



**S•P•O•H•N•C**

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

## INCREASING AWARENESS OF ORAL AND HEAD AND NECK CANCER

LINDA K. CLARKE, MS, RN, CORLN

According to American Cancer Society statistics, over 30,000 new cases of oral cavity cancer are diagnosed annually in the United States with a five-year survival rate of 50%. Unfortunately, these numbers have not improved during the past 16 years. On May 25, 2000, the Surgeon General, David Satcher, M.D., Ph.D., issued a report describing a lack of public awareness of the importance of oral health and of oral cancer as a health risk. This report also pointed to a disparity in the ability of certain racial and socioeconomic groups to gain access to oral health resources. Based on these findings, the Surgeon General called for action to promote access to oral health care for *all* Americans.

The state of Maryland has one of the highest oral cancer death rates in the United States, especially for African-American males. Maryland, therefore, took an activist approach in response to the Surgeon General's request. In the spring of 2000, Maryland Governor Parris Glendening signed legislation requiring the State Secretary of Health and Mental Hygiene to establish an oral health program aimed at prevention and detection of oral cancer, specifically targeting the needs of high risk, under-served populations. To launch this two-year initiative, the Governor declared September 16-22, 2001 as *Oral Cancer Awareness Week in Maryland (OCAW)*. The goal of OCAW was to make the residents of Maryland aware of the seriousness of oral cancer. Numerous activities took place during this week including training and education of healthcare professionals, free

statewide oral cancer screenings, and a public relations campaign featuring a "kick-off" event at Oriole Park at Camden Yards, prior to a home game of the Baltimore Orioles.

Although much is written and discussed in the media about breast, lung, and prostate cancer, little information is published regarding oral and head and neck cancer. Although the percentage of oral and head and neck cancer patients in the United States is only about 5% of all cancers diagnosed, the importance of these diseases is heightened by the fact that aesthetic differences and functional problems including articulation of speech, facial expression, respiration, mastication, deglutition, (swallowing) and taste are commonly associated with this type of cancer and its treatment.

Oral and head and neck cancer is largely preventable if individuals avoid the primary risk factors of tobacco and alcohol. Yet, ninety percent of people diagnosed with oral cancer are users of tobacco products such as cigarettes, cigars, pipes, and chewing tobacco. Although many are aware of the dangers of tobacco, few associate the use of alcohol with oral cancer. In fact, approximately 75 percent of those with oral cancer also have a history of alcohol abuse. A third risk factor is prolonged exposure to sunlight since over 30 percent of individuals with cancer of the lip have a history of increased sun exposure.

Unfortunately, oral care is often a low priority health issue. Many individuals avoid routine dental visits due to anticipated discomfort and financial constraints. Yet, the oral structures (mouth, teeth, and gums) are essential to the maintenance of one's overall health status and quality of life. Participating in oral screenings is one way to detect early signs and symptoms of oral cancer. The Surgeon General's report states that the principal test for oral and pharyngeal cancers is a comprehensive clinical examination that includes a visual/tactile examination of the mouth, full protrusion of the tongue with the aid of a gauze wipe, and palpation of the tongue, floor of the mouth, and lymph nodes in the neck. An oral examination is quick and painless and routine examinations can play an important role in controlling oral and head and neck cancer. In addition, individuals can be taught to perform self-oral examinations. An oral assessment may reveal mucosal changes that may accelerate an early diagnosis and initiation of early treatment. Delay in diagnosis allows tumors to invade deep into local structures and spread to regional lymph nodes in the neck, resulting in a high mortality. When assessing survival, early staged cancers of less than 4 cm in size and without regional lymph node involvement can be controlled in more than three quarters of the cases. (Silverman, 1997) An annual oral and head and neck screening is one means to ensure an early diagnosis of oral cancer and thereby improve an individual's chance for survival. The

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**COMING IN MAY, 2002**

Fast Neutron Radiotherapy For Salivary Gland Tumors  
George E. Laramore Ph.D, M.D.

**AWARENESS** continued from page 1

American Cancer Society recommends a cancer checkup that includes an oral exam every three years for individuals over the age of 20 and annually for those over the age of 40.

