eight

Fig. 1.1 Mask during radiation treatments

and a half, for various reasons). We next met with our radiation oncologist and his knowledgeable, empathetic nurse. Later we met with the medical oncologist who would oversee the chemo. Over the months of treatment, and after, my wife and I would come to rely on him and his team of equally skilled and caring nurses, nurse practitioners, and nutritionists.

1.3 Treatment

Once it was decided that I was a candidate for radiation and chemo without surgery, my day-to-day care was basically handed over to the clinicians mentioned above. Everyone bolstered that "can do" attitude by never talking down to me, really listening to my assessment of my physical and emotional state, and always making me feel a part of the treatment. They also informed me about *most* of the possible negative effects. Oddly enough, after preaching all this positivity, I will also say that I would have liked to have been given more information, even the negatives, so I would have had a better sense of what to expect during the long months of treatment and recovery, and beyond.

Pain was definitely discussed, and I was told the doctors would do everything they could to lessen it. At first, topical preparations like Magic Mouthwash (an elixir of lidocaine, Mylanta, and diphenhydramine) worked a bit. But soon the pain from the radiation was intense, and I rather quickly worked my way up to a 50 mg fentanyl patch, with oxycodone added in as needed.

I was told early on that after several weeks of radiation treatment on my throat, I would have what could best be described as horrible sunburn… inside my mouth and throat. This would make swallowing difficult. That was quite the understatement!

I actually had a friend who had gone through this treatment the year before me and discovered that putting a few drops of liquid medical marijuana (specifically cannabis oil with no THC) under her tongue or brewing it in a tea, allowed her to numb her throat long enough to eat without pain so she could maintain an acceptable weight. We were happy that my oncologist supported our efforts in this direction, and after my first chemo treatment immediately provided us with the necessary paperwork. Unfortunately, despite two informative and amusing trips to medical pot dispensaries, none of it worked for me. It is important to note, however, that even with a similar diagnosis and treatment approach, each person's journey with this disease is different. What works for some, does nothing for others. I think it is important to try everything and see what works best for you.

My big problem was after only a week or two of radiation, I couldn't swallow at all. It was horribly painful. The meds all helped control the pain, but I just couldn't swallow anything—no water, and therefore no food or pills—and ended up having a G-tube surgically inserted very early in the process, which necessitated all sorts of other adjustments for us. I say "us" because I really went through all this with my wife. It became very important that all the doctors and nurse practitioners deal with her directly as my surrogate, and trust that the information she gave them was accurate.

At first, discombobulated by the mere fact of the diagnosis—then later because I was so weakened by treatments and the inability to eat, plus addled by all the pain medications—I desperately needed someone clearheaded to be with me throughout all this. I needed an advocate, and someone to help translate my feelings to the doctor. I lost my voice fairly early on, and although I used my iPad to communicate—it was often frustrating and laborious. I would urge doctors to encourage their patients going through any kind of treatment like this to have a spouse, partner, or friend accompany them to all doctor appointments and treatments. They need to reach out to friends and family for help. They (and their spouse/partner/family) will need it.

I was very reluctant to do this at first. I didn't even want to tell friends and family that I had been diagnosed. But the fact of the matter was my wife had a full-time job and couldn't take me to every appointment. A friend turned us on to a wonderful website called LotsaHelpingHands.com, (there are others) which allows you to gather email addresses of friends and family, and then send them each a calendar, complete with dates, times, and locations the patient needs to get to, etc. People can simply go to the site to sign up to help and see what slots have already been filled by others. No muss, no fuss. We actually found that our friends and family were so grateful to be given a way to help, they thanked us for providing them with a means to lend a hand. It would have been terrific if one of our doctors or clinicians had mentioned this site/service, or ones like it to us. We stumbled upon it accidentally while trying to set up something similar on our own. It really made our lives much easier during this long ordeal.

