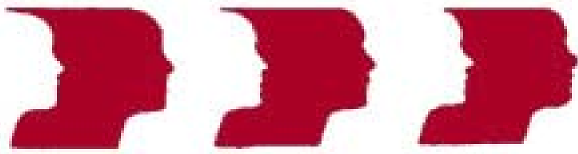

NEWS FROM

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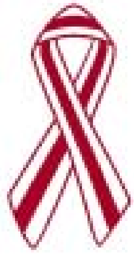

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A PROGRAM OF SUPPORT
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EVIDENCE BASED RESEARCH IN THE HEAD AND NECK CANCER PATIENT

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The Milton J. Dance, Jr. Head and Neck Rehabilitation Center at the Greater Baltimore Medical Center (GBMC) is comprised of an interdisciplinary team consisting of physicians, speech pathologists, a nurse, and a social worker specializing in the treatment, rehabilitation, and recovery of head and neck cancer patients. Staff clinical expertise and knowledge base is acquired through academic coursework, conferences, literature reviews, team discussions, and interdisciplinary patient care conferences. The most powerful lessons, however, are learned from patients' struggles, successes, and challenges as they confront cancer. Hearing the words "you have cancer" is the first step in a very long process. The newly diagnosed cancer patient must prepare to face the road ahead from treatment through recovery.

Historically, patients who presented with stage III and stage IV squamous cell carcinoma of the head and neck were treated with extensive surgical procedures including reconstructive flaps resulting in significant facial disfigurement and severe speech/swallowing impairments. They were referred for speech and swallowing therapy post-operatively. Remediation was dependent upon the site of the lesion, extent of the surgical excision and the type of flap reconstruction. Patients who were referred for radiation treatment and/or chemotherapy were not typically referred for speech and swallowing therapy.

Over the past few years, patients with stage III and IV head and neck cancer have been offered new treatment options, primarily, organ preservation protocols of combination chemotherapy and radiation therapy. Many patients are now choosing non-surgical treatment options that were previously unavailable. One of the organ preservation protocols offered at GBMC is the Brizel protocol. Named after David Brizel, M.D. who first introduced this treatment at Duke University in the mid 1990s, it invloves a rigorous protocol of chemotherapy and hyperfractionated radiation therapy (2 doses per day). Response rates for patients undergoing the Brizel Protocol have been high, with eighty-eight percent (88%) localized regional control at the GBMC.

At our center, patients are evaluated by the interdisciplinary team (i.e., surgeon, radiation oncologist, medical oncologist, speech pathologist, nurse, social worker, and nutritionist) and presented for discussion and treatment planning at the weekly Head and Neck Tumor Board. The Head and Neck Tumor Board is an excellent forum to comprehensively evaluate the patient's medical condition, swallowing and nutritional status, psychological status, support system, and the patients' ability to endure the proposed treatment. A patient's potential to undergo the Brizel protocol is determined once all diagnostic information has been gathered. Candidacy for intervention, and treatment recommendations are made with input from the interdisciplinary team.

The Brizel protocol is "not a treatment for the faint of heart," says Dr. John Saunders, Medical Director of the center, as treatment side effects are significant. The combined side effects of the very treatment that melts the tumor away also limit the patients' ability to meet their nutrition and hydration needs through oral means alone. Severe mucositis and oral discomfort may preclude patients from attempting to swallow even their own secretions. All patients at GBMC undergo the placement of a gastrostomy tube prior to initiating treatment due to the severe impact on swallowing. This ensures that patients will be able to maintain adequate nutrition and hydration during treatment and through their recovery.

Chemotherapy, when given with concomitant radiation therapy appears, to exacerbate the toxicity of radiation therapy, resulting in prolonged xerostomia, thrush, altered taste sensation, along with mastication and swallowing difficulties (Brizel et. al., 1998). These side effects of treatment appear to be the main causes of latter disability. In order to formulate a plan for rehabilitative treatment, we examined the fundamental pathophysiology of these changes.