The Maryland Office of Oral Health has partnered with the National Institutes of Health to develop an oral cancer education-wallet card outlining the eight steps of a proper oral cancer examination.

Action to promote oral cancer awareness is needed from health care professionals, consumers, and legislators in every state across the nation. Awareness programs must focus on the following goals:

- Change public perceptions regarding oral health
- Implement prevention measures
  - Provide education regarding the signs and symptoms of oral cancer
  - Teach individuals to perform oral self-exams
  - Provide tobacco prevention and cessation programs
- Educate legislators to ensure the inclusion of oral health services in health policy and reimbursement initiatives
- Increase access to oral health for *all* populations.

Health care professionals can play a major role in the campaign to increase awareness of oral and head and neck cancer by promoting public education and by offering free screenings in physician's offices, clinics, and at corporate health fairs, retirement communities, churches, and YMCAs. Screenings provide an opportunity to inform the public of the risk factors and signs and symptoms of oral and head and neck cancer. Screening participants can be instructed in performing self exams and may be referred to tobacco cessation classes, if appropriate. Planned events throughout the year, such as Head and Neck Cancer Awareness Week and the Great American Smokeout, are ideal times in which to schedule screenings and educational events. Citizens at large can also play a major role by taking personal responsibility for good oral health and by lobbying and educating legislators to ensure the inclusion of oral health services in public policy and reimbursement initiatives.

Fortunately, public awareness efforts are on the rise. The self-help group, Support for People with Oral and Head and Neck Cancer (SPOHNC) has introduced awareness ribbons and pins. It is the hope of SPOHNC that wearing and displaying this symbol will help to build an awareness of oral and head and neck cancer.

As a Head and Neck Nurse Specialist, I am proud to have been a member of the OCAW Planning Committee, working with head and neck surgeons, dentists, and members of various community agencies to organize this important health initiative. Oral health is more than healthy teeth. The campaign to achieve and maintain good oral health represents a major step in the effort to reduce deaths from oral cancer through education, prevention, early detection, and diagnosis. Determine what you can do in your state and local community to increase public awareness of oral cancer.

*Editor's Note: Linda K. Clarke, MS, RN, CORLN is a Head and Neck Clinical Specialist for the Milton J. Dance, Jr. Head and Neck Rehabilitation Center at the Greater Baltimore Medical Center in Baltimore, Maryland. Ms. Clarke is the editor of "ORL-HEAD AND NECK NURSING," the official journal of the Society of Otorhinolaryngology and Head-Neck Nurses. She is also a member of SPOHNC's Medical Advisory Board.*

## A TIME FOR SHARING *My Mother Said...*

**W**hat my mother said when I was very young and repeated often was "Don't say can't, what you really mean is won't."

It all started several months before I knew I had cancer. Probably about July 1998, the height of our bike-riding fever. My wife, Gail, and I decided we would ride in the Acura Bike Tour on March 14, 1999. The bike tour generally follows the same course as the LA Marathon. It's not really a race, just a twenty-mile tour of LA.

Gail and some very good friends worked out on their bikes every Saturday for seven weeks prior to the tour. It does take some endurance to complete the tour, as you must climb 395 feet in the first eight miles, then up and down for the balance of the tour.

As the date of the event drew near, I decided there was no way I could participate. I had only been diagnosed with SCC of the base of the tongue in August of 1998 and after surgery for the removal of the tumor and freeflap reconstruction, I completed radiation therapy in January of 1999. From August until February, I hadn't even ridden my bike around the block. Then three weeks before the event I rode one five mile jaunt. (big deal...all level streets.) About a week before the Tour I was waffling about whether I would go at all. I told Gail during one of our evening walks "I 'can't' do it. It's too cold and I won't get enough sleep". Well, I decided to go and I do what I could. Thanks to my Mom. I didn't want to tell everyone I wouldn't go and be a party pooper.

