

THE NEXT SIX MONTHS

A SURVIVAL AND FOOD GUIDE
AFTER ORAL CANCER TREATMENT

"I've walked the walk — You're not alone."

ED TOPALIAN, ORAL CANCER SURVIVOR



MY FOOD GUIDE AS AN ORAL CANCER SURVIVOR

This Food Guide was developed in collaboration with Ed Topalian, a Hoag oral cancer survivor. The content inside is Ed's personal food journey following treatment, that he journaled throughout his recovery. Hoag encourages you review his recovery guide to provide ideas during your own food journey, but to speak with your clinical care team prior to making any major changes in your diet.



About the Writer

Ed Topalian will be the first to tell you that he's not a writer. He's a contractor with a successful stair company in Santa Ana, CA. But he is also an oral cancer survivor at Hoag Hospital and a compassionate man. His experience and empathy compelled him to put ink to paper to help others with the complicated and excruciating process of eating during the six months following chemotherapy and radiation.

What follows here is a compilation of survival wisdom culled from Ed's personal culinary trial and error. You'll not only learn when he reintroduced potato chips to his diet, but also what brands he avoided. You'll also read about how he modified coffee to keep his heartburn at bay.

More importantly, you'll get a glimpse of a successful survival story, and maybe you'll get a sense of hope.

"I remember laying on the sofa in the middle of the two-month treatment," he said. "I was miserable, but I told my wife, 'I hope we can do something to help other people, so they don't feel the way I feel now.'"

Ed wrote the first version of this guide after a firefighter he knew was diagnosed with oral cancer and started asking for food advice. Ed had the typed-out guide in his briefcase when his wife, Rebecca, was admitted to Hoag to undergo a lung biopsy. A social worker visited Rebecca's room, and after talking for a while, Ed told her about the guide.

"I reached into my briefcase and handed it to her," he said. "She said, 'Are you kidding me? This is incredible.'"

Ed was asked to help found an oral cancer support group at Hoag, and he dutifully printed and distributed his guide to anyone who wanted one. Soon, doctors began requesting copies, as did oncology nurses. He started fielding calls from far and wide, as his guide was re-copied and shared all over the world.

A few times, new members of the Hoag Oral Cancer Support Group would walk in with a copy in their hands. When they learned that the guide's writer was in the room, their eyes would light up. And Ed's eyes would tear.

"To have people hold up the food guide and tell me, 'This gives me hope,' it makes me want to cry right there," he said. "I started to realize how much weight the information carried."

Six years after Ed beat oral cancer, Rebecca Topalian succumbed to pulmonary fibrosis. Ed views this guide as a kind of tribute to her. Now in its fourth edition, "The Next Six Months" has been published by Hoag to help as many people as possible.

"I am grateful to share my food recovery journey," he said. "The effect of talking with people who have said this guide has given them hope, it's one of the most rewarding experiences of my life."



This food guide is dedicated to the caregivers, friends and medical staff that helped me survive the ride of my life. I couldn't have done it without you.

Thank you, my loving wife Rebecca.

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WRITE IT DOWN - REFLECT ON IT LATER

Medication Record

MED RECORD KEEPING IS A MUST

- I had continued throat pain with little or no change for at least the first month out of treatment.
- Phlegm build-up was still heavy but started to reduce; it's one of the first major changes after radiation treatment that I noticed.
- I treated my neck burn with Aloe Vera gel, Radx cream, Radiation Relief Cream, Oncology Cream (found on Amazon).
- I tried my best to keep my neck out of the sun as it was subject to severe sunburn after radiation treatments.
- G-Tube feeding is still needed at this stage; must keep my calories up.
- I used Miralax for constipation and Prontonix (prescription) for heartburn and digestion.
- I tried to maintain good dental hygiene and had fluoride treatments prescribed by an oncology-educated dentist - I found this very important.
- I took walks to get fresh air and blood circulation to my muscles; I needed water at all times.
- I drank as much water as possible, day and night to prevent dehydration; I kept reminding myself that my body is very wounded and needs extra care.
- I tried drinking different juices, and drinks with high electrolytes in them and always kept water handy in case these drinks burned my throat.
- I realized eating solid foods will slowly come later; it takes time and patience but it will happen.
- I tried some Jell-O (not sugar free), Jell-O chocolate pudding and soft-serve ice cream; the cold temperature didn't bother me.
- I was able to tolerate chicken broth and noodles, but no chicken for now.

The Road Ahead

I used these ideas as a guideline for a more comfortable recovery. It's hard and painful now but I tried to be creative and take chances with different foods. Even though I didn't have an appetite, it came back sooner than I thought.

