



S•P•O•H•N•C

A PROGRAM OF SUPPORT
FOR
PEOPLE WITH ORAL
AND
HEAD AND NECK CANCER

SPEECH AND SWALLOWING IN HEAD AND NECK CANCER

BERNICE K. KLABEN, PH.D. CCC/SLP

Individuals with head and neck cancer managed by organ preservation treatment of concomitant (combined) chemoradiation or combined surgery and follow up adjunctive treatment may experience problems with speech and swallowing. The acts of producing speech and swallowing involve the coordination of many voluntary and involuntary muscles that synergistically work in conjunction with respiration. The degree of speech and swallowing problems depends on many factors including location and stage of the tumor, extent of surgical excision and/or reconstruction, and amount of radiation and chemotherapy. Each treatment modality comes with potential consequences; however, not every individual responds in the same way to the treatment(s).

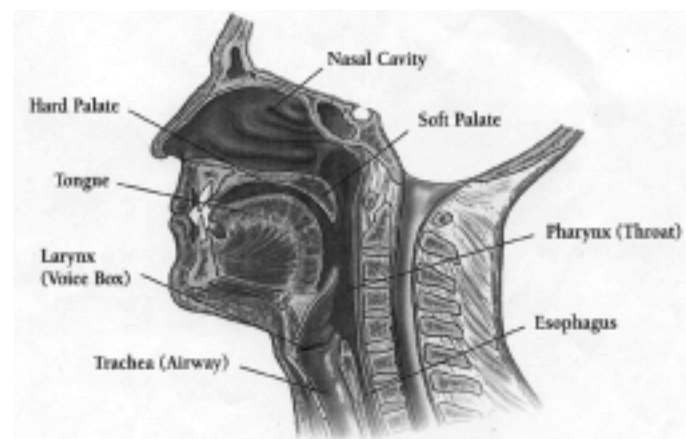
It is important to understand the normal anatomy and physiology of the oral cavity as well as the larynx to appreciate the impact when these areas are involved.

Tongue: The tongue is made of both intrinsic and extrinsic muscles. The intrinsic muscles control the shape of the tongue and are designed to elevate, narrow and elongate as well as flatten and broaden the tongue. The extrinsic muscles serve to position the tongue. These muscles help to protrude the tongue, move it back and up and position the sides of the tongue downwards. The tongue has several functions: shaping speech sounds, manipulating liquids and food in the oral cavity, and assisting in transport prior to swallowing. It moves in three dimensions and interacts with other structures including the palate, teeth, cheeks and lips. Deficits in speech and swallowing are dependent on how much of the tongue and to what extent it is permanently altered.

Mandible: Muscles that are attached to the mandible can open, close, protrude, retract, and rotate the jaw. If these muscles are affected, trismus (limited mouth opening) can become a problem and the jaw would become difficult to open. A change in diet is needed when there is loss of dentition. Loss of teeth can impair articulation, but speech patterns can be taught to improve intelligibility if dentures are not an option.

Soft Palate and Tonsillar Area: The soft palate is located between the oral cavity and the nasal area of the pharynx. The muscles on either side of the soft palate serve to elevate and tense the soft palate, elevate the back of the tongue, shorten and raise the uvula, and close the nasopharynx. If surgery is performed in this area, a palatal augmentation prosthesis can be custom-made which will aid the tongue in preparing food or liquids in the mouth to swallow. An augmentation prosthesis will also improve speech by reducing nasal emission.

Larynx: There are two groupings of laryngeal muscles: extrinsic and intrinsic. The extrinsic muscles are attached to a site on the larynx and to an external point, such as the hyoid bone, sternum, mandible, or skull base. The intrinsic muscles (thirteen) have both ends of the muscle attached within the laryngeal cartilages. When contracted, all muscles increase tension and shorten, providing a “pull” between the attachments. The primary function of the extrinsic muscles is to increase laryngeal height or tension as a unit. The larynx moves upward in the neck for lifting, swallowing, phonating, and many vegetative acts. Extrinsic muscles help to alter the shape and filtering



characteristics of the supraglottic vocal tract, which modifies vocal pitch, loudness and quality.

The extrinsic muscles are divided into the suprahyoid (above

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COMING IN OCTOBER 2005

“Management Of Dysphagia In Patients Treated With Chemotherapy And Radiation Therapy As Part Of Organ Preservation”
Dennis Kraus, MD & Ryan C. Branski, Ph.D.