Another thing I found very helpful was writing everything down. Questions I had for the doctors, their answers, how to take meds, eventually how to work the food pump, etc. At first, we had sheets of paper all over the house. Then my wife bought several spiral notebooks in which we began jotting down everything (Fig. 1.2). Once the treatments began in earnest, and there were so many medications to take and mouth and teeth preparations to do morning and night—we began dating each page and keeping track of the meds I took and when. Soon each day was recorded in detail… meds taken, pain levels, nutritional supplements, sleep, bowel movements, etc.. We would also jot down questions for the doctors. Having this notebook with me when I went to chemo or to a doctor's appointment proved invaluable. I could show them my questions and they could look at my pages to answer their questions about what had been going on with me at home.

In fact, on one follow-up appointment, the surgeon told us that the people who write things down tend to do well. He even asked to see the notebooks and we brought them to my next appointment. I think it would have been tremendously helpful if a doctor or nurse had suggested we do this at the beginning of treatment. So while the doctors prepared me somewhat for what was ahead, and dutifully answered my questions as they arose, here are a few more things I would have liked to have had more information about right from the get-go.

No one mentioned how severe the loss of the ability to make and swallow saliva would become. I know it is different for every person depending upon the facts of their individual case, and also how and where they are radiated. I was lucky not to have lost or (hopefully) have permanent damage done to my salivary glands. But… the amount of thick, ropey, heavy saliva constantly dripping into my mouth and down my throat, coupled with my inability to swallow, made for several months of horrible and almost constant coughing and spitting. We had plastic "spit buckets" (aka Tupperware wash basins lined with paper towels) stationed strategically

