Advice From Survivors to Patients With Oral, Head, and Neck Cancer

We've Been There

Oral, Head, and Neck Cancer Support Group
Concord, Massachusetts
Survivor Advice To Patients With Oral, Head, and Neck Cancer

This document serves as a resource for those of us who have been diagnosed with Oral, Head, or Neck cancer. The contributors to this document are cancer survivors who continue to work hard each and every day to maintain their health and well-being. Experiences we describe may or may not be relevant to your specific journey, but our goal is to provide you with some helpful advice that got us through our treatment and to share with you that there is light at the end of every tunnel.

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INTRODUCTION:

Shortly after receiving a diagnosis of Oral, Head and/or Neck cancer, you might hear well-meaning comments from friends like “It is just a bump in the road.” For us, it is more like the route the road now takes and its condition has changed drastically. The lifestyle changes can be dramatic and downright serious as we pass through the various forms of treatment, discomfort and uncertainty, on the road to recovery.

Cancer changes lives. It changes the lives of us who have long-term goals to be cancer survivors. It also changes the lives of your loved ones and your overall support network. We need to learn about and be prepared for our “new normal.” The “new normal” will differ from person to person, but a commonality among us all is that the majority of Oral, Head, and Neck cancer patients will have to deal with some form of physical, emotional, and/or mental challenges. Often we can feel alone in our journey and struggle to heal to better define our new normal. You may have difficulty with tasks you once took for granted or have trouble keeping up with your previous energy level and pace of your previous lifestyle.

If you are feeling this way take comfort in the fact that you are not alone. Through our own research and personal experiences we have learned that there is ample literature available to patients for post-treatment care, but specific details on how to cope with individual problems while going through treatment is lacking. For example, if you read certain recipe books for cancer patients, and you cannot tolerate spices or citrus, then your search for a satisfying meal may be unsuccessful. If you find that your usual social and community activities are no longer easily available or enjoyable, then what becomes your outlet?

This guide for post-treatment hints is an effort by a several survivors to make daily life a little easier for others who are going through a similar experience and to help in the healing and adjustment process. Three adult Oral, Head, and Neck cancer patients, well into the three-to five-year period following major treatment regimens, prepared this guide. We received assistance from our Oral, Head, and Neck Cancer Support Group leaders, who shared insights of what people might need to help us broaden our scope. We are NOT medical professionals, but out of necessity we have become medical “students.” This advice is arranged in a variety of categories for quick reference. With the assistance of an Emerson Hospital social worker and facilitator of several support groups and some recent additions to our Support Group, the writers aim to help other survivors, and in doing so, help us to heal and to pay forward all the support we have received from medical professionals, family, and friends.
Oral, Head, and Neck Cancer Diagnoses and Now Current State:

For reference, we have included three examples of different diagnoses and their prospective treatment regimens. Everyone's diagnoses and treatment plans may not look the same, but our goal in sharing this information is for the reader to have some sense of background information on how this advice was developed. We learned more than a few things during the process that we hope others will become aware of, not surprised by, and be understanding of what may happen a bit downstream from their initial treatments.

Diagnosis of Patient #1: Cancer in Right Jaw, Floor and Roof of Mouth, Right Side of Tongue:

- Cancer initially discovered in sore tongue
- Major surgery followed by radiation and light dose chemotherapy
- Skin grafts from wrist and leg to restructure mouth
- Extensive therapy for speaking and swallowing
- Stomach feeding tube for almost two years
- Roof of mouth prosthesis, now on second and final one
- Permanently narrowed esophagus

Patient #1: Current State

Treatment(s) may cause a variety of temporary and/or permanent side effects. Depending on the diagnoses and the extent of treatment, it is possible to have very few side effects and possibly very many. I have permanent side effects. The doctors tell me that I have beaten the odds. I have learned to adapt to these conditions by practicing the various activities.

I cannot chew or tolerate spices. I have a disfigured face, a narrowed esophagus and cannot swallow food in chunks. Most of my teeth are missing and I eat slowly. My diet includes liquids and a few semi-solids. I cannot tolerate citrus, strong alcohol, or yogurt. I deal with dry mouth and in cold weather some discomfort.

I am never sick and very rarely need a pain killer. I am in good mental and physical condition for my advanced age, practicing what I preach to my friends and family and sharing here with a wider audience. I am 80 years old and have a good attitude toward recovery.

