



# FRANKLY SPEAKING **ABOUT CANCER**

A PROGRAM OF THE CANCER SUPPORT COMMUNITY



## COPING WITH HEAD AND NECK CANCER FOR LONG-TERM SURVIVORS

Many head and neck cancer patients begin treatment aware of possible side effects of surgery, radiation, and chemotherapy. When treatment is finished, there is often less guidance to help patients know what to expect. Many may experience a fear of the unknown: How long will my symptoms and side effects last? Will I be able to eat normally again? Is there help available?

The good news is that there is help available. This booklet was created with you in mind. It is designed to help you through common struggles that a long-term head and neck cancer survivor may experience.

In this booklet you will find help with:

- Learning how to adjust to eating again
- Managing ongoing side effects
- Coping with common side effects that can persist for years after treatment
- Adjusting to the changing role of food and nutrition
- Keeping track of your nutrition
- Talking with your health care team

## Learning How to Eat Again

Many head and neck cancer patients rely on soft foods, nutritional supplements, or tube feeding for their nutrition. When treatment is over, some may need to continue this plan for a while. It may take time to adjust to your “new normal” way of eating. Each person’s eating plan will be different.

Survivors have switched from tube feeding even after several years of use. If this is something important to you, talk with your care team to develop a plan.

Here are some important tips to help make sure you have the right plan:

- **Meet with your health care team regularly.** Don’t ignore follow-up visits. This is important to make sure you are healing well after treatment.
- **Write down questions you have so that you can be prepared.** For example, ask:
  - When can I try eating more solid foods?
  - How often do I need to see a **dentist** (more than twice a year)? Do I need extra fluoride?
  - Do I need to see a **speech pathologist** to help me transition my diet or to have a speech or swallowing evaluation?
  - Can I follow up with the **registered dietitian** often to make sure I am getting enough calories? Or to give me suggestions on how to get nutrition in a small volume?
  - Do I need to take any nutritional supplements to provide extra nutrition?

“I’ve had to adjust to this post-cancer and post-treatment. These are things that I will live with for the rest of my life. I’m very thankful to be here but there are things you have to adjust to.”  
-Christy, 21-year survivor of adenoid cystic carcinoma



## MEMBERS OF YOUR HEALTH CARE TEAM

**REGISTERED DIETITIANS (RDs)** are experts on diet and nutrition. It is important for cancer patients to visit with an oncology dietitian to develop a plan for a healthy diet. RDs who have the letters “CSO” after their names are “Board Certified Specialists in Oncology Nutrition.” They have demonstrated experience and skills in developing healthy eating plans for cancer patients.

**SPEECH LANGUAGE PATHOLOGISTS (SLPs)** can help with swallowing problems by providing ongoing treatment and exercises. Your SLP will also work with your RD to ensure that you get enough calories by using easy-to-swallow food.

**DENTISTS (DDSes)** can help if you have tooth pain, mouth sores, or dry mouth. They may also have special training in replacing missing teeth and jaw structures. After head and neck surgery, be sure to tell your dentist about your treatment. Ask them if they have experience treating head and neck cancer patients. If they don’t, ask for a referral to a dentist who does.

**PHYSICAL THERAPISTS (PTs) and OCCUPATIONAL THERAPISTS (OTs)** can help with regaining movement and strength through exercise, massage, stretching, and other techniques. They help you learn to cope with daily activities.

- **Keep a food diary.** This will help your health care team and dietitian see how you are eating.
  - Keep a log of what and how much you eat and drink, as well as how much

formula you take in by tube each day.

- It can help your health care team see if you still need a **tube for feeding** or if you need extra nutrition supplements.
- It can help you remember the different tips and foods that worked and didn’t work.
- It may also be helpful to keep track of your weight.
- You can find an example of a food diary on the next page.