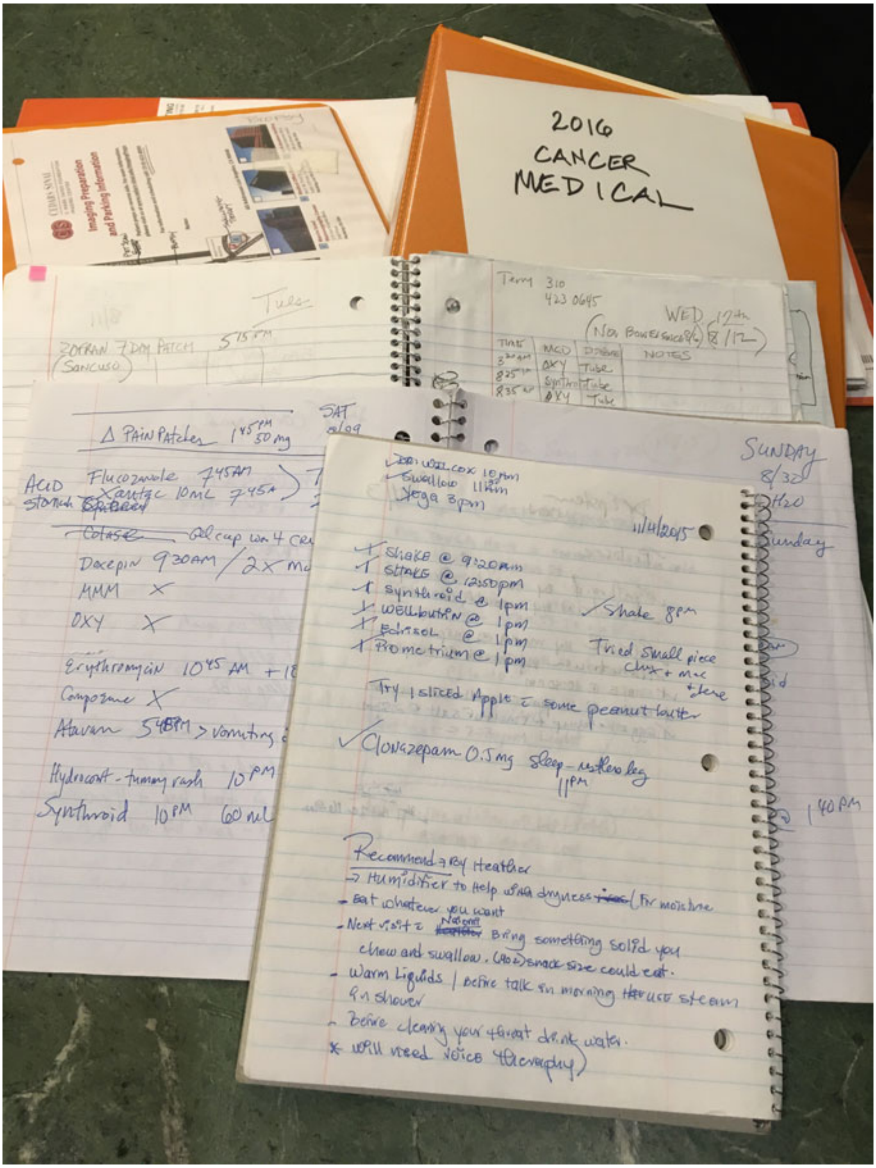

Fig. 1.2 Notebooks with questions during treatment

throughout our home. I took one with me in the car to and from treatments. Regular facial tissues irritated my lips, probably from the chemicals used in processing, but we found a type of toilet paper that did not irritate me.

The saliva and mucus production also made me constantly nauseous. If I had been told about all this beforehand—it might not have made a difference—but because I wasn't told—I spent an extremely anxious few days thinking something else was terribly wrong.

At the outset of this severe discomfort, my dental oncologist suggested I try Doxepin… but not for depression! I mixed the contents of one capsule into two teaspoons of water, swished it around in my mouth for a minute, then spit it out. For several days, this really helped to dry up the saliva and mucus, but then it abruptly stopped working. Weeks later I tried it again, and it worked again… for a few days, then ceased to make any difference. That happened a lot. I learned things might work for a few days, and then cease to be effective. Again, that would have been a useful bit of information to have going into all this.

This saliva/mucous combo platter was the agony I was sure would never end. I still have some thick saliva in my throat, and only a little saliva recovery in my mouth, but 1 year after the end of radiation treatments, it was much better. Now, almost 2 years past the treatments, it is still not at 100 present—but significantly improved. I did try several products from my dental oncologist, but none of them worked for me. Occasionally, Biotene spray would help. The problem was the products would give some moisture in my mouth, but increase the "gook" in my throat, which I hated the most. It was like a constant, horribly thick postnasal drip. I had to sleep sitting up a lot, too. Various smells also became intolerable, and overall, my olfactory sense became much more acute. Unfortunately, everything smelled bad! Perfume was a killer! This lasted for several weeks during treatment, then went away.

On a more serious note, I had never heard the word "lymphedema" until the day I looked in the mirror and thought I was developing a goiter. The front of my neck was incredibly swollen. Only then was I told that radiation can damage the lymph glands, causing fluid to collect in tissues under the skin, and that this is a chronic condition that may never resolve itself fully. Again, not really good news for me and my neck, but still something I wish I had been informed about pretreatment. In the moment, I had panicked because I had no knowledge that this could happen, let alone that it was so common. It might sound silly, but I thought my tumor might be growing back.

Once it happened to me, my radiation oncologist sent me to a lymphedema therapy specialist, (at a hefty cost that insurance would not fully cover), which proved to be very helpful. The sessions consisted mostly of a very specific neck massage, which attempts to open the lymph channels. They had me purchase a compression garment, which I still wore at night a year out, but not during the day. I probably should still be wearing it—but I don't. It is very uncomfortable. The lymphedema will probably not go away completely, but it has diminished, and the therapists taught me how to do the message myself, so I'm hopeful that its effects will continue to diminish.

Another particular problem I faced was dealing with my small and "rolling" veins. After various painful episodes during the hospital biopsy and PET scan (blood draws and nuclear med injections were extremely painful for me because of how hard it is to find a good vein on my arms), I was told to get an implantable port. There were so many blood drawing sticks and pokes, that despite the pain I had for about 10 days after the port was put in, (it hurt like hell, then became merely irritating), ultimately it was a lifesaver.