Diagnosis of Patient #2: Maxillary Sinus Cancer:

- Cancer discovered after an impacted wisdom tooth was removed and the space created allowed the tumor to drop into the mouth. The Oral Surgeon had the wherewithal to take a gum tissue sample and send it for analysis. It came back as positive for Squamous Cell Carcinoma. The Oral Surgeon impressed upon me the seriousness of my condition by telling me I had better address this in 1 - 2 months. Three weeks later I was in surgery.
- Surgical resection of left palate and left maxillary molars
- Prosthesis crafted and inserted. Am now on a 2nd one.
- Radiation
  - 7 weeks (5 sessions per week) of proton radiation
  - 6 weeks (5 sessions per week) of photon radiation
- Hyperbaric Oxygen Therapy – 60 sessions completed to help accelerate tissue growth
- No Chemotherapy
- Avoided gastric feeding tube

Patient #2: Current State

As a result of radiation, I developed a severe case of Trismus which has drastically reduced my jaw movement range. In addition, I do experience dry mouth and jaw aches. All of these limit my food intake. I drink a protein shake for breakfast and another one for lunch. I do eat a meal for dinner. It takes a long time, as I need to cut everything into precise pieces. There are very few things that I eat without cutting them up first. I have become accustomed to eating less than hot food.

My personal issue tends to be with the texture of foods. I do NOT like things that get caught between my cheek and prosthesis or around the teeth hooks of the prosthesis. That means that both sides of my mouth are affected. I do NOT like foods that shred – ground beef, chicken, or shredded pork, for example. A mental side effect is the struggle of grocery shopping, where you walk down the aisles and think “I will never eat that again.”

The radiation also impacted the range of motion in my neck. While most people have a 90-degree left and right turn of their neck, mine neck turn is 55 degrees in one direction and 45 degrees in the other. No one mentioned that as a potential side effect for me. I noticed it when I seemed to have a more narrow view when I was backing my car out of parking spots.

Normally, on most days I feel fine physically. I still travel for business. I attend more sporting events than the average person. Throughout the summer I play golf and walk the course.

Diagnosis of Patient #3: Cancer at the Base of the Tongue:
- Discovered by feeling an enlarged gland in neck
- G-tube (feeding tube) inserted before treatment
- Chemotherapy once per week for 7 weeks
- Radiation
  - 7 weeks (5 sessions per week) of photon radiation

Patient #3: Current State

Since I did not have surgery, I have no disfigurement of my face and neck. The radiation/chemo combo has left me with very dry mouth and sensitive mouth, tongue, and throat tissue. Many foods are impossible without a bland sauce or water. Pepper and most spices, as well as sugary food, burn my tongue and throat making eating uncomfortable. In addition, most desserts, pizza, tomato sauce, and most restaurant food, even when I ask for no spices, are difficult for me to consume. I make stir fried
vegetables for many meals. Other good go-to foods are avocado, smoothies with fruit (not too acidic), almond butter, coconut milk, Vega nutritional powder and Boost, occasional eggs from a friend’s chickens, oatmeal/buckwheat with flax, chia, cashew pieces and raisins. I spend a lot more time planning, shopping for, preparing and eating, than I ever used to.

I have good energy and enjoy my work and my life.

Complications and side effects of my treatment include:

- A narrowed esophagus
- Three (3) Esophageal strictures requiring four (4) surgeries to open, each stretching the tissue slightly.
- G-tube dependent for a year and a half
- Trouble increasing weight
- Lingering soreness in mouth and throat
- Intermittent excessive oral dryness
- Food sensitivities, which frequently make me not interested in eating at all.

POTENTIAL LIMITATIONS AND CHANGES

Everyone wants to know about side effects. What side effects can you or should you expect? It is the responsibility of the medical professionals to review each and every possible side effect that could occur. However, that is done at the beginning of the process. Some of that responsibility will shift to you as you experience the side effects and changes. You will need to schedule follow-up appointments with your care-provider.

Does that mean that you will get every little thing that the medical professionals review with you? Probably not. Does that mean that you should be prepared and well informed in case you do? Yes. Some patients breeze through the beginning of their treatments, while others are presented with challenges from the start. Some report having the most difficulty post-treatment, while others find that to be a time of healing. We have included a list of possible side effects based on our personal experiences and from others that we have met along the way. Again, use this list as a guide and not as certainty of any specific outcomes.

It is possible that some of the following will or may occur:

- Dry Mouth
- Swallowing Difficulties
- Narrowed Esophagus
- Change in Taste Buds
- Sore and blistered tongue, gums, throat, and neck
- Loss of Hair, including facial hair
- Nausea
- Weight Loss
- Speaking Difficulties, whether they are volume based or clarity based
- A Change in Daily Schedule to accommodate the “new” things you need to do
- Tooth Loss – causing chewing difficulties and a potential change in appearance
- Trismus – a reduction in the mouth and jaw opening
- Necrosis – dying cell tissue. This can occur in your throat or brain or other areas, depending on the radiation’s focal points.
- A Reduction in the Neck’s Swivel Range
- Disfigured Face
- Need for and reliance upon devices or appliances
- Constipation or other changes in bowel movement

Treatments seem to go as planned for a period of time, but then the difficulties may begin to influence our recovery process, our health, and our mental state. These are rather immediate effects. However, some people will experience late surgical effects, late chemotherapy effects, and/or late radiation effects that could occur several years after initial treatments. Categories of side effects may include:

- Fatigue
- Nausea
- Weight Loss
- Loss of Teeth
- Sore and blistered tongue, gums and throat
- Sores on neck
- MRSA (Methicillin Resistant Staphylococcal Aureus, a bacteria) Colonization
- A Compromised Immune System that may cause you to be susceptible to shingles or other viruses
- Trouble communicating, whether it be a speech impediment, softness of voice, or inability to remember items or concepts that were previously 2nd nature to you.
- A growing sense of helplessness and uncertainty about many things

EATING

Everyone in our group has lost weight. It is a common occurrence caused by radiation and chemotherapy treatments. While some of us would have liked a portion of the weight loss, many of us lost more weight than was anticipated. If you have some time before your surgery and your follow-on treatments and you cannot really afford to lose a significant amount of weight, you might want to try to bulk up in advance.

Some of you will experience challenges in what you can eat and how you eat it. Don’t give up on food, as your initial tastes and consumption are different before your underwent your medical intervention. Nutrition intake is an ongoing process and one that can require effort and patience. Many patients refer to their nutrition as “trial and error.” It may take some time to figure out what foods you can tolerate and the amount needed to maintain a healthy weight. This can be a challenging phase, so be aware that you may go through a lengthy testing period to determine what you like, what is easy to deal with in terms of shopping and preparation, and what is readily digestible. Once you have figured this out, you will plan and eat meals in your new diet. It is important to find favorite and comfort foods.

Be sure to watch your sugar consumption, your sodium intake, and the food’s cholesterol count. Consult with your Oncologist and the Nutritionist/Dietician on staff to test your ideas and hear new ones from them.

With the trouble that each of us has had in determining how we can maintain a healthy diet and possibly restore lost weight, we are all sharing findings that have worked for at least one of us. Here are some supplements to consider. They are listed only in alphabetical order.
• Active Nutritional Supplements in Liquid and Powder forms
• Arbonne Essentials
• Boost, including a Very High Calorie product
• Ensure, Ensure Plus and Carnation Instant Breakfast

**Notes on preparation:** Puree equipment is helpful in smooth, semi-liquid food preparation.

**Notes on eating:** Plan your meal times, including their duration, accordingly. Do not be concerned when others are finishing their meals faster than you are. Do NOT quit eating your portions just to keep up with others. After all, you need to get the proper caloric intake and enough protein to keep you healthy.

**Notes on drinking:** If you miss having a mild alcohol drink before or with a meal, try using two parts water and one part sweet wine or other liquor that you have enjoyed in the past. That may also serve as your social drink when at a gathering of people.

Your tastes may have changed, therefore tastes that you enjoyed before may no longer appeal to you. Don’t be afraid to try something new!

**A Word About Taste**

During and after radiation and chemotherapy, many people find that their sense of taste is affected, and not for the better. Reduced saliva production is partly to blame, but mostly this is due to the beating your taste buds take from radiation. The subtleties of taste are sometimes lost, leaving you to sense only the basics – sweet, salty and so on. Familiar favorites taste “funny,” even unpleasant; a lot of things taste like wallpaper paste; and even mildly acidic foods like fruit and fruit juice may be intolerably sour to some. For people who have enjoyed eating all their lives (and who hasn’t?) this can be very disheartening. With all the other things you are going through, now there’s this too? In such circumstances, a gastric feeding tube may NOT seem so bad after all, but you know that causes limitations too.

It’s important to remember that these effects are temporary, and most people eventually recover all or a good portion of their ability to taste and appreciate food. This will help you get through the dark times. You might have to give up variety for a while in favor of reliability. For example, if you find that soft scrambled eggs and ice cream with chocolate sauce taste more or less OK, then by all means have them every day. One of the bright spots here is that all those finger-wagging dietary no-nos that you used to worry about are now out the window. If it tastes good, eat it! When your body is healed and you have to go back to granola for breakfast and a pear for dessert – well, you’ll always have Paris.

The Nutrition Tips and Examples section of the Appendix is provides descriptions by our members of techniques for making liquid or easy-to-swallow foods using a variety of fresh ingredients. In addition, there are tips to help you figure out what your protein and calorie intake should be to maintain a healthy weight.

It’s important to acknowledge that not everyone has the time and inclination to do this work (and it is work). Some people are most comfortable opening a can or a pre-packaged serving of prepared food. If that describes you, you should rely heavily on the nutritional experts that play a large role in Emerson’s cancer care program to give you suggestions on foods to try and help you monitor your nutritional intake, once you have found a menu that works for you.
ORAL CARE

What is the first word in the phrase "Oral, Head, and Neck Cancer?" Oral! Now is not the time to neglect your oral hygiene. You will have to make an effort to take care of your mouth, teeth, and tongue. This effort may require more time than you have grown accustomed to over the years. It may also involve new "tools" that were never necessary before.