“Keep a journal. Write your questions down, the medicine you have to take, how often or what dosage, exercises, and jaw stretches.” – Jean, caregiver to long-term survivor of head and neck cancer

- **Alert your medical team about new or ongoing symptoms.** Don’t delay reaching out to your medical team. This is important to address complications that may occur, such as infections, trismus (jaw tightening), or aspiration (fluid/food going into the lungs). Some important symptoms to look out for are:
  - Severe pain, redness, swelling, or other oral changes
  - Difficulty opening and closing your mouth
  - Coughing or choking sensation while eating
  - Tube feeding leaking, clogging, or regurgitation
  - Pain or swelling in the areas where lymph nodes were removed (lymphedema)
  - Ongoing weight loss



**MEAL ONE**

TIME: \_\_\_\_\_

**FOOD & DRINKS****SERVING SIZE  
OR CALORIES****SYMPTOMS**


**MEAL TWO**

TIME: \_\_\_\_\_

**FOOD & DRINKS****SERVING SIZE  
OR CALORIES****SYMPTOMS**


**MEAL THREE**

TIME: \_\_\_\_\_

**FOOD & DRINKS****SERVING SIZE  
OR CALORIES****SYMPTOMS**


**MEAL FOUR**

TIME: \_\_\_\_\_

**FOOD & DRINKS****SERVING SIZE  
OR CALORIES****SYMPTOMS**


Did you make any changes to your eating habits today? If yes, what did you change? Did it help any symptoms? \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_



“The transition from the PEG tube to eating was an interesting road. We had some interesting conversations, the surgeon and I, with me telling him what I thought I was capable of, and what he thought his work was capable of withstanding.” – Terry, 6-year survivor of laryngeal squamous cell carcinoma

## Trying New Foods

Trying new foods can be challenging. It may be tough to know where to start. If you are used to using mostly your tube or only eating soft foods, here are some suggestions to keep in mind:

- **Try one new food at a time.** Stick with foods that are soft and easy to swallow such as applesauce, hot cereals, yogurt, pudding, scrambled eggs, and creamed soups. You can also puree foods in a blender to make them easier to swallow.
- **Avoid irritating foods.** Use caution with very spicy foods (such as black pepper, jalapeno, chili pepper, or heavy garlic), acidic foods (such as tomato, citrus, or coffee), and foods at very hot temperatures. These foods can be irritating to a healing or sensitive mouth and throat.
- **Try things again in new ways.** If a food doesn't taste good or agree with you, try it again in a couple of weeks, or with a different sauce or flavor. For example, a soft ravioli or well-cooked pasta may be too irritating with tomato sauce. Instead it may taste better and be easier to eat if mixed with butter or cottage cheese.
- **Eat frequently throughout the day.** It is easiest to eat a little bit at a time since you may no longer be able to eat average meal

portions. Be sure to eat slowly and chew food well.

- **Be mindful of ways to add more nutrition.** Since you likely won't be able to eat enough calories right away, add extra calories and protein to your meals.
  - Add extra calories with olive oil, mashed avocado, gravy, butter, heavy cream, and sauces.
  - Add extra protein with scrambled egg, yogurt, custard, pudding, cottage cheese, ricotta cheese, hummus, soft mashed beans, non-fat dried milk powder, and protein powders.
- **Transition from a tube feeding the right way.** Be sure to talk to your doctor or speech pathologist first to find out if swallowing food is safe for you. Your speech pathologist or dietitian can help you to come up with a plan. In most cases, your doctor will let you stop using a tube feeding when you can eat 75% of your nutritional needs by mouth.
  - Start by trying to eat one meal per day, and gradually increase to very small meals every 2-3 hours.
  - Choose soft, moist foods that are easy to swallow, then gradually increase as you can tolerate more.
  - Remember to drink a lot of fluids (if they are considered safe), especially if you will be taking less through your tube.
  - Eat foods that are high in calories and protein, and use oral nutritional supplements if your health care team recommends them.





## MANAGING TUBE FEEDING

You should have your tube feeding checked a few times a year. This helps make sure it is working well and that you still need the same formula/quantity. Do not try to remove the feeding tube by yourself. Make sure your tube and the surrounding area are kept clean. If you stop using your feeding tube, keep flushing it with water twice a day.

- **Take good care of your mouth.** Use mouth rinses, such as this **baking soda mouth rinse** and practice good oral hygiene to help your mouth heal.
  - It may be helpful to clean your mouth after each meal. You may also need to use special mouth cleaners (such as disposable oral swabs, or a water jet for teeth) or rinses as prescribed by your health care team. These may help with bad tastes in the mouth and may help prevent infection.
  - Carry travel mouth care with you on the go.



