



S•P•O•H•N•C

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

CANCER OF THE THYROID

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The thyroid is an endocrine organ, secreting thyroid hormone containing iodine, which is important in the body's metabolism rate and bone turn-over. It lies in the neck, with its two butterfly-shaped lobes hugging the trachea on each side of the neck. In the United States, where dietary iodine is abundant, it weighs approximately 15-25g. In areas of iodine deficiency, it tends to be larger. The important neighboring structures are the trachea, esophagus, recurrent laryngeal nerves, and the parathyroid glands. These small, fingernail sized endocrine organs (35 mg each) secrete parathyroid hormone, and lie near the thyroid lobes. Generally there are two parathyroids on each side.

Thyroid cancer is the most common endocrine malignancy with approximately 11,000 new cases in the US each year. Most thyroid cancers present as thyroid nodules, which are quite common in the general population and can be detected in 10-15% of otherwise healthy women. However, the vast majority of the nodules are benign. It is the role of doctor to help discriminate between benign and malignant nodules. There is a female to male predominance of 3 to 1.

Thyroid cancer can be grouped into five major types: papillary and mixed papillary and follicular (most common, approximately 70% of cancers); follicular and Hurthle cell (15%); medullary (10%); anaplastic (less than 5%) and others such as lymphoma, sarcoma and metastases from other cancers (1%).

Patients who present with thyroid nodules should be evaluated for potential risk factors associated with cancer, such as a history of head or neck irradiation in childhood which was commonly practiced in the United States in the 1950's-1970's for such benign conditions as acne, tonsillar enlargement or hemangiomas. Patients should also be questioned about a family history of multiple endocrine

cancers, some being inherited as genetic syndromes such as multiple endocrine neoplasia type 2a and 2b associated with medullary thyroid cancer, familial colonic polyposis, or Gardner syndrome. Living in iodine deficient areas or repeated exposure to volcanic lava / eruptions, such as people living in Hawaii, may also have an increased risk of follicular cancer.

Symptoms of nodules range from none (most common) to feeling or seeing a mass in the neck, having swallowing difficulty, a sensation of a lump in the throat, voice changes such as chronic hoarseness, or other neck gland enlargement. The physical examination is focused on the size of the thyroid, lymph nodes, fixation to neck muscles and vocal cord function.

Laboratory studies including thyroid hormone levels are usually normal. Serum calcitonin levels will be elevated in patients with medullary thyroid cancer.

Imaging of the thyroid is not required for the routine evaluation of most thyroid nodules. When performed, ultrasound can accurately visualize the size, shape and presence of nodules. It can also evaluate the fluid or solid nature of nodules and can be used to follow them over time. Radionuclide scanning can be used to assess overfunction or underfunction (hot or cold) of a particular area but it is not very predictive of malignancy as most nodules will be cold. Hot nodules are almost always benign, and cold nodules have approximately a 20% risk of malignancy.

The single most important diagnostic study for evaluation of a thyroid nodule is fine needle aspiration (FNA) which uses a thin needle to sample cells from the nodule. It can be performed by an experienced physician in the office, or occasionally under ultrasound guidance. It is relatively painless, inexpensive and can be very accurate in supporting a diagnosis of carcinoma or benign disease.

Patients whose FNAs are diagnostic or suspicious for carcinoma should undergo surgical resection. Those with benign results may be followed and those with equivocal results may have a repeat FNA. FNA is very accurate for papillary and medullary carcinoma. Follicular and Hurthle cell nodules will demonstrate findings consistent with a neoplasm (or new growth) on FNA. However, the distinction between benign and malignant counterparts cannot be made on FNA. This discrimination is dependent upon microscopic examination of the entire nodule. The requisite for a malignant diagnosis is the demonstration of capsular or vascular invasion. These criteria cannot be evaluated by FNA, which only samples individual cells.

Once the diagnosis of thyroid cancer is confirmed or suspected, surgical resection is indicated.