Dry mouth is a side effect that plagues a high percentage of patients. Most will keep a bottle of water readily available. There are mouth rinses and lozenges that are made specifically to reduce dry mouth.
- Try oral rinses containing cetlypyridinium chloride.
- NeutraSal is a prescription mouth rinse designed to treat the painful symptoms associated with oral mucositis. It should be started at the beginning of cancer therapy, including chemotherapy or radiation therapy.
- Biotene makes both a mouthwash and a mouth spray.

Other manufacturers provide similar products so it is just a matter of finding out what works best for you.

Dry mouth can lead to serious tooth decay. Frequent, regularly scheduled visits with your dentist for cleaning and fluoride treatment may become necessary. Instead of your two annual appointments maybe 3 - 4 or even more would be helpful in keeping your mouth, teeth, and gums healthy.

Toothpastes: There are certain toothpastes that have a higher percentage of Fluoride. Based on your doctor’s recommendation, you may need to incorporate a higher concentration Fluoride toothpaste into your daily routine. One of the toothpastes that has received a positive review from a group member is Colgate’s PreviDent 5000 Plus Fruitastic. If you have trouble using a toothbrush, there are oral swabs that can be beneficial for cleaning teeth and renewing that fresh mouth feeling. There are also plastic picks, with mini-brushes at the tip that may help remove food that is stuck between teeth.

EXERCISE

If each morning you do 10-15 minutes of stretching exercises and isometrics and walk 1-2 miles daily, you will be more physically fit than a majority of our population. Continue to be active, but be careful of over-extending yourself. Do yard work or household chores in ½ hour increments. You will accomplish things that will make you feel good and not have put a strain on yourself or your sleeping habits. Go outdoors to enjoy the natural environment as much as possible. Bike trails, hiking trails, and golf courses count.

Exercise also covers the things you need to do to continue to try to get back to normal or at least not regress. If you have experienced Trismus, you will need to do jaw, tongue, and neck exercises to try to extend your range of motion. If you can no longer expand your range, you should continue exercising, so you can maintain the range improvements you built. If the jaw stretching and/or tongue and neck exercises are recommended early, as part of your recovery plan, it would be wise to consistently follow the plan.
REST

As you exercise and go through your “new” normal daily activities, you may become physically or mentally tired. Take the time to relax periodically during the day. Even a few minutes may allow you to focus better on your next task. Rest may involve reading, watching (some) TV, listening to music, pursuing one of your hobbies, just taking in the scenes from gazing out your window or even taking a nap.

SLEEPING

Sleeping is your opportunity to rest and recuperate after your day. Do NOT short-change yourself. If you have nighttime medications, please remember to take them. Your schedule and past history will dictate the amount of sleep you require. Be aware that adjustments may need to be made in terms of your body position as you sleep. That may require a switch of the preferred side of the bed. Also, if you have lost weight, you may need an extra or at least a heavier blanket to maintain a conducive body temperature for peaceful, uninterrupted sleep.

In preparation for a good night’s sleep, you may consider a hot shower for relaxation and for facial and body comfort. Depending on any difficulties getting to sleep, your doctor may prescribe a sleeping aid.

To help reduce dry mouth during sleeping hours, you may want to keep a glass of water on your nightstand to moisten your mouth when needed.

With the reliance on much more of a liquid diet and your constant companion of a water bottle, you will need to be prepared for possible nighttime bathroom visits.

THERAPY

Take advantage of professional swallowing, speech and physical therapy. Adding acupuncture and therapeutic massage on a long-term basis is very helpful. Therapists can be your “cheerleaders” also. Out-of-pocket costs are well worth the investment in time and personal benefits.

Some hospitals offer Oral, Head, and Neck Cancer Support groups that meets periodically. Some meetings you might simply be taking in information. In other sessions, you may have a lead role in building awareness of things that would help the other individuals in the group. You are not obligated to volunteer for work or be tasked with work. People are in different zones in their recovery process. That will dictate their needs and their readiness to share or assist.

PSYCHOLOGICAL
Post-treatment, major changes to your lifestyle become your “new normal.” The adjustment period may be painful and will differ by patient. Still, the time and effort you put in can have very positive benefits in further development of your character and your empathy for others.

Be aware that Oral, Head, and Neck cancer survivors may be a high risk for depression or at least frustration. This is in part due to the inability to accomplish things that seemed so easy in the past. The additional time it takes for you to prepare for the day may be maddening. And should you forget to do something or take something with you, you may get upset with yourself or the world around you.

Don’t be afraid to ask your friends and support network for help.

You may opt to see a psychologist or psychiatrist. Depending on their experience helping people that have had Oral, Head, and Neck cancers, they may provide insightful help and solid ideas to assist you.

SOCIAL

Disfigurement and severe eating limitations may lead to less social contact, either intentional or unintentional. Being in small groups where folks support and care for each other is beneficial. You may opt to avoid large gatherings especially when you might be tired, feeling low, or not feeling up to the effort.