### BAKING SODA MOUTH RINSE



Rinse your mouth out before and after meals with a homemade baking soda rinse. Swish and spit. **DO NOT SWALLOW.** Prepare a new batch each day.

- ☐ ½ tsp salt
- ☐ 1 tsp baking soda
- ☐ 1 quart of water



## Long Term Side Effects: What to Expect

Many patients want to know what to expect after treatment ends. Head and neck cancer patients and survivors helped us with this fact sheet. They have shared their experiences with us, so that we can help you. These symptoms can occur after a year, 5 years, or permanently after treatment. Here are some of the common tips that may help with these long-term symptoms of head and neck cancer survivors. Everyone has a different cancer experience. You may have some, all, or none of these side effects.

COMMON SYMPTOM	HOW TO MANAGE	RECIPE SUGGESTIONS
(See other suggestions for coping with these symptoms in our Eating Well with Head and Neck Cancer booklet at <a href="http://www.CancerSupportCommunity.org/EWHNC">www.CancerSupportCommunity.org/EWHNC</a> )		
Visit <a href="http://www.CancerSupportCommunity.org/recipe-gallery">www.CancerSupportCommunity.org/recipe-gallery</a> to find these recipes.		
<b>Dental issues</b>	Follow up with your dentist regularly.  Keep your mouth clean.  Clean your mouth after meals as needed with brush, gum brush, or swab, as directed.	<b>Turkey Barley Vegetable Soup</b>  <b>Mixed Berry and Yogurt Crepes</b>  <b>Potato Frittata</b>
<b>Dry mouth</b>  	Drink plenty of fluids before, during, and after your meal.  Always carry a water bottle to sip throughout the day.  Use a spray bottle with saline to moisten your mouth.  Use a moistening gel at nighttime. Keep a humidifier in your room.  Be mindful of other medications that can worsen dry mouth.	<b>Roasted Cauliflower Soup</b>  <b>Baked Apple Yogurt Parfait</b>  <b>Colorful Lentil Soup</b>  



COMMON SYMPTOM	HOW TO MANAGE	RECIPE SUGGESTIONS
Visit <a href="http://www.CancerSupportCommunity.org/recipe-gallery">www.CancerSupportCommunity.org/recipe-gallery</a> to find these recipes.		
<b>Chewing or swallowing problems</b>	<p>Choose soft moist foods like hot cereals, soups, stews, and casseroles.</p> <p>Cut food into small bites.</p> <p>Use extra sauces, gravies, oil, butter, avocado, mayonnaise, or dips to moisten foods.</p>	<p><b>Mango Lassi</b></p> <p><b>Overnight Oats</b></p> <p><b>Sweet Potato Chili</b></p> <p><b>Chicken, Broccoli, and Noodle Casserole</b></p>
<b>Chronic pain in mouth or throat</b>	<p>Eat moist foods like soups, stews, flaked fish, crockpot meals, mayonnaise-based salads, and mashed avocado.</p> <p>Avoid irritating foods, like citrus, spices, and pepper.</p> <p>Use numbing rinses as prescribed by your health care team.</p>	<p><b>Kiwi Green Smoothie</b></p> <p><b>Almond Banana Wheatberry Cereal</b></p> <p><b>Chocolate Hummus</b></p>
<b>Muscle and jaw problems</b>	<p>See a speech pathologist or physical therapist who can help you prevent or manage muscle and jaw problems.</p> <p>Get the right jaw exercises and stretches to help, and do them every day as directed.</p>	<p><b>Ginger Turkey and Wild Rice Soup</b></p> <p><b>Herbed Lemon Salmon</b></p> <p><b>Polenta with Fruit Compote</b></p>
<b>Taste changes</b>	<p>Experiment with new flavors that can add more taste to foods such as marjoram, thyme, cumin, flavorful sauces, and salad dressings.</p> <p>Be open to trying different and unique flavors.</p> <p>Keep track of what works and what doesn't.</p>	<p><b>Golden Milk Popsicle</b></p> <p><b>Creamy Beet Hummus</b></p> <p><b>Savory Stuffed Spaghetti Squash</b></p>