Radiation therapy, one of the three main therapeutic modalities (surgery, radiotherapy and chemotherapy) was, by the year 2000, used as one of the primary treatment approaches in approximately 40-60% of all cancer patients (Abitbol et. al., 2000). Radiation therapy alters tissue and is associated with oral fibrosis (Pillai and Balaram, 1991). The major presenting sign of oral fibrosis is the progressive

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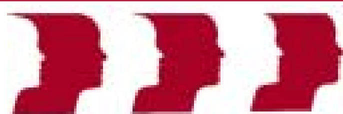

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COMING IN SEPTEMBER 2006

"A Review of Depression in Head and Neck Cancer"
William M. Lydiatt, M.D.

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inability to open the mouth, known as trismus, which is often accompanied by muscle degeneration. Fibrosis has been attributed to difficulty in mastication (chewing), speech, swallowing and pain in the throat and ears. Fibrosis is also correlated to muscle disuse and results in disuse atrophy.

Radiation therapy, either with chemotherapy or following surgery, causes fibrosis and atrophy (muscle wasting) of the muscles of the mouth, jaw and throat (oral and pharyngeal muscles), frequently resulting in swallowing problems (i.e., dysphagia).

The muscles of mastication consist of the temporalis, masseter, medial pterygoid and lateral pterygoid. Each muscle plays an important role in mastication (chewing). When a muscle is damaged, it can cause limitations in jaw opening, and a pain reflex may be stimulated. This condition, called "muscle guarding" results when muscle fibers engender pain when they are stretched. This pain causes the muscles to contract, resulting in loss or range of motion. The patient cannot control this contraction. Thus, in treating this condition it is important to recall that rapid motion, or the use of powerful forces may be self-defeating. Rapid motion may cause muscles to contract, thereby making stretching of connective tissue difficult or even impossible. Slow, gentle mobilization has been reported to be most efficacious in mobilizing the restricted joint and muscles for the treatment of this condition (Maloney et al., 2001).

Regardless of the immediate cause, mandibular hypomobility (restricted movement) will ultimately result in both muscle and joint degeneration. Studies have shown that muscles that fail to move through their range of motion for as little as ***three days*** begin to show signs of atrophy. Similarly, joints, which are immobilized quickly, begin to show degenerative changes, including thickening of synovial fluid (substance found in small amounts in joints) and thinning of cartilage. In the case of patients receiving radiation treatment to the head and neck, restricted jaw opening or trismus may progress slowly, even going unnoticed for months, which may cause secondary changes to both muscles and joints. Thus treatment, consisting of gentle passive motion, should begin as soon as possible.

Radiation therapy is also associated with hyposalivation (abnormally reduced salivation) and xerostomia (dry mouth) resulting from damage to salivary glands that are included in the radiation field during treatment of head and neck cancers. Secondary effects of salivary gland dysfunction are tooth decay, change in oral microflora, altered taste sensation, and difficulty in mastication. Subacute reactions may include: persistent xerostomia, persistent edema and erythema of the oral and pharyngeal structures, lymphadema, cervical esophageal stricture and trismus (Hamlet, Fauli et. al. 1997). Lymphedema is a common condition that affects quality of life for many cancer survivors. It is caused by the accumulation of protein-rich lymphatic fluid in the soft tissues, engorging and enlarging vessels and often causing visible swelling, tenderness, and pain. Left untreated, the affected tissues may continue to swell, and can become hardened, fibrotic, and susceptible to infection. These intense side effects have challenged the rehabilitation team to find new ways to address patient's needs.

Current academic discussions on chronic swallowing disorders suggest that impairments may be caused in part by muscle fibrosis. Historically, swallowing therapy has not been approached from a preventative perspective. Exercises to maintain mobility limit atrophy

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and fibrosis of the oral, pharyngeal and laryngeal muscles were generally not provided. Patients' problem lists included, restricted jaw opening (trismus), reduced tongue range of motion and strength, swelling (edema) of the throat, pain when swallowing (odynophagia), and restricted neck and upper body range of motion. It was presumed that patients would not complete exercises secondary to mucositis and other soft-tissue reactions. These problems may be partially due to lymphedema and muscle fibrosis.