With lower volume in our voices (and hearing issues growing in our friends and associates), it may be wise to seek out an individual or two to enter into conversation, rather than be part of a larger group. If you do have trouble hearing or being heard, find a corner or step into the hallway to continue your conversation.

Continue to try to do the things you enjoy. If you like attending events and need to get something to eat beforehand, realize that you will need more time to consume your meal, and therefore plan accordingly. You will need to determine whether the effort is worth the enjoyment.

SPIRITUAL

If you believe that you are a spiritual being having a human experience, practice meditation and/or prayer. The power of the mind, through spiritual practices can greatly help in recovery. Hope is the energy of change.

KEEPING A JOURNAL

Some people find that writing in a journal helps them clarify their thoughts and put their experiences in perspective. Long-time journal keepers would certainly give their cancer treatment a prominent place in their journal entries. Even if you have never written a journal before, you might consider trying it at this stage your life. Writing down your thoughts, in any format you like — this is for your eyes only and there are no rules other than those you make — can be a big help when coping with a life-altering challenge like cancer.
For example, it would be very rare for a person in your situation not to feel fear. Fear can be debilitating. It can even take over a person’s waking life and haunt his or her dreams, especially if it is the worst kind of fear: fear of the unknown.

Journaling may help you get through the current state of your life with your spirits and emotional well-being intact. Writing down your thoughts gives you more time to focus on them, better understand what they mean to you, and offer ideas to help you cope.

Start from the general, go to the specific, and then list some coping ideas. Here are a couple of examples. Remember, no one will be grading your journal. It is your own private record of this phase of your life. It is a build process for your thoughts; some of which you will be able to implement and others that may give you difficulty in realizing. But your effort will make things clearer in your mind.

General: What are the things about my treatment and its aftermath that I am most afraid of?

- Specific: I won’t be able to eat “normal” foods and I can’t go to restaurants and friends’ houses. I will become some kind of recluse.
  - Coping Idea: I will try to eat something or drink my supplemental shake at home before I go out to dinner. This will still give me social opportunities. I can always order something and not be concerned about getting enough nutrition for that meal. I will not feel people are waiting on me to finish. And, I can take the leftovers home and eat them at my own pace tomorrow.

- Specific: I will become disfigured and people will be uncomfortable around me.
  - Coping Idea: I am still the same person inside. My friends will like me for what I have been my whole life. I may have some trouble making new friends and acquaintances, but with friends’ comments and my actions, I think I can win them over. If not, I will consider it their loss.

General: How did I handle other frightening periods in my life? What worked and what didn’t?

- Specific: After a bad car accident, for almost a year I had to rely on family, friends and friends of friends to drive me around. I hated that loss of independence, but others didn’t seem to mind as much as I did.
  - Coping Idea: I realize they felt bad for my current situation. I have helped them in the past and they were either paying me back or paying it forward. It is great to have the support network that I do.

- Specific: My wife/husband/partner helped me a lot. At the time of my accident, I didn’t have any religious affiliation, but I do now. I will frequently rely on my spiritual advisor. I am concerned that my relatives think I have changed and therefore we will not have the same relationship as we did.
  - Coping Idea: I do want my relatives to understand that I have changed, but that change was for me and it is helping me. I promise I will not be active in letting them know how and why I made the change. I will not try to convince them to change. They are my relatives. We will always have family bonds. I want to keep those strong.

The best thing about journaling is that your daily thoughts are preserved in writing and will trigger your memories when you read them again after a week or a month or longer. You don’t have to remember
how you felt back then — you wrote it down and there it is. You have a lot on your mind, and a journal will help you bring back the past so you can keep the present and the future in perspective.

TRAVEL

There are a few types of travel. One is personal and the other is business-related. They can be day trips or multiple-stay trips.

For day trips on the road, bring a container filled with items of interest to you. Examples include a thermos with hot pureed soup, a few store-bought protein drinks like Ensure or Boost, a sealable container of your “homemade protein shakes, and packages of your snacks. Difficult as it may become, based on others schedules and desires, try to follow the same routine and habits that you do at home.

If you are going to see family or close friends, it will be easier to follow your routines. Overnight travel is difficult, but can be managed by bringing all your food preparation equipment, being sure to bring a hot plate, and verifying that a refrigerator and a microwave are available for trips where a hotel stay is part of the mix.

Distant travel to a family residence can be pre-arranged by having all the same equipment and food all set up for you when you get off the plane. Air travel is risky and scary because any major delays can lead to intense hunger since eating airline or terminal food is difficult at best and sometimes impossible considering your limitations or the amount of time you have to wait for the food and then consume it. Bring a few bottles of Boost or Ensure (sealed) in your checked luggage. Destinations and air travel availability will dictate whether you can fly non-stop or must take connecting flights.