Papillary or Mixed Papillary Follicular Cancer

This is the most common malignancy of the thyroid. Both subtypes have similar biologic behavior. Up to 30% of cases have

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COMING IN APRIL, 2002

Increasing Awareness of Oral and Head and Neck Cancer
Linda K. Clarke, MS, RN, CORLN

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multiple cancerous areas throughout the thyroid. Lymph node metastases are common yet do not appear to have survival significance. The prognosis is usually excellent with high cure rates, especially in small lesions. The five year survival rate is 95% and the ten year survival rate is 90%. Total thyroidectomy is often recommended. There are some surgeons, however, who consider thyroid lobectomy and isthmusectomy in patients with small nodules and low risk factors.

Follicular Lesions

Once a FNA has shown a predominance of follicular or Hurthle cells, removing the side of the thyroid which harbours the nodule is usually required to allow full evaluation of the nodule's architecture. Removing only the nodule is not indicated as it may spread cancer. If the diagnosis of carcinoma is made subsequently by the pathologist on permanent histologic material, removal of the remaining thyroid is usually indicated. Survival rates are 90% at five years and 70% at ten years.

Medullary Carcinoma

Treatment of medullary carcinoma usually employs total thyroidectomy and aggressive lymph node excision as nodal metastases are usually present at the time of diagnosis. This cancer produces calcitonin and CEA (carcinoembryonic antigen) and blood levels can be followed to assess possible recurrences. Approximately 25% of medullary carcinomas are associated with an inherited syndrome. Patients diagnosed with medullary cancer should undergo readily available genetic testing for the inherited syndrome of MEN (multiple endocrine neoplasia) 2. Medullary cancers can be associated with other endocrine tumors including pheochromocytomas, which should be ruled out before surgery is performed. The survival rates for medullary thyroid carcinoma are 80% at 5 years and 60% at 10 years.

Anaplastic Carcinoma

This is a very rare, aggressive cancer that can occur in the setting of long-standing nodular thyroid disease. It demonstrates a very rapid growth. Occasionally tracheostomy is necessary. Radiation therapy and chemotherapy have limited success. Survival beyond one year is very rare.

Lymphoma

This entity usually can be successfully treated by chemotherapy and only rarely needs surgical resection. The main role of the surgeon is to establish a diagnosis and obtain adequate material for tumor markers.

Controversial Areas

There continues to be debate about the optimal operation for well-differentiated thyroid cancer. Total thyroidectomy removes potential bilateral disease, reduces risk of recurrent disease in the contralateral lobe, improves survival for lesions larger than 1.5cm, reduces reoperations, allows use of thyroglobulin (a protein only made by the thyroid) as a marker for disease recurrence, and allows the use of radioiodine as a diagnostic and therapeutic tool. There are some surgeons who advocate thyroid lobectomy, rather than total thyroidectomy, for

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relatively small well-differentiated thyroid cancers.

The surgery is remarkably safe if performed by an experienced surgeon. It usually requires general anaesthesia and an approximately 4cm (1.5-2 inches) incision in the neck. Patients undergoing this surgery should have their vocal cords evaluated by laryngoscopy before surgery to see the function pre-operatively. The main risks of surgery are: (1) injury to the recurrent laryngeal nerve which innervates and helps move the corresponding vocal cord. Recurrent nerve injury leads to paralysis of that cord with ensuing hoarseness (risk should be less than 2%). (2) temporary or permanent hypocalcemia due to injury of the parathyroid glands is the other risk, albeit also infrequent.

Surgery is only one component of the overall management of thyroid cancer. A team approach involving the referring physician, surgeon, pathologist, radiation oncologist and endocrinologist is required for optimal

management. Radioiodine scanning and treatment is usually used after total thyroidectomy to ablate residual thyroid tissue and diagnose and treat recurrent disease. Chemotherapy and external beam radiation therapy are rarely employed in the treatment of thyroid carcinoma.

Lifelong hormonal replacement is necessary in patients who have had total thyroidectomy. Careful adjustment of thyroid hormone levels is required to maintain low TSH (thyroid stimulating hormone) levels in order to suppress potential growth of residual tumor.

Risk factors for recurrence are older age, large primary tumors and inadequate resections. Measurement of serial blood levels of thyroglobulin is a sensitive way of detecting early recurrence.

Summary

Thyroid nodules are common, especially in women after the age of 50 years. Of all

thyroid nodules, only 5% will prove to be malignant. The role of the physician is to discriminate benign from malignant nodules that will require further surgical treatment.