If I thought I could eat it, I try it! It was important to get my throat and jaw moving. For the next several months almost everything I ate came with some pain and bad taste, but it slowly subsided and got better.

**Get as much rest as possible, stay hydrated and,
most importantly, stay positive.**

- Food and eating continue to be my top priority—to me, food equals wellness.
- My throat was still sore at times.
- I was thankful that I no longer needed pain medication.
- I tried some soft foods, soups and fruit.
- Scrambled eggs cooked as soft as possible with sour cream on the side to dip them in worked well for me.
- Watermelon even burned my throat the first few times I ate it—it's amazing how much damage I've endured.
- I tried cantaloupe but it also stung at first. I kept eating it and eventually it tasted fantastic.
- Top Ramen noodles and broth worked well.
- Fudgesicles and ice cream were something I finally mastered. Ice cream and shakes at times were tough to swallow just because of the cold.
- Fresh-squeezed orange juice was finally good but eventually it started causing heart burn—I rarely drink it now.
- I tried protein shakes at least once a day if not more—they are a great meal substitute with big calories!
- The shakes I made had high calorie sports protein mix, frozen blueberries, banana, bee pollen, flax seed, ice, and vanilla ice cream.
- I tried mashed potatoes with lots of butter and sour cream on the side to help lubricate my throat.
- I tried a lot of different yogurts before I found the brand that worked for me.

Foods I Stayed Away From

During the 2nd month, I stayed away from black pepper, raw and cooked onions, salsa, peanuts, chocolate candy, raw carrots and chicken breast meat, as it can be very dry at times.

Most candy I tried was very sweet and hard on my throat and as the sugar started to melt, it caused instant phlegm.

Coconut cream pie, macaroon cookies and most baked cookies and cakes were very difficult to process for me at this time. Nectarines, grapes, cherries and plums were harder for me to eat at this stage.

If I thought I could eat it, I'd try it! It was important to get my throat and jaw moving. For the next several months almost everything I ate came with some pain and bad taste, but it slowly subsided and got better.

Experiment with food. If It works, eat It again the same day
as there aren't many food options at this stage.

M O N T H
03

New Food—My Path to “G” Tube Removal

- My throat was feeling a little better by this point and my excess saliva became less evident.
- My appetite was improving and it was time to get serious about eating again.
- I started to reduce liquid food intake as much as possible and replace it with high-calorie solid foods.
- My doctors and dietitians wanted to see about a month of eating solid or liquid foods without weight loss prior to approving my G-Tube removal.
- I started planning my meals well in advance for today and tomorrow (very important) so I wasn't searching for something to eat all the time.
- My stomach was very small at this time and meals were small and slow to eat. I needed to take my time to eat and not worry about anyone else.
- Egg salad with mayo minced celery and salt—no pepper and no bread—worked well.
- Hamburger with lettuce and mayo—no bread—worked well.
- Mayo, sour cream and melted butter were great lubricants for lots of my food choices.
- I ate fruit every day (some, if not all, did sting).
- Pan-seared scallops in butter was a great meal and very slippery. It was the first meat that I was able to eat—I just took a chance on them.
- I tried steamed and grilled crab legs with drawn butter. It was fantastic and the perfect consistency.
- Lobster tail grilled or steamed was incredible with butter—another fantastic food experiment that worked for me.
- Steamed asparagus and cauliflower well done (as soft as possible), and of course, with added butter.
- Grilled bone-in steak and pork chops also worked well.
- Avocado with a little salt is healthy fat and high calorie food. It was one of my go-to foods at this time.
- Cucumbers are very forgiving; they are mostly water.
- Tomatoes sliced with light salt tasted great—I was surprised when I was able to eat it so early. I kept telling myself to try everything.
- I tried hot dogs—no bun with mustard. I found Wienerschnitzel hot dogs to be the easiest to eat; all hot dogs taste different.
- I tried sautéed mushrooms in butter, thinly sliced.

Food Notes

I had to remind myself that what I couldn't eat at that moment, could be a different story the next day or weeks to come. I tried the same foods for months and then finally, I was able to taste and eat them. It's a work in progress. Start working on it—your recovery depends on it!

I tried different restaurants, made sure to ask what was on each food, and told them exactly how I wanted it prepared.

I tried to stay away from rice for some time; it's very sticky and easy to choke on.