Patients were referred several months post-treatment when deficits were already significant due to muscle disuse atrophy and tissue fibrosis. Clinicians and patients worked together to remediate the problems. Rehabilitation efforts were directed towards severe, late effects of treatment in the absence of an early intervention protocol. Results were often sub-optimal because of the severity of the deficits. Success was not always at hand.

Changes in rehabilitation referral patterns occurred as our treatment approach moved from surgical to combination chemotherapy and radiation therapy. The speech pathologists soon realized that patients were not being referred for treatment until six to twelve months or longer after chemotherapy and radiation treatments for stage III and IV head and neck cancer. By that point, trismus and swallow function were found to be severely impaired. A greater number of conservation treatment patients required tube feeding in comparison to our similarly staged surgical patients. Patients, who returned to eating by mouth, often required a restricted diet, such as puree and thickened liquids. This reinforced that the mere presence of anatomical structures does not always mean that the structures can adequately function.

Based upon all the information learned and the severity of patients' problems after treatment, the need to provide early, prophylactic intervention to the head and neck cancer patient undergoing chemotherapy and radiation therapy was realized. An evidence based research study *The Efficacy of Prophylactic Swallow Interventions in the Head and Neck Cancer Patient Undergoing Organ Preservation Cancer Treatment* was subsequently developed through interdisciplinary team discussions. The center's study was designed to investigate the efficacy of prophylactic oral and pharyngeal swallow exercises on the ability to maintain effective swallowing in patients with head and neck cancer during and post radiation treatment. Another goal was to determine the impact of such prophylactic therapy on quality of life (QOL) during and post treatment.

In our study, patients are randomized into either a control or treatment group. Interdisciplinary assessments are conducted at the same time intervals for both study groups. Patients in the treatment group are instructed to perform twice daily oral-pharyngeal motor exercises. All patients in the treatment group are followed on a weekly basis by the speech pathologist, nurse specialist, and social worker. The speech pathologist focuses on swallowing and oral care issues. The weekly sessions provide support and encouragement for patients to comply, as tolerated, with the daily exercise program. Patients' are provided with recommendations to maintain adequate daily oral care. Nutrition and hydration needs as well as patients ability to manage the side effects of treatment are addressed. Post-treatment clinical swallow reassessments are conducted at specified time intervals. The speech pathologist may recommend compensatory swallowing strategies to promote a safe and efficient swallow (Logemann and Pauloski, 1997).

The nurse specialist administers a structured oral-care assessment. The social worker administers a quality of life (QOL) assessment, to address physical as well as psychological issues that may interfere with a patient's ability to comply with the rehabilitation process. From a psychosocial standpoint, studies have indicated, and patients have self-reported, that dysphagia symptoms may be triggered by emotional trauma. Moreover, psychosocial intervention can have a positive impact on patient compliance with the intervention protocol. M.D. Anderson Cancer Center has studied the impact of swallowing difficulty on QOL, concluding that head and neck cancer and its treatment does adversely affect QOL.

The initial pilot study has shown promising results. Patient feedback has indicated that ongoing support and monitoring from the center's team before, during and after treatment, was beneficial to the recovery process. Our staff believes that the collaboration of team members working to provide patient and family education, early intervention treatment, and support to patients and families members throughout cancer treatment and recovery can influence outcomes and improve quality of life.

Editor's Note: The authors of this article are members of the interdisciplinary team which specializes in the rehabilitation of head and neck cancer patients at the Milton J. Dance, Jr. Rehabilitation Center at the Greater Baltimore Medical Center.