Although doctors, of course, know what chemo and all these tests entail, I had no idea how many times my blood would be drawn and drugs (steroids, antinausea drugs, potassium, the chemo drug itself) would be pumped into me. Before the port was inserted, caregivers and I quickly learned to ask for an experienced person to take my blood. When someone knows what they're doing, it makes a world of difference to the patient. And although over the course of long months of treatment, drawing blood might seem like a little thing to a doctor, to the patient it can mean the difference between a good day and another very bad one.

One other salient patient point; I had a lot of pain and discomfort with both the port surgery and the post-surgery G-Tube insertion. I was repeatedly told neither was a big deal, but for me they were. And I'm sure I'm not alone. The port also hurt like hell coming out—but I could never have had that many injections and blood drawings without it. I just wish I had been told about the port option earlier on, and that when I went through these surgeries, my very real feelings of pain were not questioned, but acknowledged as such.

I was told my taste buds would get burned and things would begin to taste bad, or have no taste at all. It was more the former, as everything, even and especially water, tasted like rocket fuel (or what I imagine rocket fuel to taste like). For a while, I was able to drink sips of carbonated water, but then that too began to taste horrible.

As I said, I do know each patient is different, and perfect storm of complications—how quickly the radiation shut down my ability to swallow, coupled with my already lousy digestive system (acid reflux and pre-Barrett's)—made me incapable of keeping down much of the several different nutritional supplements prescribed to keep up my weight and energy. It also caused a great deal of acid pain in my chest, stomach, and throat.

Not being able to keep any of the liquid nutrition down meant it came up… by way of my radiated and very raw throat. I actually had only a few days of bad chemo nausea and vomiting—but many, many weeks of total nausea and vomiting because of the supplements. The whole process of having the G-tube inserted and then trying to function with it became my Achilles heel in all this.

Because I could not swallow at all, everything had to go through the G-tube, including all medication, either crushed or in liquid form… and it came back up a lot. At various times I was prescribed many things to try to keep the acid reflux, nausea, and nutritional supplements down, including; Zofran, Carafate, Compazine, Prilosec, Reglan, Milk of Magnesia, you name it! Because of my weight loss (86 lb total on a five-foot four-inch frame), which continued even after I completed chemo and radiation, I ended up needing IV fluids several times a week. I developed mouth sores and much worse, thrush. I was prescribed Fluconazole and a Nystatin rinse. Even after I tested negative for thrush, I still had a very thick, white coating on my tongue and inside my mouth, which was very uncomfortable. My acupuncturist said it was a part of the saliva issue and would dissipate in time. It has.

I was throwing up about once or twice a week starting around 2 weeks before the end of treatment—and for some weeks after treatment. Since I wasn't eating, it was mostly violent retching with nothing but a little blood and some fluid brought up. It was very painful and felt like I was throwing up the lining of my throat.

I was told to drink as much water as I could manage, but dehydration was a big problem for me. Lack of water led to shaking, fainting, and extreme fatigue. I never knew how sick one could feel just from not drinking enough water.

I experienced anxiety at different levels. At one point, I couldn't watch any TV shows where anyone died, although CSI and crime shows had been my favorites. Instead, I watched DIY sports, and nature shows… and some comedy shows… if I could follow them. I had pretty rough bouts of being scared. I saw a shrink for this for one session and it helped. Ativan was a tremendous help for anxiety and sleep. I took it before bed and often during the day as well.

Speaking of trying to follow things… "Chemo Brain" is real, and another thing no one mentioned to me early on. During the months of treatment, it was very hard to focus. Today my memory is still a bit spotty, and I'm told this can go on for some time. People have gotten frustrated with me because it seemed like I wasn't paying attention, but it's the chemo. I just couldn't retain information. I'm much better now, and am even back to work, which was unthinkable several months ago.

1.4 Posttreatment Recovery

I had been told that the days after my radiation treatments ended might be the worst. A nurse explained that you "keep on cooking" while your body is also dealing with the greatest accumulation of all the chemo and radiation. This turned out to be true for me. (And it's a good example of getting negative information early on, which proved to be helpful). After my treatment ended, I had lost so much weight and was so weak; I spiked a fever and was hospitalized for 8 days. I remember going back to chemo for hydration and potassium, and feeling so sick and now really scared. Here I was, finished with all the hellish treatments, yet I felt like I was dying. One of the nurse practitioners realized what was going on with me; that I had hit the wall emotionally. She realized I had been sent home after my last radiation treatment and pronounced "healthy", but I was still sick… and in a way, having withdrawal from all the care and attention I had been getting while undergoing treatment. I hadn't even realized that, but once she said it I cried in recognition and relief.