COMMON SYMPTOM	HOW TO MANAGE	RECIPE SUGGESTIONS
Visit <a href="http://www.CancerSupportCommunity.org/recipe-gallery">www.CancerSupportCommunity.org/recipe-gallery</a> to find these recipes.		
<b>Thick saliva</b>	<p>Drink plenty of fluids to thin saliva.</p> <p>Try papaya juice or homemade enzyme rinse to help thin secretions (approve with medical team).</p>	<p><b>Cranberry Coconut Popsicle</b></p> <p><b>Banana Melon Smoothie</b></p> <p><b>Chocolate Mint Smoothie</b></p>
<b>Weaning from tube feeding</b>	<p>Transition slowly from tube feeding to eating by mouth.</p> <p>Talk to your health care team if you have any problems with swallowing, nausea, gas, bloating, diarrhea, or constipation, or notice weight changes.</p> <p>Be patient. It may take more than one try to switch back to eating by mouth.</p>	<p>For recipes to help with this transition, visit our partners <b>AICR</b> and <b>SPOHNC</b>.</p>
<b>Weight loss</b>	<p>Choose high-calorie foods.</p> <p>Use nutrition shakes and smoothies to add more calories in between meals.</p> <p>Think of food as medicine.</p> <p>Follow up with a registered dietitian regularly.</p>	<p><b>Cheesy Chicken Millet Bake</b></p> <p><b>Avocado Macaroni and Cheese</b></p> <p><b>Turkey Meatballs with Butternut Squash Dipping Sauce</b></p>



## Get Support

You may feel nervous, afraid, or anxious about the long-term effects of head and neck cancer and its treatment. This is normal. If these feelings do not go away or are impacting your day to day life, talk to your care team about getting help. You are not alone.

Find a local support group. Support groups are helpful because you can talk to others who understand what you are going through. Support groups are not for everyone.

Individual counseling can help you work one-on-one to process your thoughts, fears, and emotions. Ask if you can talk to a social worker. They can help provide you with a list of qualified professionals in your area.

*"In my Gilda's Club support group, it's good for us [head and neck cancer patients] to be together and talk about this stuff, because we all understand what we're saying." – Christy, 21-year survivor of adenoid cystic carcinoma*



# The Changing Role of Food

In today's fast-paced world it can be hard to adjust to a time frame that is out of our control. Healing after head and neck cancer can take time. Patience and persistence are important. Things may never go back to the way they used to be. Instead, a "new normal" will develop, especially with the right support.

Here are some important tips to remember:

- **Take your time to eat.** Eat slowly and chew food well. This will help ensure that you can tolerate food. Eating too quickly may irritate the mouth, throat, and digestive system.
- **Don't use food as a reward.** Most of us are used to "treating ourselves" with a favorite meal. Many favorites may not taste the same or be as easy to eat. Get in the habit of using other things as a reward instead, like a movie outing, shopping trip, massage, or hobby.
- **Plan ahead for holidays and social gatherings.** Eating around other people can be stressful. In the beginning, family and friends may not be aware of your condition. Here are some suggestions that can help you make your meal more enjoyable and tolerable:
  - Pack foods and snacks that you know you can tolerate, such as yogurt, cottage cheese, pudding, travel baby foods, and canned soups.
  - Eat ahead of time if you are worried about time issues at the gathering.
  - Don't be afraid to make suggestions for family gatherings and holidays.
  - When dining out, talk to your waiter or waitress. Ask if they can puree your food or ask for extra sauce, gravy, or less spice to be sure the food will not irritate your mouth.
  - Order an appetizer-sized portion, which may be easier to manage.
  - Bring extra napkins or tissues for secretions.
  - If you don't want to eat in public, try to find different ways to be social with friends and family so you don't feel isolated.



## Survivorship Care Planning

If you are getting ready to finish cancer treatment or recently have stopped treatment, it is important to talk to your care team about what comes next. A survivorship care plan can help.

A survivorship care plan is a guide for your care after cancer treatment. It includes information about your diagnosis and treatment.

It also has symptoms and side effects you might experience and who to call if you need help. It may have a schedule of the types of follow-up care you will need in the years following treatment. You may need to have scans, labs, or appointments every few months.

Talk to your care team about your survivorship care plan. If you live far away from where you received cancer treatment, ask your care team if there are local health care professionals who can support you in between yearly visits.