MEMORIAL GIFTS have been received In Loving Memory of

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by
Wallace & Lois Allan

Frank W. Beatty
by
Keith & Rebecca Bryan
Amy Fletcher, Megan Pennington
Friends at Sea Villa

Frank Busto
by
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A TIME FOR SHARING

In retrospect it's difficult to remember precisely how it happened. But then during those difficult months, there are many things that are a bit hazy. This I know for sure: for over 2 years I did not eat—not a single bite of food. I was at one point, in fact, warned by my ENT not to try to eat as the risks were very great that it would create problems for me in choking, possible pneumonia and other catastrophic consequences. And of course by then I believed him since I couldn't even swallow water and took everything through the tube into my stomach and later into my jejunum: food, water and medication. For the longest time I did not care as it appeared my days were numbered.

This is my story about overcoming my belief that I could not eat and learning how to eat again after that long absence. Some of the obstacles were my belief and some were finding the right help and the right advice from the right people. And, of course, doing the exercises and having the patience to learn how to do it differently than I had for 45 years.

On that fateful day when I got the bad news (cancer), and then the very bad news (extensive and poorly located cancer), I had two choices. The first involved extensive surgery that would involve removing my tongue, my voice box and probably part of my jaw. That meant I would never speak again, never eat again and would be substantially disfigured. The thought of this outcome was devastating to say the least and my wife and I spent the next couple of hours crying in the exam room. Clearly life was to be very different, if I even lived since my chances of survival were small.

Hours later, when I got to see the radiation oncologist, I was given another choice: fight it with massive doses of radiation and chemotherapy—I might be able to retain some function and while my survival chances would be slightly less, they wouldn't be significantly less. Although I did not give them my answer for a few days, I pretty much made up my mind that night: I was only 45 years old with three teenagers. I was not ready to face the kind of life I imagined with the first choice.

For many long months afterward, I had great uncertainty about whether this was the right choice, especially as the first round of treatment did not kill the cancer and I had few choices available after that, with surgery not an option given the massive dose of radiation I had absorbed. I knew going in that the radiation would eliminate surgery as an option but dove in anyway. Now it looked like that might have been the wrong choice. Eventually, I entered a phase three clinical trial that my medical oncologist felt was my best hope for survival, even though it was clearly "experimental". I spent the next 18 months getting chemotherapy every week and fighting incredible side effects of nausea, illness, weight loss and near death along with a couple of near misses with blowouts in my carotid artery. Due to nausea and massive weight loss, I eventually had to resort to TPN (intravenous feeding) for nutrition but after numerous bouts of blood infections, went to a J tube to move the nutrition directly to the jejunum, bypassing my stomach but requiring being hooked up to the feeding pump for 12 hours every night.

Eating problems showed up early on as the treatments began. It became increasingly more difficult to swallow. I went from eating full meals to trying to get some soft foods in to finally not eating at all and relying completely on the tube feeding—partly because of swallowing difficulties and partly due to great fatigue, illness and lack of motivation. It was easier to just plug in the tube, hang the bag and lay on the couch. Not only did I stop eating, I stopped drinking water also. The radiation damage made swallowing painful and I began to cough when I attempted it. Even water, I eventually found, would make me cough uncontrollably and hurt going down.

Over time, I lost my will to eat and became dependant on tubefeedings altogether. At first I tried to eat some things as my radiation oncologist urged me over and over to keep trying to eat "softs", and drink. He warned me that the throat muscles could "forget" how to swallow. I didn't listen—either due to disbelief (thinking I could swallow again once the radiation was over) or simply not caring at that point. I was so ill that I was not rational at times and depressed enough not to really care. I thought I was going to die anyway—and a few times wishing it might come sooner—so what was the point of worrying about it? I just kept plugging in the tube and dripping the nutrition in.