The best diagnostic tool is the FNA, which can often determine the likelihood of malignancy and allows adequate operative planning. A clear diagnosis of thyroid cancer or suspicious findings on FNA mandate surgical resection. Radioiodine can be used as adjunctive treatment to treat papillary and follicular cancers. Thyroid cancer is treated by a multidisciplinary team consisting of the primary care physician, endocrinologist, surgeon and radiation oncologist. Overall, patients with thyroid cancer have an excellent prognosis with prolonged survival, especially in patients less than 45 years old.

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Updates from the Cancer Information Service (CIS)

New NCI Network Formed to Increase Consumer Advocate Involvement
<http://newscenter.cancer.gov/pressreleases/carranov132001.html>

Head and Neck Cancers
http://www.cancer.gov/cancer_information/cancer_type/head_and_neck/

NCI Releases New Report on Nation's Progress Against Cancer
<http://newscenter.cancer.gov/pressreleases/lowtar.html>

Information about cessation programs and the health risks associated with using tobacco products.
<http://cis.nci.nih.gov/resources/smoking.html>
<http://cis.nci.nih.gov/asp/FactSheetPub/AlphaSubList.asp?alpha=100>

New Surgeon General's Report Provides Strategies For Halving U.S. Smoking Rates By Year 2010
<http://www.hhs.gov/news/press/2000pres/20000809.html>

Low-Tar Cigarettes: Evidence Does Not Indicate a Benefit to Public Health
<http://newscenter.cancer.gov/pressreleases/lowtar.html>

Teen Smoking Strongly Linked to Tobacco Use in Movies
<http://newscenter.cancer.gov/pressreleases/Tobaccomovies.html>

Questions and Answers: Monograph 13: Risks Associated with Smoking Cigarettes with Low Machine-Measured Yields of Tar and Nicotine
<http://newscenter.cancer.gov/pressreleases/lowtarQA.html>

Prevention and Cessation of Cigarette Smoking: Control of Tobacco Use (PDQ)
http://www.cancer.gov/cancer_information/doc_pdq.aspx?version=1&viewid=381fd4eb-d413-4032-b16d-fd202e7dfa1b

Publication Ordering Service
<https://cissecure.nci.nih.gov/ncipubs/>

NOTE: The CIS now provides live online assistance to users of NCI web sites through LiveHelp, an instant messaging service available from 9:00 AM to 5:00 PM Monday through Friday. Through LiveHelp, information specialists provide answers to questions about cancer and help in navigating the NCI web site.

A TIME FOR SHARING

In January of 1993 at the age of 29, I was diagnosed with advanced stage cancer of the tongue and lymph nodes. Like many members of SPOHNC, I underwent chemotherapy and radiation therapy. I am lucky to be alive; however, I live with many lasting side effects and problems that have occurred due to the radiation treatments that saved my life.

For years I suffered from chronic dry mouth. I was always armed with a water bottle, synthetic saliva, lidocaine solution and orabase paste to ease the constant pain I felt in my mouth and tongue. It was often difficult to talk and be heard, particularly over the phone.

Eating anything but liquids, was difficult and painful. I had a very hard time eating enough to get above 100 pounds which was not enough to support my 5' 5" frame. I was weak and hungry all the time and barely had the energy to work full time as an Assistant District Attorney. I had no energy for a social life. Eating was not only a very unpleasant chore, but a virtual battle for eight years.

Then in January 2001, my mother's dentist told her about Dr. Richard Niemtow, a radiation-oncologist who was using acupuncture to help alleviate dry mouth and restore saliva in his patients who had been irradiated for head and neck cancer.

We contacted Dr. Niemtow at the Navy Medical Center in San Diego, California. Following several phone conversations with Dr. Niemtow, he told me he felt confident that he could restore at least some salivary function to my mouth, as he had done for other patients.

However, there was one major obstacle to my receiving treatment. Dr. Niemtow is a Colonel in the United States Air Force and is presently on active duty with the US Navy at The U.S. Naval Medical Center in San Diego, California. As a civilian, I am

not eligible for medical treatment at a military facility. Therefore, I had to petition the Secretary of the Navy, in Washington D.C., to be seen by Dr. Niemtow. The task seemed daunting and the prospect of treatment improbable.