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the hyoid bone) and the infrahyoid (below the hyoid bone). The suprahyoid muscles raise the larynx by pulling the hyoid bone forward or backward and upward. This action is important during swallowing, as laryngeal elevation can help protect the airway from aspiration. The infrahyoid muscles pull the hyoid bone and larynx to a lower position in the neck.

The intrinsic muscles are responsible for abducting (opening), adducting (closing), and modifying the vocal fold's length, tension, and thickness which alters pitch and loudness of the voice.

Innervation: Neural input from the brainstem provides motor and sensory innervations to the palate, tongue, lips, tonsils, pillars of fauces, pharynx, larynx and esophagus. These neural pathways are important for both voluntary and involuntary phases of swallowing.

Normal Swallowing: By the brief description of the structures mentioned above, one can see that the act of a normal swallow is a complex event which relies on precise timing and coordination of neural and muscular activity. There are four phases to a normal swallowing which include the oral preparatory phase, the oral phase, the pharyngeal and the esophageal.

Oral preparatory phase: In the oral phase, food is chewed and mixed with saliva, reducing the size of the bolus and forming it into a consistency that would be easily swallowed. This phase of swallow involves the lips, tongue, teeth, jaw, and soft palate. The lips and teeth prevent the food from coming out the mouth.

Oral phase: This phase involves the tongue propelling the food towards the back to trigger the pharyngeal phase of swallow.

Pharyngeal phase: This involuntary phase of swallowing begins when the bolus enters the pharynx, triggering the soft palate to elevate, and elevation of the larynx and the epiglottis superiorly closes over the vocal folds to protect the airway. The cricopharyngeal sphincter (upper esophageal sphincter) relaxes secondary to the pressure changes from the bolus and permits it to enter the esophagus.

Esophageal phase: The esophageal phase involves involuntary transport of the bolus through the cervical and thoracic esophagus into the stomach. Peristaltic waves of the esophagus propel the bolus downward, past the lower esophageal sphincter (LES) and into the stomach. The total swallow time from the oral cavity to the stomach is no more than 20 seconds.

Diagnosis

A number of assessments are used to exam the swallow, however, the most common diagnostic method is the videofluoroscopic swallow study or sometimes referred to as the modified barium swallow test. This test assesses the oropharyngeal and hypopharyngeal phases of swallowing and identifies which foods and liquids are the easiest and safest for an individual to swallow. It shows changes in the muscular activity in the mouth and throat and where there is a problem in the swallowing mechanism. Aspiration of liquids and/or foods

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into the lungs can also be viewed. Another common exam is the fiberoptic endoscopic evaluation of swallowing (FEES) or fiberoptic endoscopic evaluation of swallowing and sensory testing (FEEST) uses a flexible scope inserted through the nose. This exam can be used as a therapeutic and biofeedback tool as well as a diagnostic test.

Research

Lingual progressive resistance exercises are currently being studied to document the effects of tongue strength and fatigability with individuals demonstrating reduced tongue strength. In healthy normal elderly individuals, results from a study by Dr. JoAnne Robbins showed maximum isometric tongue pressures increased after eight weeks of exercise. Also, average swallowing pressures increased at three different tongue locations with the greatest change noted in the anterior part. MRI studies were conducted on four individuals and all showed increased tongue volume which is an indication for an increase in muscle mass.

Ongoing research looking at temporal coordination of breathing and swallowing appears to be altered in individuals treated for oropharyngeal cancer (Martin-Harris, 2004). During the pharyngeal phase of a normal swallow, apnea occurs when the epiglottis comes over the larynx to protect the airway preventing aspiration. Dr. Bonnie Martin-Harris has noted this respiratory sequencing differs in individuals with oropharyngeal cancer during the act of swallowing.

A randomized clinical trial is currently being conducted at centers throughout the U.S. looking at the effects of swallowing therapy in head and neck cancer patients. The principal investigator of this research is Jeri Logemann, Ph.D. at Northwestern University. The focus of this study is to determine the effects of two therapy programs (active exercise therapy or sensory posture therapy) on swallowing functions. Individuals who qualify for this study include supraglottic laryngectomy, oral cavity resection, pharyngeal resection, and chemoradiation for oral cavity, pharynx, larynx, and unknown primary. The speech and swallowing function as well as diet, oral

intake, xerostomia and mucositis are concurrently being studied.