Several hours later, I was admitted to the hospital with "failure to thrive" listed as a reason for my hospitalization. At one point, I'm told, I was on two antibiotics, plus all the other meds, and I was given a blood transfusion. I say, "I'm told" because I really remember very little of those 8 days. Finally, in the hospital, they hit on a nutritional supplement that—for the most part—stayed down and in my system. My fever dissipated, and I was sent back home with an electric stomach pump to ensure the nutritional supplement would drip very, very slowly into my G-tube, 24/7. The tube would remain in place another few months as I healed.

My voice became very gravelly during the duration of treatment. Trying to talk or whisper was painful. Relying on the iPad was frustrating as the heavy-duty meds and chemo brain made me very slow to put thoughts together and use a keypad. We placed bells in every room so I could summon my wife or "sitter" for the day. Yes, dear reader, I needed a sitter. I could not really be left alone for several weeks because I was so addlepated, and could not be trusted to dispense my own meds—which had to be crushed, mixed with water, and poured into my G-Tube… or to keep a close eye on my temperamental nutrition pump.

It took several weeks and much exercise to regain most of my voice, but I still can't sing. (Before cancer I could sing. In fact, during my younger days I was an actress/singer). I used to sing all the time, so I really miss it. Using a humidifier, breathing in steam, and doing the exercises I was given and continue to do, have helped. I had a good speech/swallow therapist, and though I stopped seeing her months ago, I continue to do the exercises she taught me. They aim to open the swallowing muscle in your throat that radiation can shut down. Mine is opening again, though I still have a little "back up issue". Sometimes water feels like it's backing up and trying to get into my windpipe. I have to re-swallow to keep it going down.

At 1 year out, I still had to be careful with many things. I flossed religiously after meals and at night. Without saliva, everything got stuck in and around my teeth and above my gums. I also brushed with a concentrated prescription fluoride solution—SF 1.1% Gel—after the regular electric toothbrush cleaning. I didn't rinse my mouth after the fluoride, just spit and then trap the little bit left on my teeth under my mouth guard at night to further protect the teeth from decay. I was told to keep on top of this, as once again the radiation will keep on cooking, sometimes for years.

Because I kept up my regimen—now, 2 years later, I am greatly improved. I've recovered more saliva than anticipated; I have almost no swallowing issues.

My tumor was to the right middle of my tongue, so now I have some scar tissue on the right. Occasionally, if I don't chew food long enough, or if I try to swallow a big pill, it will get stuck on the right. I can easily cough it back up, chew and/or re-swallow on the left. The first time this happened, however, it terrified me and I thought I would choke to death. I have to drink water with every bite of food to form the necessary bolus so it can be swallowed. If I don't, little particles of food can get stuck in my throat and even get inhaled into my trachea. This happened once and scared the heck out of me, but now I drink water constantly. I never liked water before I had cancer. I hated the taste. But I'm ever so grateful for it now.

I drink a meal replacement protein drink every day. A month or two post-radiation, I could only get down a little scrambled egg and, oddly, pancakes with pure maple syrup. Soon I could do chicken vegetable soup, and things like turkey burgers and other protein crumbled into tomato soup. In fact, tomatoes, and anything tomato based (pasta sauce, soup, etc.) became my go-to food. As I said earlier—it's very different for each person. The rate at which tastes return and are pleasurable again varies greatly. I would try something that would taste bad, but try it again a few weeks later to find it tasted good again. The list of foods I could eat comfortably grew over time. I would advise taking it slow, experimenting, and trying not to get too frustrated.