My parents contacted Rear Admiral Alberto Diaz, Jr., the Commanding Officer of the U.S. Naval Medical Center, located in San Diego. In a tremendous showing of goodwill and compassion, Rear Admiral Diaz wrote to The Secretary of the United States Navy, strongly recommending that I be given a waiver, so I could be treated at the Naval Medical Center.

...For the first time in years, I am enjoying and can actually eat a wider variety of foods. No longer must I stick to a bland soft and liquid based diet...

Several months went by as we nervously awaited a reply. The day we received the letter of approval was joyous! For the first time in years, I had reason to believe something was about to happen that might vastly improve the quality of my life.

A few months later I went to San Diego for a week of treatment. I was filled with mixed emotions. I was excited, nervous and also a bit skeptical. I was wary, as I had been told many times, that radiation had completely destroyed my salivary glands.

It was wonderful to finally meet Dr. Niemtow. He is a very kind and knowledgeable physician. He immediately made me and my parents feel at ease. After an initial examination, Dr. Niemtow put two acupuncture needles in each of my ears and

in two of my fingers. It was painless. In less than an hour, there was saliva in my mouth. I could actually spit into the sink!

Surprisingly, my initial reaction was not of joy but of fear. I went home a bit dazed. I feared that I would wake up with no saliva. I had a hard time believing that my long lost salivary function had truly returned.

I went for a total of four treatments in one week. By week's end I realized that indeed, I had saliva.

Since receiving Dr. Niemtow's treatments and regaining some salivary function, my life has improved profoundly. I am no longer dependent upon synthetic saliva, bottled water and pain solutions to achieve some comfort level in my mouth. It is literally a weight off my shoulders and mind not to have to carry these items with me everywhere!

For the first time in years, I am enjoying and can actually eat a wider variety of foods. No longer must I stick to a bland soft and liquid based diet. I can actually eat some fried and mildly spicy foods, rice, cookies, vegetables, bread and lettuce. I now enjoy the flavor of chocolate and recently ate my first a corn dog at a local fair. I feel comfortable going to restaurants, no longer fearing there will be nothing I can eat on the menu. I am also able to eat faster and swallowing has become easier.

I have gained weight and am no longer in fear of becoming emaciated if I get sick. People say I look healthier and happier than I have in years. My social life has most definitely improved and I will be getting married in May of 2002.

Although it is uncertain whether my salivary flow will be permanent, I am most grateful to The United States Navy, Rear Admiral Diaz and Dr. Niemtow for contributing to a significant improvement in my quality of life.

Katherine Lauth
Alameda, CA

CARETAKING

by Joanne Fishman, PhD

The role of the “caretaker” in the management of head and neck cancers cannot be underestimated. From the initial diagnosis, through myriad treatments to resultant outcome, the caretaker remains an integral part of a process characterized by potential chaos, uncertainty, existential issues and enormous stress. I write this piece from the dual vantagepoint of a caretaker and clinical psychologist. Ironically my training included a postdoctoral fellowship at Memorial Sloan-Kettering Cancer Center prior to being thrust into the role of caretaker.

In October of 1991 my previously healthy, vibrant mother was diagnosed with an invasive tumor of the soft palate. Immediate action was indicated. However, the shock of this news immobilized her, and sent me into a maelstrom of activity. While my mother considered what this cancer would mean to her existence, I made numerous appointments with head and neck surgeons in New York City. The planning and implementation of treatment and treatment options remains an integral function for caretakers. It behooves a second party to ask difficult questions, while maintaining a sense of calm, which facilitates crucial evaluation of all treatment recommendations and quality of life issues.