On the day of the event we got up at 3:45 AM and arrived at the Sports Arena parking at 5:00 AM. We arrived late; I think there had to be eight or nine thousand cyclists already there. We heard that 15,000 cyclists would be participating. That's right, 15,000. And here I was recovering from oral cancer, it's freezing cold, and there are bikes everywhere. I only had half the use of one shoulder and limited use of the other wrist - but I'm in the thick of it anyway. What a lunatic I am! I could fall and screw up who knows what!

We used our cell phones and met up with our friends. They were already in line. The line was at least a mile long. It took over 30 minutes for every one just to past the start line. I told everyone I would go as far as I could and then hang around the finish line area. Finally at 6:00 AM it all started and they went ahead. It was so crowded I de-

cidated to wait awhile.

After 20 minutes it was still thick with bicycles but I ventured into the thick of it. We were all cruising along about 5 or 6 MPH. Then about 10 blocks after the start, I ran into a neighbor, and his daughter. I rode with them until we changed directions. Here was the place where the first "I can't" was really "I won't." However, I felt fine so I decided to keep going. No "won'ts" for this kid. Did I think about being 56 years old, just had a major surgery and radiation therapy that put me in bed for two weeks? No not me, no "won't" here.

What was interesting at this point and for the duration of the ride until I got in the car to go home was I did not have any problem breathing through my mouth. I mean my mouth did not become dry. I couldn't understand why. My saliva was running, my nose, too.

Next thing you know I'm on the Santa Monica Freeway. There's quite a climb at this point. Weird, I just kept going. It was all uphill. Then came the first "Bailout" or tour route back if you can't make it. NO WAY! I was going on.

Although it had been all uphill to this point, I didn't pull over to rest, I just kept going. I soon realized that the number of cyclists was really thinning out, probably 90% had passed me. I continued several more miles uphill. I was totally numb. At this point I don't know what kept me going. Finally the course turned downhill. It felt good going downhill but I was really too tired and sore to enjoy it. I do remember getting up to 20 MPH just coasting. It was sort of scary because I was only using one arm or the other most of the time since I couldn't bend my neck up enough to see and my shoulder was killing me.

And then I saw her for the first time. I'll never forget her, but I can't tell you what her face looked like. She was a black woman, maybe in her early thirties. She was thin and her legs looked to be in good shape. I remember because I couldn't figure out why she was going so slowly. By this time I was barely able to keep going, and I could see only one or two other riders. Every time I was going to stop there would be some people along the route cheering me on and chanting "You can do it, You can do it" and applauding. This gave me strength. I remember riding several blocks and looking back to see

if anyone else was coming or was I really last. There were no spectators now. I saw no one, just the guards at each intersection. I started up a little hill and finally had to stop and rest. I had come about 16 miles. I sat on the curb and there she was riding by. She was wearing grey riding shorts and a green pullover shirt. She was eating one of those power bars and she asked if I wanted something to eat or drink. I was breathing so hard I couldn't speak so I just smiled and waved her on. As she went by I'm sure I looked her straight in the eye - but I can't tell you what she looked like. It was sort of strange being on Wilshire Boulevard all alone; this is one of the busiest streets in LA, but here was no one but me and this one other rider.

I got going after about five minutes and continued up and down the small hills. I had a few more hills to climb but by now I needed to rest and walk over them. Each time she was there. I remember now as I write this that I would be walking along pushing my bike with only one or two riders with broken bikes in sight and all of a sudden she would be there. Each time she rode by I was able to get back on and ride some more. I finally got Gail on my cellphone. I told her where I was. Gail couldn't believe I had gone that far. Then the cellphone connection went dead.

Now I was really talking myself into continuing, each breath a job and each pedal full of pain. Somehow I kept going. I was almost there. I thought how exciting, just a few more blocks. I couldn't tell which way to go as the barricades and signs were all gone. I rode to a point that I thought was the finish line. It wasn't. I fell from my bike and collapsed on the grass. I remember looking around for my friend to tell her we were almost there, that we had done it. She was nowhere to be seen. I didn't see her again.

After a few minutes I reached Gail on the cell phone and she walked over to meet me. After resting a while Gail directed me to the finish line about 500 yards away. I had done it. I didn't plan to. I really didn't want to, but I did. By the way I think I placed at number 15,001. Thanks, Mom, you inspired me. Remember, when you say "can't" you really mean "won't."