If you are required to travel for your work, additional planning becomes necessary. You can pack certain things you know you will use: a travel mixer, packets of whey, mouth exercise devices, dry mouth lozenges etc. You should then make it a priority to visit a grocery store and/or pharmacy to purchase nutritional drinks, juices you know you like, and of course, anything you forgot! At the hotel’s breakfast bar, you can usually find peanut butter and jellies, if those interest you. Of course, the scrambled eggs may have some appeal too.

LONG-TERM MAINTENANCE

Maintaining a limited diet, a new life style, a different exercise routine, and various doctor appointments is difficult. The fact that you have done it (and are planning to do it for years) requires strength of character, persistence, and a sense of satisfaction when any of those items are achieved.

Considerable courage and persistence are needed for sustaining a lifelong recovery effort. In addition to regular activities like therapeutic massage, acupuncture, and dental care, hospital-connected support groups have many benefits. The support groups will offer potential new ways to eat, exercise, and rest effectively. They will also provide different methods to build mental and physical health. Being a member of a support group also gives the individual the satisfaction of helping others in a similar condition.

Continue to seek out activities that are good for the mind, body, and soul. You should consider combining research on items that are of interest to you either physically or based on your situations, with different
physical efforts (strength and skill permitting), and with ideas and actions to help others. Opportunities to learn more may arise in conversation when providing a ride to others for their appointments or running errands for them when they are in time of need.

Continue to enjoy yourself by devoting time to your loved ones, your interests, and your hobbies.

THINGS TO CONSIDER AVOIDING

- Loud restaurants and those that do not offer the types of food you enjoy
- Large and or loud gatherings of people eating, talking, and laughing
- An intense travel agenda
- Trying to keep up a fast pace of life as previously experienced
- People who are self-focused and do not understand that your new normal is a sacrifice of a number of things you used to enjoy and could do fairly well
- People who always say they were sicker than you

Some of the above tend to be personal preferences. In large, noisy gatherings, you can still find someone to talk with, even if you need to step into the hallway to hear each other. You may also choose to live vicariously through others’ experiences, so you may bear through less than ideal scenarios.

SUMMARY

To deal with your new “normal,” develop a routine that will work for you. Here are some ideas to consider:

- Keep life simple and accept help. But, try to accomplish as much as you can yourself. It is empowering! However, do NOT be afraid to ask for help. Many people want to see you succeed and are very willing to provide any assistance they can.
- Make the time for some type of exercise. Walk each day. If such an effort is not possible, incorporate informal programs in your own home. Walk up and down the stairs or do a few laps through various rooms in the house. Start slowly and increase the length or amount of time, as you build up your stamina.
- Develop a healthy diet. Eat soft food and consume drinks that round out needed nutrition areas, like fruit or vegetable juices and protein-based drinks.
- Apply lotions and creams to areas of need. It may be areas affected by radiation. It could be where a skin graft was taken for other purposes.
- Take care of your teeth and try to minimize your dry mouth by brushing, using dental rinses, and using dry mouth medications. Consider increasing the number of dental cleaning visits you schedule.
- Complete exercises to keep flexibility in your neck, jaw, and tongue. Invest time and effort in strengthening your back, arms, and legs, too!
- Stay connected to friends and family.
- Schedule or attend various therapies and activities (massage, art creation, Support Group participation)
- Make arrangements for rides, as needed, so you do not feel you are burdening an individual. Options may include the Visiting Angels, the Neighbor Brigade, or the Council on Aging.
APPENDICES:

NUTRITION TIPS AND EXAMPLES:

Here is a little bit of background that helped one author to figure out what was needed to fulfill most of his dietary needs:

Body Mass Index (BMI) = (weight * 703)/(height * height), where height is in inches
For my gender (male) and age (60), my target BMI is between 18.5 and 24.9. Mine is 23.7, so I am classified as being at a healthy weight.

Here is an online calculator, where you can enter the necessary criteria to determine your BMI - http://www.c calculator.net/bmi-calculator.html

Recommended Diet Goals (for my age, gender, height, and lifestyle):
- Calories – 1970/day
- Protein – 55 - 70 grams/day (depending on the various calculators used)

Based on these goals and his inability to actually eat an appropriate amount of food, he makes two nutritional shakes each day to help him achieve these goals. He drinks one for breakfast and consumes the other for lunch. The shakes are still delivering the levels needed to maintain a weight he likes.

Note: I mention the Boost Nutritional Drinks. They are available in local stores and on Amazon. I just buy them at CVS. Here is the Boost website to confirm their nutritional composition - http://www.boost.com/. Ensure makes a similar product. I began with Boost Plus (360 calories, 14 grams of protein). I then switched to Boost High Protein (240 calories, 15 grams of protein). I now use Boost Original (240 calories, 10 grams of protein). I also used to use ice cream in place of the yogurt in one of the day’s shakes, but haven’t done that for more than two years.

Available only online is Boost Very High Calorie, with 530 calories per 8-oz package. If you find its taste and consistency a little off-putting, add water and/or sweetener that you like.