Two years after treatment, I can eat most things, although I still have trouble with sugar and sweets. All sugar tasted like bad chemicals in my mouth. Several months after treatment, I discovered one kind of dark chocolate that tasted good to me… and believe me, I had to try a lot of different types of dark chocolates before I found the one that worked. For a long time, rice, bread, and anything dry were untenable. All bread was horrible and tasted like paste except, for some reason, English muffins. Go figure! Now I can eat bread, especial if it's dipped in oil or sauce. Good-bye SIZE ZERO!

I had some burned skin on my neck, but all the doctors said I escaped remarkably unscathed compared to other patients. Early on my radiation oncology nurse recommended I use a natural lotion called Calendula. I used it two or three times a day on my neck and still try not to let my skin get too dry.

From the beginning of radiation to the end, my weight sank from 189 to 103 lbs. After my weight stabilized at 112 lbs, I was finally able to have the G-tube removed. I know it saved my life, but it was a pain to deal with. For instance, showering involved wrapping my mid-section in saran wrap and tape to keep the tube insertion area dry. Along with the clear plastic sleeve, I wore to keep the port dry, I was quite the bathing beauty! I was also thrilled to be done with the nutritional supplements and the constant hum of the electric pump. Now with my taste and swallow returned, my weight is at 130 lbs.

I would advise patients to take advantage of all the post-cancer and rehab treatments around them. I began to do restorative yoga, which was offered in the building where I went for my chemo treatments. It is a gentle, slow-moving form, which was very helpful in getting my strength back, and building up my energy and range of motion. The yoga made me stronger! I can't emphasize how even just a little non-strenuous exercise greatly improved my balance, fatigue energy, and concentration levels.

It seemed mostly to consist of lying on a mat and ever-so-slowly raising and lowering each extremity until I dozed off in class. But they encouraged that. It was like a meditation. I never thought I'd get my energy back, and I still have a day here and there of deep fatigue. But when I do, I surrender to it. I realize rest is very important. This is not the sort of thing you "power through", and I try to be gentle, kind, and patient with myself.

I was also told about a physical therapy rehab program offered free of charge by the hospital, and it has been a godsend. I had been walking a bit and wanted to go back to a gym, but was still too weak, and frankly too afraid I might hurt myself. In this program, I was evaluated by a doctor and then trained by professionals who slowly increased my regimen. Like the yoga, it's been incredible to see how little it takes to regain movement and strength.

Along with dealing with the physical aspects of recovery, there are emotional ones to contend with as well. When my first PET/CT scan showed that everything was all clear, I felt compelled to get rid of everything that reminded me of what I'd been through. I needed to purge myself of the cancer experience. I had no idea I would have this reaction. While going through treatment, I found it best to just accept it all and take each step as it came. I also had to recognize that many things (taste buds, saliva, aches, pains, etc.) would go away, but then come back again for a while. Recovery can be very frustrating, yet it helps to remember you're going in the right direction… toward wellness. Having and keeping a sense of humor is also very helpful.

Before I started treatment we went to Old Navy and I bought about six tee shirts, four pairs of stretchy pants, and some slip-on sneakers: my chemo clothes. I couldn't wait to give them all away. I kept my radiation mask thinking I'd use it in some cool art project… but after hanging it from a tree in our front yard last Halloween, I threw it away, too! I decided it was best to get rid of it all. I don't need to have any reminders.

I was also in the enviable position of being semi-retired. I had worked for years in the film business as an art director and production designer. I had segued from that to get my contractor's license and was now doing home remodels. I didn't work for a year during treatment and recovery, and came back slowly with one or two small design projects during the next six months after that. It was really all I felt I could handle because of the chemo brain effects. During this time I was very frustrated with my lack of focus and memory issues. The good news is that now at 2 years out, I feel that I am at 90% and getting better every day.

Since the cancer, I have given up the contracting part of the job—too much heavy lifting and stress—and now design home remodels, furnishing clients with plans and models.