Another clinical trial by Dr. Logemann is investigating the effectiveness of the Shaker exercise in individuals with swallowing deficits in head and neck cancer patients. These exercises involve head-raising which strengthen the suprahyoid muscles. Research has shown improvement in the swallow physiology in individuals with abnormal upper esophageal sphincter (UES) opening after a six week exercise program.

Conclusion

Assessment of swallowing and speech is essential for an individual receiving treatment for head and neck cancer. Effective management of speech/swallowing problems requires a complete understanding of what part of the physiology is or is not functioning to accurately address and then individualize treatment based on the deficits.

The preliminary data on swallowing research involving head and neck cancer patients is encouraging, however, many of the studies are in the early stages and outcomes are still to be determined. It is encouraging that multi-institutional clinical trials are underway with trained therapists conducting treatment. These larger treatment studies will give speech language pathologists the evidence based therapy techniques that can be used effectively in the individual's speech and swallowing rehabilitation program.

Editor's Note: Bernice K. Klaben, Ph.D. is Director of Clinical Practice at The Blaine Block Institute for Voice Analysis and Rehabilitation in Dayton Ohio.

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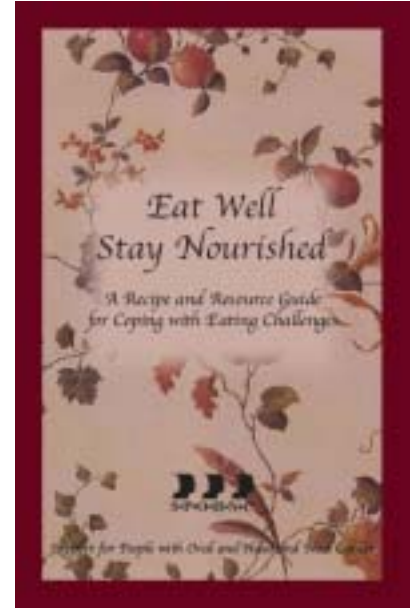
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A NEW RESOURCE FOR ORAL AND HEAD AND NECK CANCER SURVIVORS



“Eat Well – Stay Nourished: a Recipe and Resource Guide for Coping with Eating Challenges” is a resource book of more than 200 pages providing support and encouragement to people with eating challenges. This book contains special pages of information about swallowing problems and nutrition, cancer journeys of survivors, and suggestions and “Tips from the Pros” (SPOHNC’s members and head and neck cancer survivors).

Under a decorative, full color hard cover you will find a helpful resource including the special pages, and more than 270 recipes, each with nutritional information, that have been contributed by cancer survivors, caregivers, friends, and health care professionals. The black spiral binding with the title in white, makes this book easy to find on a shelf.

This recipe and resource guide is certain to be a valuable asset to oral and head and neck cancer patients as well as caregivers and health care professionals involved in their care. The cost of this guide is \$17.50 plus \$2.50 for postage. Please call SPOHNC at 1-800-377-0928 to reserve a copy or reserve online at www.spohnc.org. Availability: mid September 2005.

DEEPENING YOUR SPIRITUAL RESOURCES WHILE LIVING WITH CANCER by Kava Schafer, M.Div.

Part I

Most of what I know about strength, courage and spiritual resilience emerges from my relationships with patients living with cancer. These individuals continue to be my teachers. Over the years, I have witnessed countless people who manage to maintain a sense of spiritual well-being while undergoing treatments, various setbacks, and sometimes even death. The vagaries of living with cancer often feel like an assault on physical, emotional, and spiritual integrity. The question becomes an inquiry into what allows certain individuals to experience themselves as spiritually intact in the face of great adversity and challenge. What is it that promotes a sense of blessing and spiritual growth while facing situations that strive to fragment and pull us off center? We will only be able to explore the surface of these questions because each person develops his or her own unique strategy. Much of the clinical medical literature describes spirituality as a means of coping. That definition is accurate for as far as it carries us, but those individuals who deepen into their spirituality often will tell us there is the possibility for new life even while grieving the breakdown of the body, the changes in identity, and the painful losses that often accompany serious illness.