When making the two shakes, I put each of them in a 32-ounce container and usually reach about 28 ounces of capacity. Sometimes, I may top it off with milk. I make both shakes at the same time and it takes me close to 30 minutes to make them – switching spoons, peeling and cutting fruit, and mixing. I use a hand-held Cuisinart Smart Stick as my blender. It is small, which is convenient because I take my containers and smart stick with me when I travel. A standard blender would work; I just don’t want to focus on the cleanup afterwards, before going to work.

My breakfast shake combines:
• 30 grams of whey protein powder (I use the CVS store brand, but there are many out there. I don’t like the grit of some.), giving me:
  - 140 calories
  - 25 grams of protein
  - 2 grams of sugar
  - 0 grams of dietary fiber

• 4 ounces of yogurt, delivering:
  - 100 calories
  - 4 grams of protein
  - 15 grams of sugar
  - 1 gram of dietary fiber
  - 17% RDA (Recommended Daily Allowance) of Calcium

• 1 Tablespoon of Barleans Omega Swirl (a Flax Oil Supplement usually bought at Whole Foods. It is about $23/bottle, but lasts for a couple of months.) providing
  - 65 calories
  - 10% of the RDA for Omega-3

• 8 ounces of Boost Original, providing:
  - 240 calories
  - 10 grams of protein
  - 25 grams of sugar
  - 0 grams of dietary fiber

• 1 tablespoon of peanut butter, with:
  - 90 calories
  - 3.5 grams of protein
  - 1 gram of dietary fiber
  - 1.5 grams of sugar

• 7 ounces of Odwalla Drinks, either Blueberry Superfood or Strawberry C Monster
  [http://www.odwalla.com/good-products/superfoods/blueberry-b](http://www.odwalla.com/good-products/superfoods/blueberry-b) or

Showing the Odwalla/Naked Splits
  - 100 calories/120 calories
  - 0 gram of protein/1 gram of protein
  - 21 grams of sugar
  - Various vitamins in both

• Half a peach or the equivalent of mixed fruits
  - 80 calories
  - 1 gram of protein
  - 1 gram of dietary fiber
• 1470 calories
• 89 grams of protein

Testimonial:

I’m Marion. My turnaround moment came when Jim brought all the fixings to prepare and provide tastes of his shake to our group meeting in mid-December 2012. I had been on the G-tube since August 2011 and didn't see an end in sight. Still unable to regain any of the weight I had lost and unable to increase the number of cans (8 ounce cans of liquid nutrition) associated with my G-tube, my weight was actually going down. I couldn't increase the count of cans. My body was beginning to rebel. At one point I had been up to taking 7 G-tube cans each day, but was now tolerating only 4. I had been told the G-tube could come out when I was able to discontinue its use for a month without any further weight loss. I loved the taste of Jim's shakes, so set to work to make it a success for myself. At the anticipated weigh-in – I was 3 pounds over my December weight! Confidently, I had the G-tube removed the next week and have been managing fine on my own intake ever since. Thank you Jim!

My shakes have the following ingredients:

I mix up my next day's shakes the night before. I use a Cuisinart Smart Stick and separate into two containers, one to drink for breakfast and one for lunch.

• 1.5 bottles of boost - very vanilla
  - 540 calories
  - 33 grams of sugar
  - 21 grams protein
• 1 scoop of Vega Nutritional vegetable powder
  - 123 calories
  - 2 grams of sugar
  - 15 grams of protein
• 2 – 3 oz Unsweetened Coconut milk (Thai Kitchen)
  - 140 calories
  - 1 gram of sugar
  - 1 gram of protein
• 2 TBS Almond Butter
  - 190 calories
  - 2 grams of sugar
  - 7 grams of protein
• 1 cup Unsweetened Soy Milk
  - 80 calories
  - 1 gram of sugar
  - 7 grams of protein

Combined Breakfast and Lunch Totals:
- 1073 calories
- 51 grams of protein.
For lunch and dinner I generally make steamed vegetables (cut up and cooked until soft) and rice, quinoa or a legume. In addition, I add a fruit in season if possible (I went crazy with peaches; not so much with apples – which I soften first by cooking). I have never actually counted the calories I get with my meals but hope it comes up to 900-1000. I try to stay away from sweets (refined sugar) in deference to keeping my teeth as long as possible. Anyway, sugar just doesn't really taste very good to me anymore and is somewhat burning to the palate and throat.