I also have quite an impressive woodworking shop, filled with every tool and machine imaginable. I loved spending time building and repairing furniture, models for work, other people's mangled DIY projects… you name it. But early in my recovery, I told my wife to sell everything, since I believed I'd never again have the strength or the desire to work in my shop. Wisely, she didn't listen to me, and a few months later, one day out of the blue, those thoughts and feelings lifted and I found myself puttering away… then rebuilding several old chairs I had collected. In retrospect, I realized the pall lifted after my physical rehab had begun to take hold and the chemo brain had begun to lessen. Now I'm back at work for clients, and spending hours in my shop again.

We were very lucky that my wife's full-time job included great health insurance and sympathetic bosses and co-workers who allowed her ample time off to deal with my issues.

I know many others would not be so fortunate, and I again urge anyone dealing with this to put out the word amongst family and friends and allow them to help. It was an extremely welcomed gift when, after my hospitalization at the end of radiation and chemo, my brother offered to pay for a trained LPN/caregiver for a few weeks. Having her there gave my wife the ability to be at work full time, and get a bit of a break from the 24/7 routine my medical needs demanded.

I do understand that perhaps you want to tell the patient only so much, and some of this posttreatment information can and should come… post treatment. Perhaps doctors tell us just as much as they think we need to know to get through the steps right in front of us. They don't want to overwhelm us. But a lot of what I experienced, even weeks after my hospitalization, was never mentioned or discussed. As I've said, things like being told by one nurse in oncology that I'd "keep cooking" after radiation treatments ended, proved very helpful. It allowed me to mentally prepare myself for the weeks ahead, and not expect to feel great a few days after the dreaded radiation dosing was done.

So on an individual basis, I think a doctor needs to make a judgment as to whether their specific patient can handle more. I would have liked to have been told more about what to expect upfront. In several instances, if I had been armed with that information, when it happened to me I would not have been so afraid that something else was wrong.

My hope is that some of the information in this chapter will allow doctors and caregivers to realize the daily minutia faced by their throat cancer patients, thus being better able to allay their fears, and arm them with creative ways to make their treatment more comfortable and effective. Doctors and caregivers need to keep in mind the patient's struggle continues outside the treatment rooms, and for many months after that. Any and all aid they can give them regarding what to expect down the road is very valuable and will be much appreciated.

I think because we met medical professionals on every level who were kind, empathetic, communicative, and worked in conjunction with each other and us—our experience was better than most. All those skills proved to be critically important in getting me through this nightmare. We were, of course, extremely trepidatious going into this, but all of the doctors, physician assistants, nurses, and med techs—with very few exceptions—were terrific. One year out from all this, I cannot overemphasize how much being surrounded by positive clinicians, family, and friends aids in one's recovery. Even when telling patients the unvarnished truth and the worse case scenario, if doctors can also be encouraging, and empower the patient with that optimism, it will go a long way toward affecting a positive outcome.

1.5 Epilogue

The silver lining in all this was discovering how truly empathetic and supportive friends, family, and people, in general, could be. Folks I met in chemo, in restorative yoga class, and physical therapy rehab… waiters and waitress who worked with me so I could find something to eat on their menus… even our once nameless neighborhood pharmacists—they all became members of Team

Francesca, pushing me steadily and patiently along the road to recovery. If they had faith in me, how could I not work hard to get through this ordeal?

Now, 2 years out, I am healthy and strong and cancer free. I am back up to 130 lb (Fig. 1.3), mostly regained muscle, since I am still a size 4. (Although I will forever cherish those 4 glorious months I was a Size 0!)

Fig. 1.3 Disease-free 2 years after completing treatment

I am so grateful to my wife, doctors, clinicians, family, and friends. I am even grateful for the experience of having had cancer, because I was allowed to come out the other side with a renewed appreciation for living every day to its fullest. I am working on a kitchen remodel and adding a second story to a client's home, traveling, eating well, exercising, and about to celebrate my 70th birthday!

Sure, you're going to have bad days, even weeks, but I urge anyone going through this trial to stay strong, ask questions, accept help, and fight the disease with everything you have. In an unexpected way, post-cancer, we've been given the opportunity to appreciate and embrace life in a whole new way.