When we choose to relate to our spiritual selves, we enter a place of paradox, which is a partial explanation for the difficulties that researchers encounter when they attempt to measure spirituality in the health care setting. Here is the heart of the paradox: when we acknowledge that we need help in the face of overwhelming limitations which arise in living with cancer or any disease for that matter, we often feel empowered by asking for help from that which is greater than ourselves. I will call that something God, but other people might use different language for what encompasses the Sacred in their lives. Much of the clinical literature focuses on patients taking charge of their lives and reclaiming their sense of autonomy and control while living with illness. We do not seek to contradict those strategies. However, the spiritual strategy often paradoxically teaches us that by understanding our ultimate inability to control

everything, we may find a place of empowerment that comes from acknowledgment of our human frailty. Of course, I cannot say that this is universally true for everyone, but spiritual growth often emerges out of the depths of pain and struggle. They sometimes seem to be wedded to each other, but the experience of living with cancer certainly offers an invitation to examine the way one has been living. Cancer may be an opportunity for many people to reflect on what is really of importance. Not that anyone would ever choose to grow under the harsh discipline of illness, but the realities of sickness, dependency, and limitation may yield spiritual riches while providing the strength to live moment by moment.

So what do we mean when we speak of spirituality? It is not an easy task to define spirituality because any way we attempt to define it threatens to put a limit on our understanding of something that is deeply mysterious in its spaciousness and expansiveness. For the purposes of this article, I am describing it as the indefinable essence of vitality and animating force within human beings. The English word roots in the Latin, *spiritus*, which means breath. Historically, that breath referred to the breath of a god. This linkage with divinity or something beyond our individual selves enables us to comprehend the spiritual strength that can come when we feel filled with the breath of the divine. One does not have to believe in God to be spiritual because the breath of something greater than ourselves may find its ultimacy in family, nature, or whatever signifies for us a transcendent value that surpasses our individual self. In the spirit of inclusion, for those who are not comfortable with the use of God language, we could use the word, Sacred, to denote that which we each hold of ultimate meaning in our lives. We are in the realm of spirituality when we ascribe meaning and value to our life experiences and also when we question life's purpose. Taken from this perspective, one could almost imagine that spirituality suggests something so individual that we are speaking of something exclusively private in nature. Yet another one of the

paradoxes of spirituality rests in its capacity to transcend our personal definition of self by revealing just how interconnected we all truly are.

So spirituality arises from inwardness and then expands in greater radiating circles out into the world beyond. Our spirituality has this overarching definition because it encompasses an interconnection within ourselves, between others, and our environment. Often patients share with me how their spirituality has caused them to reach out more deeply to others who are in need. Their sense of compassion for others often seems to deepen in proportion to their own experience of personal vulnerability. What is it that gives us our vitality and our aliveness?

Each of us comes into this world as spiritual beings. No one can sell us our spirituality or take it away from us. It is our birthright as human beings. In this culture, sometimes we are led to believe that spirituality is simply another tool for coping among other strategies. This is a diminishment of the unique spiritual core of each human being. One of our human tasks is to discern how to foster and give expression to this innate psychic core. When each of us is able to connect with our own deepest self, we can then say that we are relating to our authentic spiritual selves. This connection roots us in our spiritual wholeness. Yet there is a paradox in that this spiritual wholeness also often translates into increased ability to let go and detach from pressing personal problems and find fulfillment in a relationship with one's greater self, God, or whatever is Sacred in one's life. Staying connected to our unique spiritual wholeness is essential in how we will respond to the challenges of cancer or any other major life challenge. Recognizing this center within and nurturing it through prayer, meditation, or whatever means people often employ, produces the additional benefits of impacting positively on physiological health.

Many people foster their spirituality by coming together in communities, which share a system of religious beliefs and values. Religious rituals and practices enable communities to approach God in an integrated

relationship, while also providing traditional ways of developing and fostering inwardness. The Latin word, *religio*, suggests that there is a binding and fastening in the relationship with God through organized community. Religion and spirituality share a lot of common ground, often they overlap, but it is completely possible to be deeply spiritual and not consider one's self to be religious. Using Sister Mary Casey's language, we can imagine our spirituality to be a river flowing through us. The health of the river is shaped by the riverbank. The riverbank can be imagined as religion and other spiritual practices that give shape and form to the way the river moves. This imagery powerfully suggests that the river is vital and fluid and the course of it can change and modify depending on circumstances of life and spiritual growth.