Eventually, a miracle of sorts occurred and I somehow recovered from the cancer—and the treatment. But that is another story for another day. I stopped treatment after over two years and slowly regained strength and a semblance of health with time and physical therapy and just plain activity (and no chemo!). However, I was still not able to eat and if I went anywhere, I had to pack up my portable pump, enough cans of Nutren, and the various and sundry accessories needed to feed myself. I also had to pump water into myself often enough to not become dehydrated—a constant issue. I hadn't lost the interest in eating, but assumed for a long time that eating was a thing of the past. I even named myself "The Man Who Never Eats". But I longed to eat very badly. So much so that I often daydreamed about food—especially high fat, junk food like bacon cheeseburgers, pizza with pepperoni, potato chips, etc. (Can you tell why I was overweight before cancer?). In fact, I developed a kind of "meditative state" when I had to undergo my frequent MRI's—I would dream about food (to the point where I didn't want to end the MRI because I was deep in my food meditation).

But when I experimented, I paid the price. I swallowed water once in a while but it always resulted in massive coughing attacks. On a whim I shoved a French fry in my mouth once but of course I ended up spitting it out and rinsing my mouth as I couldn't chew it up and swallow it. I had no idea what to do. And I was told more than once, not to try to eat as it was dangerous for me to do so. Still I persisted in asking about it until finally my ENT referred me to a speech pathologist (I couldn't figure that out at first) for an evaluation. It went horribly as I gagged uncontrollably with the thickened juice she gave me and coughed for what seemed like a half an hour. I gave up for a while after that and tried to adjust to being a non-eating person in a food obsessed world (watch TV sometime and notice how many food commercials there are). I remember the Thanksgiving where I sat at the table with my wife's extended family and the obvious discomfort they all had as I sat and watched them eat. Any social event proved awkward when some of the people did not know my situation—the hostess urging me to try this or that food she had prepared. A Christmas dinner

all sat down to eat and I retired to a nearby chair. I was invited to meet a couple of people from church for a "lunch meeting". Instead of telling them I didn't eat, I would just politely decline and say I was not hungry or similar.

NOW comes the Good Part. It was an odd incident that led me to start thinking I might be able to do something by mouth. I had a follow-up PET scan after treatment stopped. As part of the preparation I had to drink a glass of something. I was told to drink it all down, don't sip it. Till then, I had sipped water only occasionally to relieve the awful dryness in my mouth and cut the thick mucous I experienced following radiation. Often I just swished and spit. This time, I took the cup they gave me and I chugged it all down, not stopping. I held my breath and I swallowed several times as hard as I could to move everything down. I coughed, but only a little. "Wow", I thought, "I chugged that and only coughed a little at the end". Not perfect, but the germ of an idea formed.

I convinced my ENT to refer me to the speech and language pathologist again for another evaluation. When I returned for the testing with the applesauce, I shared the "chugging" experience. We discussed what the problems were with my post radiation throat and site of the tumor and she explained what factors came into the picture—weak muscles, lack of saliva, poor tongue movement, incomplete closure on the left where the tumor had shrunk. We tried the swallow test. I still had coughing, but by swallowing real hard and several times, it was not nearly as bad as the first time! I was encouraged somewhat. I was sent home with a shopping list (food thickener, apple juice) and some exercises. After some experimenting with this applesauce approach at home for a couple of weeks and working on my "technique", I returned to the swallowing specialist. She wanted me to see another pathologist for a "scope". Hope was not just born, it was growing.

I saw the 2nd speech pathologist a couple of times for the scopes and more instruction and education. He scoped me (and gave me a film of it) while I watched on the monitor. I had to swallow the green applesauce (yummy…) He found a bit of a gap on the left (where the tumor had been) and gave me some tips and tricks to try: exercises to strengthen my throat muscles, information on why water was actually more difficult than the thicker applesauce—water moves into the opening faster—and to turn my head to the far right, thereby pushing the food more that way past the incomplete closure on the left. He reinforced what the first speech pathologist had said, but now I was more focused on the specifics rather than my failures. I was to do the exercises several times a day (they were very hard to do at first—stretching and strengthening my neck and throat muscles) and thicken up all my liquids, keeping the consistency to the consistency of thin applesauce. Mix up the sauce and swallow it several times a day. Do the exercises religiously.