Physician Assistants and Nurse Practitioners in Head and Neck Surgery

2

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Abstract

This chapter explores the role of advanced practice clinicians (APCs) and patient care coordinators in the head and neck cancer setting. APCs, which include physician assistants (PAs) and nurse practitioners (NPs), are licensed professional healthcare providers who diagnose and treat illnesses, order and interpret diagnostic tests, and prescribe pharmaceutical and non-pharmaceutical therapies. Although the training, education, and licensure differ between PAs and NPs, their roles are quite similar in head and neck surgery. They collaboratively participate in the medical and surgical management and coordination of head and neck cancer patients in a variety of settings including outpatient clinic, inpatient, and in the surgical suite. APCs can function autonomously in an outpatient clinic with the medical management of postoperative visits and new consults. In an inpatient setting, they perform daily inpatient rounds and manage patient care preoperatively and postoperatively. In head and neck surgery, registered nurses (RNs) usually function in the role of patient care coordinators. They serve as a liaison between the patient and all members of the multidisciplinary team. APCs and patient care coordinators work closely with medical oncologists, radiation oncologists, surgeons, and other allied health professionals to provide high-quality care and achieve optimal patient outcomes in the head and neck cancer setting.

Keywords

Head and neck · Cancer · Physician assistants · Nurse practitioners
Patient care coordinators · Registered nurses

2.1 Advanced Practice Clinicians Educational Background and Training

Advanced practice clinicians (APCs) are a subset of clinicians that include physician assistants (PAs) and nurse practitioners (NPs), each sharing a major role in the management and treatment of head and neck cancer patients. In order to practice in this specialty, APCs must undergo rigorous postgraduate-level training. PAs and NPs are licensed professional healthcare providers who diagnose and treat illnesses, order and interpret tests, and prescribe pharmaceutical and non-pharmaceutical therapies. APCs practice medicine and serve in both rural and urban communities nationwide in the United States (U.S.). Though each APC training program varies (Table 2.1), each licensed clinician can collaboratively participate in the management and coordination of the intricate medical care often required in a head and neck surgery practice.

Table 2.1 Comparison of background and training required of PAs and NPs

	Physician Assistant-Certified (PA-C)	Nurse Practitioner (NP or DNP)
Bachelor degree required?	Yes— any discipline	Yes— BSN or other undergraduate degrees
Postgraduate degree obtained?	Yes— MSPA	Yes— MSN or DNP
National board certification required?	Yes— PANCE	Yes— NCLEX-RN, specific population focus exam for NP certification
Recertification?	Reexamination every 10 years—PANRE	Option to recertify by continuing education and clinical practice hours or by examination every 5 years
Residency?	Optional, 1–2 years and specific to specialty	None
State licensure required?	Yes	Yes
CME required?	Yes	Yes
Ability to diagnose illness and prescribe medications?	Yes	Yes
Eligible to apply for DEA license?	Yes	Yes
Eligible to first assist in OR?	Yes	Yes—requires additional certification, RNFA
Requires supervising physician?	Yes—In-person oversight and chart co-sign requirements vary by state	Varies by state

2.1.1 Physician Assistants

PAs are certified at the national level and licensed in the state of their practice. They work with one or more supervising physicians (SPs) allowing them to extend the physician role in the operative, inpatient, and outpatient settings. The scope of practice of a head and neck surgical PA includes but is not limited to evaluation of patients in clinic, performing in-office procedures such as direct laryngoscopy, assisting in the operating room, making daily inpatient rounds, and seeing patients for long-term surveillance (Fig. 2.1). The average accredited PA program is approximately 27 months long and admission requirements generally include a bachelor's degree, completion of prerequisite courses similar to that of medical schools, and prior direct hands-on patient care experience [1]. PA programs are accredited by the Accreditation Review Commission on Education for the Physician Assistant (ARC-PA). The majority of PA programs award a master's degree and this will become the ARC-PA standard by 2020 [1].

PA education strongly emphasizes team-based care and the curriculum largely focuses on general or primary medicine. The first year of the curriculum is a didactic classroom-style education often taught by instructors with a Doctor of