DIET EXAMPLES:

Examples of liquid/semi-liquid diet (no solids)

- Breakfast:
  - Prune juice diluted with water
  - 1 serving hot wheat cereal with milk and maple syrup
  - 10 ounces of homemade eggnog (milk, sugar, vanilla, nutmeg, whey protein, and eggbaters)
- Lunch and Supper:
  - A 10 ounce nutritious drink (milk, Ovaltine, or Carnation Instant Breakfast with whey protein, and Benefiber)
  - 1 can Campbell’s soup, pureed and strained
  - 4 ounces of pureed and strained cantaloupe, honeydew melon, or applesauce
- Snacks and Desserts:
  - Chocolate ice cream soda
  - Malted milk shake
  - Ensure
  - Custard
  - Soda

Solid food items that one might try include (if not restricted to liquid diet)

- Stir-fried vegetables
- Oatmeal with flax, hemp hearts, chia seed, raisins, buckwheat, oat bran
- Fruits: oranges, apples, kiwi, grapes, pears (cut up small or juiced)
- Salads: lettuce, cooked beets, seeds, nuts, mushrooms, peppers ...
- Protein drinks: Vega from Whole Foods
- Foods that provide extra calories, but not from refined sugars, include Avocado, coconut milk, and cheese.
- Snacks that are small and thin, like Nonpareils, Junior Mints, or (Trader Joe’s) Powerberries.

As mentioned in the Eating section, you will need to determine what will work best for you.

Here is another meal example. It is Pureed Steak and Potatoes created by Jeff.

Steak and Potatoes
- 4 oz. cooked steak (pot roast works well)
- 1 cooked potato
- 8 oz. beef stock
• Some chives
• 2 scoops of sour cream
• 3 pats of butter (or more)
• A dash of steak sauce
• Enough water to puree (about 2-3 cups). Thickness is a personal preference.

The ingredients are designed to be standard items that you would have on hand for steak and potato night. If you think about it - it is really beef stew puree. This is literally a “combine the ingredients in the blender and puree” recipe. When blending the ingredients you will need to monitor how much water you are adding. It is hard to judge how much water the potato is going to need, as different potatoes are different sizes and have “dried out in the pantry” differently.

This recipe is a basic design, so if you have special dietary requirements, be sure to modify as needed. For example, I know a number of people with dairy restrictions. I have tried the recipe with and without sour cream and butter and it still tastes great.

Jeff has a goal to publish 100 pureed meals. Look for the meals (and the count!) at http://jeffscotthoyland.blogspot.com/

RESOURCES:

Here is a list of potential resources for you to view. They encompass Diet and Eating Ideas, Support Groups and Facilities, Transportation Tips, and Legal Advice. Within each subsection, there is no order or sequence to the resources listed.

General Cancer Information Dissemination Sites:

Get FIRSTHAND Insights into Cancer Treatments - https://www.whatnext.com/. Conduct a search on Oral Cancer and you will have many options to choose from.

The Oral Cancer Foundation (Information - Support – Advocacy – Research ... and Hope) – http://www.oralcancerfoundation.org

The Virginia Thurston Healing Garden (a Healing Environment for Those Affected by Cancer) - http://www.healinggarden.net/ (Northeastern Massachusetts focus)

Diet and Eating Ideas:


The Art of Being Better (Jeff’s Blog on Pureed Meals) - http://jeffscotthoyland.blogspot.com/

“Eat Well Stay Nourished”, a recipe and resource guide for coping with eating challenges published by Support for People with Oral and head and Neck Cancer (SPOHNC) www.spohtnc.org
Transportation Options: (Concord MA area)

Visiting Angels (Living Assistance Services) - http://www.visitingangels.com/assisted-senior-care-sudbury-massachusetts-01776_373. There are several sites in Massachusetts.

Neighbor Brigade (Help is Next Door) – http://www.neighborbrigade.org/what_we_do/. Find your local chapter for help nearer to home.

Council on Aging (Improving the Quality of Life of Our Citizens over 60) - http://www.concordma.gov/pages/ConcordMA_COA/transportation. This website is for the town of Concord, MA. There will be other Council of Aging organizations in other towns.

Legal Help:

The Massachusetts Bar Association (Lawyer Referral Service) - http://www.massbar.org/for-the-public/need-a-lawyer. If you have a need for a lawyer and do not wish to go to one of the big law firms, you can utilize this lawyer referral service. Be sure to understand and be able to explain what issues lay before you and the type of help you need. It will help identify someone qualified to take up your cause.

Equipment:

Blenders:
- The Vitamix 500 - The Vitamix has a “SOUP” setting that will puree the food right down to a liquefied drink. If you are a friend of someone going through Oral, Head, or Neck cancer you might consider joining with friends to purchase the survivor a Vitamix. They are not inexpensive; however, they are a Godsend for the patient and the caregiver.
- A Waring Model 51BL26 – Even after 10 minutes, The Waring Blender will puree the food down to having very small but perceptible pulp.
- A hand-held Cuisinart Smart Stick – This item is not as powerful as the others mentioned. However, if you are dealing with soft solid and liquid ingredients, it will do the job. It is also easier to bring with you on a trip, if you are flying somewhere.
- NINJA, low cost excellent food processor, available at Walmart.

Jaw Exercise Equipment:
- The Therabite - http://www.atosmedical.com/For_professionals/Focus_areas/Mouth_and_Law.aspx/
- Trismus Screw (Glass) – more information to be included