As far as my lone riding friend is concerned, maybe it's true - "Friends are angels who lift us to our feet when our own wings have trouble remembering how to fly."

*Jerry*

# HOME REMEDIES FOR A DRY OR SORE MOUTH

(Why and How to Use Them Correctly)

By Nancy Symonds, RDH

When you are undergoing head and neck radiation there can be many changes to your mouth and you just don't have the time, energy, or money to try all the different remedies that may or may not work for you. Here are some simple things for you to do that have helped our patients. Patients have also told us about remedies that have helped them. Many remedies are based upon ingredients that are in your kitchen or bathroom cabinet. As with all remedies that you buy to help yourself, use common sense and stop their use if an irritation arises. Also, consult your doctor before using a new remedy if you have any concerns or questions. The best maintenance is obtained by keeping your mouth moist and clean. Cleanliness includes everything that goes in your mouth such as partials, dentures, and fluoride trays.

## DRY MOUTH

- Use of fluoride: How do you clean your mouth when it is very dry? First keep it moist by using a baking soda/salt rinse as often as necessary. (See instructions that follow). When your mouth is extremely dry, you will have more plaque and food particles sticking to your teeth, gums, tongue, palate and inside cheeks. For head and neck cancer patients who are using fluoride trays, the best time to take your fluoride is after your last meal or food (snacks) at night as that is the longest time you will be going without food. You should floss your teeth first, then brush, and then insert your fluoride trays in your mouth for 5 minutes. Spit out the fluoride but no rinses, food or water for 30 minutes after the fluoride treatment. After other meals, the reason you floss first is that the fluoride from your toothpaste will adhere to a clean surface better. Fluoride is very important to head and neck radiation patients with a dry mouth as their mouth becomes more acidic and can cause cavities if they don't use their fluoride nightly.
- Rinse with a solution of 1 to 2 tea-

spoons of baking soda and 1/2 to 1 teaspoon of salt in a 1 quart of warm water made fresh daily. Omit the salt if you are on a salt free diet. Swish, gargle and spit out and then rinse with water. Do this as often as necessary as the rinse will reduce the acidity and bacteria in your mouth.

- Avoid coffee, tea, alcohol, tobacco, soft drinks, and mouth rinses with alcohol, as they will dry your mouth.
- Drink lots of water. Carry a water bottle with ice chips in it and drink from it often
- At nighttime, if you continually wake up with a dry mouth and need water, try taping your mouth shut. A patient told me that he had done this to stop snoring, but consequently, he had his first night of not having to continually drink water and then go to the bathroom. Use a non-allergic tape that can be obtained at a drugstore. This also helps if you wake up with a sore dry throat in the morning.

## DRY CHAPPED LIPS

- Use anhydrous lanolin, K-Y Jelly, cocoa butter, or any vegetable oil based product
- Do not use vaseline or any petroleum based product, as these will dry your lips.
- Beware of drying lipstick.
- Do not use any oils or moisturizers before radiation therapy or if you are on oxygen. Consult with your radiation oncologist.

## MOUTH SORES

- If sticky plaque is not removed from your dry mouth, bacteria can form in the plaque and cause mouth sores. It is extremely important to clean your teeth and mouth after meals and before applying topical coating agents or medication for mouth sores as the plaque will prevent the coating agents and medication from adhering to the sores. You may clean your mouth with a gauze square wrapped around your finger or a popsicle stick dipped in the baking soda/salt rinse. Clean your palate,

tongue, inside cheeks and gums. You may also use a Q-tip dipped in the baking soda/salt rinse to reach into tight areas. This must be done before you apply the topical oral medication.