While the initial diagnosis and pretreatment phases of caretaking are characterized by the higher cortical functions i.e. problem solving, planning, critical evaluation, etc., the commencement of treatment represents a level of emotional upheaval that can often be debilitating. The “benign” denial that facilitated the prior activities now crumbles and leaves the caretaker vulnerable to a host of stress responses. While the “patient” endures medical procedures and focuses on getting through treatment regimens, the individual in the caretaking position may for the first time confront their own attitudes and feelings towards illness. Caretakers are not immune to their own fears about sickness,

debilitation and mortality. Grief and mourning are characteristic responses for caretakers who are emotionally involved with the head and neck patient. Caretakers must confront their own bouts of anger, depression and isolation while attempting to keep themselves focused on the needs of the cancer patient. Additionally, profound changes in physical appearance, overall functioning and personality can occur for those with head and neck malignancies. These changes often represent the greatest impediments to a full recovery following treatment. The caretaker must explore and ultimately accept his or her own emotional responses to these changes. It is only with the acknowledgement of personal fear, disbelief and anger that the caretaker can offer the patient a sense of hope while maintaining an honest, open attitude towards the very distressing changes that can threaten the very integrity of the head and neck patient.

The process of being a cancer patient includes the post treatment, return to life phase. This phase is not confined to patients. Caregivers must adjust their expectations and possibly reallocate their resources as individuals with head and neck carcinomas return to “civilian” life. Often times this phase allows for a relaxation of prior tensions and concerns. Both caregiver and the cared for can enjoy the fruits of their respective labors as treatment related debilitation begins to fade. An important aspect of this time period includes a re-negotiation between the two parties. As patients gain strength and adjust to the differences in their lives resulting from illness, they will begin to search for a more independent existence. The caretaker must be sensitive to this striving for autonomy and yield the reins. While the need for caretaking may continue, a necessary part of recovery from a major illness is the reclaiming of those aspects of life that are theoretically within the purview of the patient. Therefore, the caretaking function may change in both form and function. Ad-

ditionally, cancer-patients often experience an increase in anxiety with the cessation of a treatment episode. Individuals can experience heightened apprehension if they feel they are no longer “fighting” the cancer with ongoing radiation, chemotherapy, etc. Caretakers can provide important psychological and emotional support for patients by discussing these ongoing concerns as well as other evolving needs. This acknowledges the passage of time for both parties as well as clarifying the dynamic, always changing physical and emotional requirements that are inherent in the process of a cancer diagnosis.

A person’s sense of control and coping abilities are in large measure dependent on the ability to predict the occurrence and outcome of life events. We appear to possess an internal “template” of possibilities that define human experience. The diagnosis of a chronic or life threatening illness disrupts the preconceived notion of safety that is inherent to our personal universe. This alteration in sense of personal control is dramatic for both the patient and the caretaker. As with fear, grief and anger the caretaker and the individual with head and neck cancer are on parallel emotional paths in their coming to terms with uncertainty.

Caretakers must continue to acknowledge their own emotional reactions and needs. It is imperative that they seek help and support from friends, relatives and when necessary, professionals. The sharing of emotional experience between caretaker and patient can be a transcendental experience. This level of interaction can only be achieved if the caregiver has addressed their emotional issues. Finally, caretakers cannot necessarily change fate. However to accompany someone through his or her greatest challenge is an honor without equal.

Editor’s Note: Joanne Fishman, PhD is a clinical psychologist serving as the Clinical Director of the Four Winds Consultation and Evaluation Center in New York City. She also has a private practice.

“Becoming Well Again” Through...Managing Fatigue

Jerry finished radiation therapy three weeks ago. While he was glad to complete his treatments, he found he was so tired he couldn't enjoy the milestone this represented. He worried something was wrong; he had expected to return to his full activities as soon as his radiation was complete.

A few months into chemotherapy, Martha felt so tired that taking a shower left her totally exhausted. Just lifting her arms became an effort... let alone washing her body.

As caregiver for his wife, Carl tried to save a few minutes for himself at the end of each day. Yet when that quiet time finally arrived, Carl found himself unable to stay awake. He often fell asleep with the lights on and the television still playing. In the morning, he felt exhausted.

For patients and caregivers alike, the fatigue associated with cancer treatments can be overwhelming. It is a tiredness unlike any other. The symptoms of fatigue can range from mild to so disruptive they bring daily activities to a halt. Fatigue may accompany surgery, radiation, chemotherapy, or biologic therapy. Although it occurs most frequently in those undergoing treatment, fatigue may continue following completion of treatment.