I believe this metaphor also provides insight into the way spirituality has the

potential to foster resiliency in the face of the disorientation of cancer and its resulting losses. The impact of serious illness threatens to disrupt the security of life's routines. Nursing and clinical psychological literature have isolated various components of the challenge of living with illness. The brevity of this article prevents us from offering little more than a broad schematic outline, but according to Soeken and Carson, some of the broad categories include low self-esteem, pain, isolation, powerlessness, hopelessness, and anger. Then of course, we could endlessly speculate about the changed dynamics in family systems that result from the lived experience of any of these powerful emotions. Most would agree that receiving a diagnosis of cancer and then the coping that follows as treatment proceeds carries with it the real possibility of serious rupture in one's perceived notion of identity in all of its many

guises. Rupture often leads to imbalance and a strong experience of disharmony. What will be the individual's response to the new bend in the river's course? Will the reorganization of the patient's world move towards transformational growth or will a new balance elude him or her? We know that many cancer patients adapt and a new harmony or equilibrium is found through spiritual searching. There are spiritual dimensions to every life experience. Our challenge lies in developing the ability to discern what spiritual resources need renewal to remind us of our core integrity. Some people define this capacity for maintaining equilibrium as an experience of spiritual well-being.

Editor's Note: In the October issue of News From SPOHNC, Rev. Shaefer will discuss the core issues that face head and neck cancer patients and examine the spiritual correlates to the impact of treatment and the resulting recovery time.

A TIME FOR SHARING

It was Tuesday, April 8, 1986. This was the day that I was diagnosed with nasopharyngeal cancer. I was only seventeen years old at the time and very frightened to hear this diagnosis. My treatment consisted of two weeks of chemotherapy, followed by seven weeks of radiation. It was a difficult time in my young life. Like most people undergoing treatment for their cancer, I suffered from side effects. First, I needed to have teeth removed, then as a result of the radiation, I suffered from trismus. I had some blood clots and damaged tissue in my head and neck areas. My hearing was diminished and to this day, I have difficulty moving my head from side to side. I also continue to have speech problems.

However, one of the most frightening things, was when the doctor told me that I might never be able to have children. Fortunately, he was most definitely wrong. On November 25, 1987 I gave birth to a baby daughter. Sadly Julissa died the day after her christening on February 8 1988. The doctors said she died as a result of a crib death. But through GOD'S benevolent grace & mercy I was blessed with another daughter who was born on the exact same day and month as little Julissa. And as time

went on, I was blessed with five more children, including a set of twins.

After a marriage of 11 years, filled with mental and physical abuse, I was forced to leave my home, and live in a shelter; a victim of domestic violence. I went from being a homeowner of ten years to being homeless. Together, my husband and I had owned a small insurance company and driving school. However, my husband was an unscrupulous man and eventually, I lost everything.

I'm presently on disability raising six children on my own. It's not easy, but I am doing it. My children are my inspiration and what keeps me strong.

Each of these experiences, with cancer and a broken marriage, with both trials and triumphs have contributed to helping me become a stronger person. To anyone who has cancer, it is so important to tap into the inner spirit, the source of life that can only come from GOD.

Yes, you have cancer, but try an adopt an attitude of gratitude for what you have and use the resources around you to encourage and inspire you. If you believe in GOD, STOP/THINK and realize that GOD has a plan and a purpose for you. Live

to Love not to complain, worry or to be angry or in denial, but embrace the challenges that confront you to propel yourself into learning how to experience the lessons of living in the moment.

The physician and medical team members can administer medical treatments to you, but how you respond mentally, emotionally and psychologically depends on YOU! Think positively regardless of the condition or circumstance. Keep laughing and smiling. Believe that your best defense is you and believing in yourself, thinking positively, and helping others. Count your blessings to help relieve your stress and depression. Make a decision today, not to dwell on the unfortunate things in life, but to go forward and SOAR into New Beginnings. Because it begins with one positive thought, I WILL SURVIVE! No matter what happens; I know that with GOD's help all things are possible because I BELIEVE!

I want to leave you with this message, regardless of your circumstances, there is always hope. Never give up!

Marilyn Floyd
Brooklyn, NY

RAISINS FIGHT ORAL BACTERIA

Compounds found in raisins fight bacteria in the mouth that cause cavities and gum disease, according to researchers at the University of Illinois at Chicago.

“Our laboratory analyses showed that phytochemicals in this popular snack food suppressed the growth of oral bacteria associated with caries and gum disease,” said Christine Wu, professor and associate dean for research at the UIC College of Dentistry and lead author of the study. Phytochemicals are compounds found in higher plants.