- If your whole mouth is sore, you may swish and spit out coating agents such as Maalox, milk of Magnesia or Kaopectate.
- If you have a few isolated sores, you may take the coating agent and pour a small amount on a spoon and let it foam and settle down and then paint the residue on the sore with a Q-tip. Rinse with water after 15 minutes.
- Some mouth sores may come from fungal (yeast) infections and will need an antifungal medication from your doctor. Compounding pharmacists can make this medication for you with a lot less sugar in it. If you wear dentures, you will have to disinfect them. You can use 1 teaspoon of bleach in 1 cup of water and soak the dentures for 1 hour. Do not soak any dentures or partials that have metal as the bleach can corrode the metal. Also, do not use a higher concentration of bleach or leave the dentures in the solution for over an hour as that can change the color of the dentures. Rinse the dentures in water and brush thoroughly before putting them back in your mouth. If your gums are very sore, only wear your dentures while eating and leave them out the rest of the time to allow your gums to heal.

## SORE MOUTH

- Use extra soft toothbrushes and soften them further by putting them in warm water. Junior or baby toothbrushes are softer. Change brushes often. Brush after every meal.
- Rinse as many times as necessary with the baking soda/salt rinse mentioned under "dry mouth"
- If your gums are too sore to brush or floss, dip gauze in the baking soda/salt rinse and wrap it around your finger or a Popsicle stick and use that to clean your teeth.
- Toothettes do not remove plaque as

well, but can be used to clean your soft tissues but do not use the flavored ones.

- If highly flavored toothpastes irritate your mouth, use plain baking soda.

#### SWALLOWING PROBLEMS

- Your saliva may dry up leaving you with thick, ropy saliva that can form a lump or bolus in your throat making it difficult to chew and swallow. If this occurs, try the following hints.
- Swish and then swallow papaya juice from a glass (not metal) container to cut thick saliva.
- Lubricate your mouth with 1/4 teaspoon glycerin in 1 cup water just before eating. Swish and spit out. You may also put several drops on your tongue before eating. Do not use glycerin for other purposes as using it excessively can dry your mouth.
- Use a blender to prepare your food.

Take some of the food that is prepared for your family or yourself, add a nutritious liquid such as vegetable stock and blend it to the consistency of baby food. You can vary the consistency with the amount of liquid that you add to get the consistency that is easiest for you to swallow. Foods served at room temperature are usually easier to swallow. Prepare foods that are bland. Don't use spicy or acidic food that could irritate your mouth. Proteins and calories are needed at this time to keep up your immune system.

#### BLEEDING IN MOUTH

- If you have bleeding in your mouth that doesn't stop in 1/2 hour or you have a temperature, notify your doctor. Do not take aspirin.
- Cold and pressure help to stop bleeding. Suck on ice chips or rinse with ice water. Use a partially frozen tea bag and

gently press against the area that is bleeding. You may also use gauze that has been dipped in ice water.

- If bleeding is generalized, you may have to stop brushing and flossing until your mouth gets better. If the bleeding is just in one place, you may stop flossing in that place until it heals. Get help from your dentist or dental hygienist as you may be flossing incorrectly in that spot.

Hopefully, these household hints will help to minimize your problems. Be sure and consult your doctor if you have any concerns.n.

*Editor's Note: Nancy Symonds, RDH has given special attention in her dental hygiene practice to oral care for cancer patients undergoing head and neck radiation and chemotherapy. This article originally appeared in News From SPOHNC in November of 1997. Ms. Symonds has added to the original article and we are pleased to present this updated version in our newsletter.*



## Do You or Someone You Know Have Dry Mouth As a Result of Radiation Therapy?

There is a study in progress at various treatment and research centers throughout the country to determine the effectiveness of an investigational treatment for dry mouth resulting from radiation therapy for head and neck cancers. Eligible participants will be given capsules to take three times a day for three months. The capsules will contain either the investigational drug or a placebo. Every three weeks the study participant will be required to be evaluated by a doctor.

#### Who Can Participate

A participant must be at least 18 years of age and have completed external beam radiation therapy for head and neck cancer at least 4 months prior to entry in the study. He or she must show evidence of salivary gland dysfunction as documented by mod-

erate-severe dry mouth for at least 3 months prior to entry into the study.