Nursing research brought this treatment effect to the forefront of medicine. Fatigue is the most common side effect experienced by cancer patients. While scientists are still unsure of its exact cause, there are several theories. Some researchers believe fatigue may be caused by the waste products produced as a tumor shrinks, or may be related to the energy your body needs to fight the disease. Others believe fatigue may be related to interruptions in the signals sent through the nervous system. A low blood count, sleep disturbances, stress, depression, poor nutrition, infection, or medication side effects can all contribute to this exhaustion.

The symptoms of fatigue are different than “feeling tired.” Fatigue can begin suddenly; it can be all-consuming; naps may

not help; and fatigue can be physically and emotionally draining on the patient as well as the family. General weakness may be accompanied by limb heaviness, decreased ability to concentrate, sleeplessness, and/or irritability.

If you are experiencing this type of extreme tiredness, begin by speaking to your nurse or doctor about it. A few simple tests, including a blood count to check for anemia or infection, and a physical examination will help your doctor make a diagnosis. If your symptoms are fatigue-related, there are several things you can do to help manage those symptoms. These suggestions are helpful for both patient and caregiver:

1. Develop your own “energy conservation” program. Re-define “necessary” and sort out the really important activities from those that can wait. Keep a journal to learn your energy patterns. Pace yourself through the day, saving necessary activities for the time of day you tend to have more energy. Forgo jobs that need not be done every day, such as making beds. Ask your doctor about an occupational therapy evaluation to teach you energy-saving strategies.

2. Eat healthful, appetite-stimulating foods. The complex carbohydrates found in pasta, fresh fruits, and whole grain breads provide long-term energy. Try easy-to-prepare high carbohydrate foods that look good, such as vegetable-flavored bow-tie pasta or whole wheat couscous with raisins and apricots. The American Cancer Society's new Healthy Eating Cookbook can be purchased by calling ACS at (888) 227-5552 or through online bookstores.

3. A moderate amount of exercise may actually help improve your energy level. Find a friend to walk with; he or she can encourage you to get out when you're tempted to stay in.

4. Ask your doctor if your fatigue can be treated with medication. In addition to

exploring the newest medical treatments for fatigue, you'll make your doctor aware of the severity of your tiredness.

5. Keep a “Wish I Could” list near your phone. When a neighbor or friend asks what they can do to help, tell them!

6. Try to get undisturbed sleep. Go to bed at a regular time each day and follow a regular routine. The routine will begin to serve as a signal to your body that it's time for sleep. Ask your doctor if your medication schedule (or your loved one's) can be adjusted to allow several hours of sleep at night. Use an answering machine to screen phone calls so you need not get up.

7. Learn more about fatigue, and educate your family so they can be supportive. The Oncology Nursing Society offers suggestions for dealing with patient or caregiver fatigue and nurses to answer fatigue-related questions. This free service is available online at www.cancerfatigue.org.

8. Information about managing the potential side effects of treatment, including an extensive list of helpful suggestions for dealing with fatigue, can be found at our web site. Visit us at www.abta.org; select Brain Tumor Information; select A Primer of Brain Tumors, then click on Side Effects and Their Management. Call us at (800) 886-2282 if you do not have access to the Internet—we'll be happy to mail the information to you.

This article is the fifth in the ABTA quality of life series “Becoming Well Again.” If you would like copies of the previous articles addressing Rehabilitative Medicine, Cognitive Retraining, Financial Aid Resources or Stress Management for Caregivers, please call us at (800) 886-2282.

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from PAT'S PANTRY
PROVENÇAL

Eggplant Caviar

- 1 large eggplant
- 1 clove garlic (minced)
- 3 Tbsp. olive oil
- 1/2 cup chopped parsley
- 1 tsp. tahini or sesame oil
- Salt to taste

Cut the top off a large eggplant and poke it a few times with a fork. Bake at 425 degrees for about 30-40 minutes or until soft. Cool slightly and peel off the skin from the top down with your fingers. Slice the eggplant and place in blender with other ingredients. Blend, adding milk to desired consistency. Chill. Serve as a cold starter course.

March Tip: Eggplant Caviar has a light, unobtrusive flavor and is a wonderful vegetable to try. Always remember to vary your nutrients daily. In Provençe, we try to eat 10 different vegetables and fruits every day!

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