I went out and bought a huge can of thickener (Thick-IT) and started a regimen of daily exercise and swallowing thickened apple juice and other stuff, including coffee (yuck). I was doing tongue exercises, neck exercise and most of all, swallowing thickened juice. Soon I went shopping for baby food (double YUCK! Don't babies have taste buds?).The swallowing specialist was alarmed that I was pushing so hard and warned me not to overdo it, warning me about choking and pneumonia. I was not to be stopped however and felt confident with each passing week.

I recall the day I decided to try to swallow one of the cans of Nutren that I put in the pump every night. I thickened up a can, held my nose (it tastes terrible) and chugged it down as hard as I could. I swallowed hard several times and then "harrumphed" a few times and swallowed again. A little coughing, but not too much. SUCCESS! I had swallowed a whole can of Nutren with minimal coughing. Suddenly, the possibilities seemed to come into focus. Even if I couldn't eat regularly, perhaps I could at least get rid of the J tube and the pump! If I could at least swallow my liquid nutrition, I could live a little more normally.

Now kids, don't try this next trick at home by yourselves. I wanted to go on vacation with my family to camp in a national park. I was still tubefeeding and needed to recharge the batteries to my pump every day (or have AC power available) which proved challenging given the lack of electricity at the camp sites. I decided then that I was going to go at it with oral feeding. I started swallowing my Nutren (which I quickly switched to Boost Plus and Ensure Plus) morning, noon and night.

When it came time to go on vacation, I had to decide whether to take the pump with me (I had not used it now in about 2 weeks). With a prayer and a great deal of faith, I took the plunge and left it behind. I never looked back and never used that pump again—and in a couple of months had my J tube removed (with a great deal of reluctance on the part of my physicians). Not only that, I began to expand my menu to eat soft things like applesauce, cream of wheat and—my favorite—EGGS! I "egged out" after I discovered I could get them in by whipping them up with a little water and milk and pushed them down with my Boost or thickened milk. Soon I was mixing in a little crumbled sausage with my eggs, and mashed it up, and adding cheese and pushing it down with a little liquid. Ice cream was now on the menu, pudding, and various soups. I learned how to make the best pea soup in the world (look for it in the SPOHNC cookbook) and began to expand my menu.

To get rid of the tube, however, required one more big leap of faith. I had to be able to get medication in me without the tube. I had to swallow pills. Fortunately all the ones I had to take were smallish. One afternoon, on my own, I decided to give it whirl. A large glass of water and a small pill looked at me for about 10 minutes as I wrestled with possible consequences and anxiety swept over me. Finally I went for it: popped the pill in and chugged it down with a bunch of water. BANG! It went down. I was on my way to freedom from the tube.

Over time I was able to expand my menu to more and more things. I began to stop using the thickener as I learned how to swallow in a way that did not result in coughing or choking—positioning the food carefully, take a small sip of water or milk, swallowing, then kind of "harrumphing" leftovers out of the weak and dead area and repositioning and swallowing. It's been almost 2 years now and I have progressed over that time to where I can enjoy most foods, in some quantities, as my throat muscles have strengthened over time with "practice" and my technique has improved. I must be careful as I can and do choke occasionally if I forget and try to talk while eating or I try to swallow too large a piece. Lots of liquid is needed, but it works.

I would like to say that I am back to eating pizzas and cheeseburgers. And I am, sort of. I can say I can eat most anything, given enough time and liquid. I have indeed eaten a small cheeseburger with lots of mayonnaise, lots of time and lots of liquid. I have been able to eat a piece of pizza here and there—lots of sauce, cut off the crust and

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lots of liquid. Of course, I cannot eat those things as a regular diet, but I am able to sample them. Eating a small cheeseburger might take me an hour or longer, but I can do it. I rarely visit fast food restaurants now, and if I do it's for a shake. Early on I have ordered my main meal as "mashed potatoes with lots of gravy on the side" when trying to eat out with the family.