Make sure you know how to access your medical records. Bring a copy of your treatment summary if you change doctors and when you return to your primary care physician.

Ask your care team how often you should meet with specialists after finishing treatment. You may need to continue meeting with your dietitian, speech pathologists, or other specialists to monitor your recovery and provide you with other support.

## Cost of Care

Even though you may not be in active treatment for cancer anymore, you may still feel the burden of medical costs. You may have medications that are used to treat the long-term or late effects of cancer treatment or other conditions. You may need to buy nutritional shakes, enteral nutrition formula, or other meal replacements. Or you may have costs due to ongoing medical appointments. You may even still be receiving bills for treatment you had in the past.

Talk to your care team to see what resources are available to manage the cost of care. Ask if there is a patient navigator or financial counselor who can help you find copay assistance. They may be able to help you find medications at a lower cost directly from the drug company.

For more tips about how to manage the cost of care visit **[www.CancerSupportCommunity.org/cost](http://www.CancerSupportCommunity.org/cost)**.



## HEAD AND NECK CANCER RESOURCES

American Cancer Society • 800-227-2345 • [www.Cancer.org](http://www.Cancer.org)

American Institute for Cancer Research • 800-843-8114 • [www.aicr.org](http://www.aicr.org)

CancerCare • 800-813-4673 • [www.CancerCare.org](http://www.CancerCare.org)

Cook for Your Life • [www.CookForYourLife.org](http://www.CookForYourLife.org)

Head and Neck Cancer Alliance • 866-792-4622 • [www.HeadAndNeck.org](http://www.HeadAndNeck.org)

HNC Living Foundation • 913-402-6028 • [www.HNCliving.org](http://www.HNCliving.org)

Oley Foundation • 518-262-5079 • [www.oley.org](http://www.oley.org)

Oncolink • [www.oncolink.org/cancers/head-and-neck](http://www.oncolink.org/cancers/head-and-neck)

Support for People with Oral and Head and Neck Cancer (SPOHNC) • 800-377-0928 • [www.spohnc.org](http://www.spohnc.org)

Savor Health • 888-721-1041 • [www.SavorHealth.com](http://www.SavorHealth.com)

Thyroid and Head and Neck Cancer (THANC) Foundation • [www.THANCfoundation.org](http://www.THANCfoundation.org)

## CANCER SUPPORT COMMUNITY RESOURCES

**Cancer Support Helpline®** — Have questions, concerns or looking for resources? Call CSC's toll-free Cancer Support Helpline (888-793-9355), available in 200 languages Mon-Fri 9am-8pm ET and Sat 9am-5pm ET.

**Open to Options®** — Preparing for your next appointment? Our trained specialists can help you create a list of questions to share with your doctor. Make an appointment by calling 888-793-9355 or by contacting your local CSC or Gilda's Club.

**Frankly Speaking about Cancer®** — Trusted information for cancer patients and their loved ones is available through publications, online, and in-person programs.

**Services at Local CSCs and Gilda's Clubs** — With the help of 170 locations, CSC and Gilda's Club affiliates provide services free of charge to people touched by cancer. Attend support groups, educational sessions, wellness programs, and more at a location near you. [www.CancerSupportCommunity.org/FindLocation](http://www.CancerSupportCommunity.org/FindLocation).

**Cancer Experience Registry®** — Help others by sharing your cancer patient or cancer caregiver experience via survey at [www.CancerExperienceRegistry.org](http://www.CancerExperienceRegistry.org).

**MyLifeLine** — CSC's private, online community allows patients and caregivers to easily connect with friends and family to receive social, emotional, and practical support throughout the cancer journey and beyond. Sign up at [www.MyLifeLine.org](http://www.MyLifeLine.org).

**Grassroots Network** — Make sure your voice is heard by federal and state policy makers on issues affecting cancer patients and survivors by joining our Network at [www.CancerSupportCommunity.org/become-advocate](http://www.CancerSupportCommunity.org/become-advocate).

This booklet is available to download and print yourself at [www.CancerSupportCommunity.org/HNC](http://www.CancerSupportCommunity.org/HNC).

For print copies of this booklet or other information about coping with cancer, visit

[Orders.CancerSupportCommunity.org](http://Orders.CancerSupportCommunity.org).

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