#### Who Cannot Participate

Anyone with significant heart or lung disease, uncontrolled asthma, a certain type of glaucoma known as angle closure glaucoma, or significant gastrointestinal disease may not participate. Pregnant women may not participate. Subjects taking certain medications that either cause dry mouth or cause an increase in saliva may not participate.

#### To Participate

If you meet the participation criteria and would like more information about the research study and where it is taking place, please call our toll free number...1-866-751-0725.n



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# Head and Neck Self-Exam

Early detection and treatment of cancer often leads to a cure. Several forms of head and neck cancers can be easily seen, yet they go unnoticed because people don't know what to look for. Often, because these lesions are painless, people tend to feel it unnecessary to see their physician.

Individuals at risk include:

- Heavy users of any kind of tobacco
- Heavy drinkers of alcohol
- People with histories of radiation treatment to the head and neck area in childhood or early adult life.

See your doctor if you notice any of the following:

- A sore that does not heal
- Pain on chewing or opening mouth
- Persistent sore throats not relieved by medication
- Difficulty in swallowing
- Persistent hoarseness
- Persistent pain in the ear
- Loss of smell, a bloody nasal discharge or coughing up blood
- Persistent nasal congestion that does not improve
- Persistent bad breath
- A lump or mass in the neck

You can help yourself by seeing your doctor and dentist annually. If you have had cancer of the head and neck, continue to see your doctor as requested.

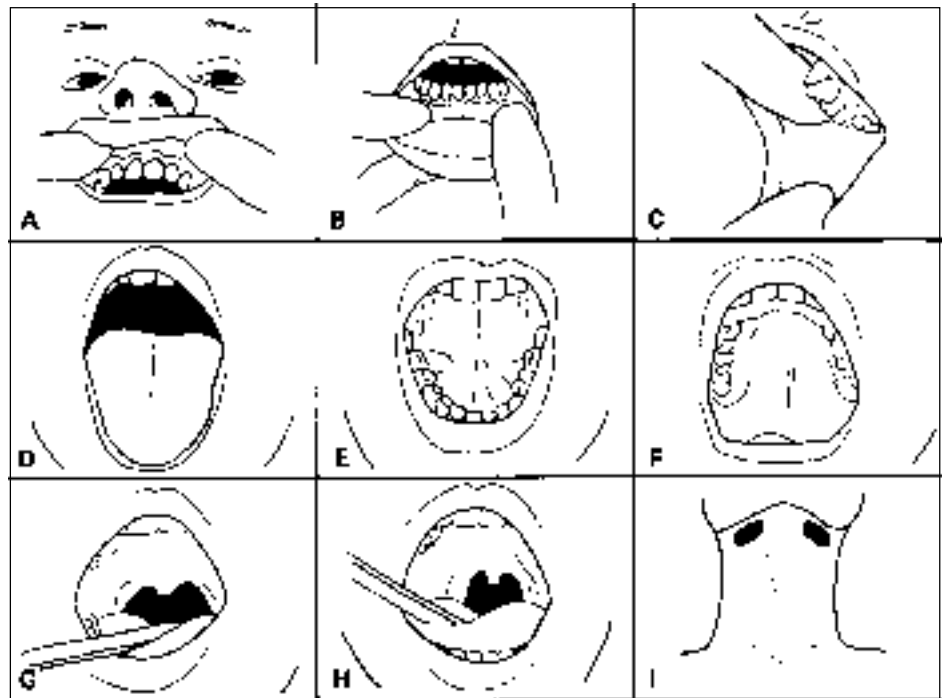
**REMEMBER EARLY DETECTION AND TREATMENT CAN LEAD TO A CURE**

## *BASIC H&N EXAM*

1. Look in the mirror at your face for visible sores that have not healed or for swelling of the face.
2. In a well-lighted area, check your mouth for unusual areas such as velvety red patches, white patches, swelling or hardened areas.

Look and feel (see illustrations below):

- A. your upper gums
- B. your lower gums
- C. your side walls
- D. the top and side of your tongue extended out
- E. under the tongue
- F. the roof of your mouth
- G. the back of your mouth
- H. the back of your tongue
- I. Sometimes glands are felt here, one on each side; they should be equal in size, soft and movable.



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