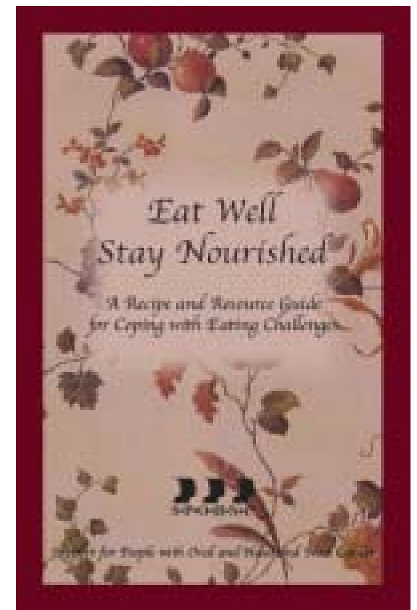
I am working with cooking things well, using mixers and blenders and choppers, gravies, sauces, and learning the joys of soups. Restaurants are still challenging and it is hard to find things on some menus, but most often I can find something—soup, or a casserole or mashed potatoes or an appetizer. I look for smorgasbords or places where I can pick and choose from many things or places where the quality of the restaurant allows me to ask the chef to prep my food a little differently, add more sauce etc. (don't try this at one of the chain places as you'll be disappointed). The first time I went to a restaurant with my wife was on the occasion of her birthday almost 3 years after my diagnosis. I went to the restaurant in the afternoon and spoke to the hostess about my needs and scanned the menu for possibilities.. She assured me the chef would puree or do whatever was necessary (again, not a chain restaurant). That night, my special order went in, well cooked veggies pureed, double or triple sauce on the fish, mashed potatoes instead of rice and keep the water glass full. It went swimmingly. I took home a doggie bag of course (with extra sauce) but I was able to eat in a restaurant for the first time in three years.

I cannot eat just anything and cannot eat a lot of some things. I don't try to eat steak, but I can eat meatballs with sauce. I can't eat a grilled chicken breast, but well cooked chicken legs with gravy and chopped up fine, I can push in. I still drink supplements to maintain my caloric count to keep up my weight, but I no longer have to sit at the table and just watch. I can eat some of everything, even if just small amounts and I have found it satisfying to get some portion of my calories from regular old food. Restaurants are still a thing to navigate and choose carefully and it can be frustrating with the typical "grilled menu" at many of the chain places. The flavor of that pepperoni pizza is no longer just in my dreams, although admittedly I will never get fat again eating pizzas.

How did I do it? Partly by accident, but partly by willing it to happen and to persist in asking for help even after being told that it wouldn't happen. In retrospect, I realize I probably could have begun to eat long before I did, but I am not second guessing myself. No one can possibly prepare for that ordeal. Could I have gotten more help during the ordeal to keep me eating? I think I could have and should have. But that is the past. This is now.

What it takes is education, persistence, and doing the exercises—knowing why you can't swallow as before. Scoping helped to "visualize" the issues and a lot of patient explanation about food consistency, esophageal functioning, location of the problem, importance of liquid to replace saliva loss, knowledge about loss of muscle mass and strength and strategies. I can't eat everything and some things are almost impossible for me, but I do eat now and am able to sit at the Thanksgiving table once more. I can sample some or most of the items at a party. I can drink beer (yes!). All my food requires a good deal of liquid and a full meal takes a long time to eat, but for this survivor, eating is again a reality, not just a dream. Of course, I now need another strategy to get through those interminable MRI's…but I'll deal with that. For now, pass the gravy.

Tom Yohe
Wilmington, DE



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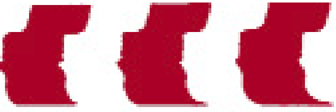

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