The data were presented on June 7, 2005 at the annual meeting of the American Society for Microbiology in Atlanta.

Wu and her co-workers performed routine chemical analyses to identify five phytochemicals in Thompson seedless raisins: oleanolic acid, oleanolic aldehyde, betulin, betulinic acid and 5-(hydroxymethyl)-2-furfural.

Oleanolic acid, oleanolic aldehyde, and

5-(hydroxymethyl)-2-furfural inhibited the growth of two species of oral bacteria: *Streptococcus mutans*, which causes cavities, and *Porphyromonas gingivalis*, which causes periodontal disease. The compounds were effective against the bacteria at concentrations ranging from about 200 to 1,000 micrograms per milliliter.

Betulin and betulinic acid were less effective, requiring much higher concentrations for similar antimicrobial activity.

At a concentration of 31 micrograms per milliliter, oleanolic acid also blocked *S. mutans* adherence to surfaces. Adherence is crucial for the bacteria to form dental plaque, the sticky biofilm that accumulates on teeth. After a sugary meal, these bacteria release acids that erode the tooth enamel.

Wu said that the findings counter a longstanding public perception that raisins promote cavities.

“Raisins are perceived as sweet and sticky, and any food that contains sugar and is sticky is assumed to cause cavities,” Wu said.

“But our study suggests the contrary. Phytochemicals in raisins may benefit oral health by fighting bacteria that cause cavities and gum disease.”

“Moreover, raisins contain mainly fructose and glucose, not sucrose, the main culprit in oral disease.”

In an earlier unpublished study, Wu’s collaborator Shahrbanoo Fadavi, a pediatric dentist at UIC, found that adding raisins alone to bran cereal did not increase the acidity of dental plaque. Raisin bran cereal with added sugar, however, did raise acidity levels.

“Foods that are sticky do not necessarily cause tooth decay. It is mainly the added sugar, the sucrose, that contributes to the problem,” Wu said.

The present investigation was funded by the California Raisin Marketing Board.

Wu’s main collaborator in the study was A. Douglas Kinghorn, an adjunct professor in the UIC College of Pharmacy. Other UIC faculty involved in the work were Baoning Su, in the College of Pharmacy, and Jose Rivero-Cruz and Min Zhu in the College of Dentistry.

Tips From the Pros

Rita Burfitt

(SPOHNC-MORRISTOWN, NJ)

- Write down all the questions you want to ask your doctor.
- Take someone to appointments with you to help remember what is said.
- Get a second opinion.
- If a laryngectomee, see a speech pathologist before surgery to discuss options for “speech”.
- When getting scans done, get a copy right away. This way they are read where they are taken and also by the doctor’s hospital. That is an immediate second opinion.
- Get copies of all your reports of scans, tests, etc. This can be very helpful when you go to another doctor. (I even have the surgical reports)
- Don’t be surprised if things take longer than the doctor said. It’s always better to think it’s going to take longer to recover and be surprised if it takes less time.
- Get a pill crusher, but first ask your doctor if pills can be crushed.
- Get physical therapy if you need it.
- Don’t be a hero - take pain killers if needed. When you are in pain, you heal more slowly.
- Get a Medical Alert Bracelet - Patients who have had head and neck cancer should have one in case of an emergency. I also carry my history and list of meds. I have it attached to my handbag, since in some states they cannot go into your bag.
- Carry a small bag of supplies. (I have a small cosmetic bag with compartments, so I can carry the things I need).
- Recliner - this can become your best friend after surgery or treatments. When you can’t sleep in your bed, many times you can fall asleep in the chair. Someone told me later that some insurances will pay for this. Check with you insurance company and get your doctor to write a letter of necessity.
- Raise the head of bed - put blocks under the legs. If you can’t do that, put pillows under the mattress to raise it.
- Use Vitamin E cream when you can to massage your scars.
- Swish club soda around in your mouth. This may help with thick mucous. I wasn’t able to swallow, but it helped with the thick stuff and made my mouth feel clean and refreshed.
- Use a humidifier to help with thick mucous.
- Join a support group. If there isn’t one near to you check online. Try to speak to someone who has gone through a similar experience to yours.

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SUPPORT FOR PEOPLE WITH ORAL AND HEAD AND NECK CANCER (SPOHNC)

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