**Make your wellness from food intake a priority for both you
and your caregivers.**

- With clear PET and CT scans, proper diet and weight, my clinical team began discussing my G-Tube removal. In month 4, my G-tube was removed.
- Once It was removed, I had to be able to eat and maintain my weight. It was not easy, but it was a great achievement.
- My heavy saliva and constant spitting started subsiding by now.
- I would plan meals in advance to reduce the stress and anxiety of eating and searching for foods to eat.
- I tried pasta with olive oil basil, diced tomatoes, but no garlic yet.
- Pasta marinara worked great for me, but everyone makes it different so I was sure to ask how spicy it was, or if it had garlic in it.
- *Most Italian or good fish restaurants have fresh baked bread without the preservatives that caused me irritation. I would spread with butter and dip in marinara sauce. Yum!
- Corn on the cob tasted great for me, of course with butter and a little salt. It was one of a few things that never changed in taste for me.
- Creamed corn was great as well; I found a lot of recipes online.
- Stir-fried vegetables (without chicken for now) and fried spring rolls at a local Thai restaurant tasted great and were fairly easy for me to eat.
- Steamed artichokes were also good and seemed to go down pretty well—I tried melted butter or mayo for taste and lubrication of the throat.
- I thought half of an avocado with salt and some fresh blue cheese or ranch dressing in the pit area was incredible—plus lots of calories!
- *Wing Stop restaurants have fresh-made daily blue cheese and ranch dressing that didn't bother my throat
- Rotisserie chicken was great and juicy but only the dark meat—I did not try white meat yet.
- Cream of mushroom at Souplantation was very fresh and great with their sourdough bread.
- I tried Caprese salad—with sliced ripe tomatoes, fresh basil, olive, balsamic vinegar and salt, but no pepper yet.
- Pasta salads tended to be hard to eat as they get a bit sticky—I waited to try it later.
- I tried sautéed baby spinach in butter—thoroughly cooked to avoid choking on it.
- Chocolate cream and banana cream pies worked pretty well at this point.
- New York cheese cake was fantastic at this stage—450 calories a slice!
- I tolerated white peaches better than yellow peaches.
- Cold cuts wrapped in lettuce worked well, however I purchased high quality meats with less additives, which equaled less irritation.

M O N T H

04

Time to Eat Again CONTINUED

The Next Step

I remember that everything that had preservatives in it (from a package or a can), caused burning sensation in my throat, including most breads, soups, salad dressing, etc. I tried to think “fresh” not “shelf life.” It took me a long time of trial and error to figure out what worked for me. I hope some of these ideas will help expand your expectations for healing and reclaiming your life again.

Take some notes each day to remember what and when you ate a particular food. It’s important to monitor your healing progress.

Soda tasted terrible to me, and nearly everyone I’ve talked to. However, fresh brewed iced tea with lemon tasted great to me. Coffee tasted great, and at this stage I drank it daily. I used cream to avoid heartburn.

Just because you can’t eat It today, doesn’t mean
you won’t be able to eat It tomorrow.

- My appetite was getting better by now.
- It was time to take some food risks and expand my menu options (but no garlic yet).
- Pan-seared tilapia is very light and crispy when cooked in butter, paprika, fresh lemon juice and with added basil sprinkles after cooking.
- Cheese pizza was back in my life by now. I made it fresh at home on a pizza stone or went to a good pizza place (but no red peppers).
- Crab cakes with mango sauce was a pleasure to eat again for me.
- Rubio's fish tacos with mild salsa were a great discovery for me; the fried, crispy, tender fish was easy to eat.
- Wahoo's beer-battered onion rings were another experiment but I could only eat a few as it gave me heart burn.
- Homemade pickled beets with olive oil and white balsamic vinegar tasted great and didn't burn.
- The joy of eating a plain bagel, lightly toasted with butter and a little cream cheese returned! (I couldn't believe I was eating bread again.)
- Some muffins work, some don't. I tried them all and ate them warm.
- Flour and corn tortillas, preferably freshly made at a good Mexican restaurant, with butter and some pico de gallo was one of my all-time favorites.
- Sautéed shrimp in butter sauce worked well but I would avoid overcooking them.
- Grilled lamb chops / grilled rack of lamb worked well.
- Additives in foods were still bothersome, so I still avoided bacon and sausage at this stage.
- I found that fried egg sandwich worked on white breads or flat breads; wheat bread was very hard to process.
- Huevos rancheros with fruit tasted good, but I tried to be careful of anything spicy.
- I experimented with omelets.
- Lightly toasted English muffins with butter and jam were easier for me to eat than regular breads.

Looking for More

I tried to continue to keep an open mind, to explore my food options. For me, it was like learning to eat all over again.

I tried to get creative with some different sandwiches on flat breads with mayo, cucumbers, lettuce, tomatoes and a meat of my choice. Tomatoes can sting, but I like them so much that I continued to eat them. I kept that in mind for favorite foods—I tried it and kept trying it.

I focused on eating slowly with small bites to avoid choking—everything you eat is all new to your throat and body now.

I tried making high-calorie shakes to help control weight loss. I found a lot of great protein and gainer mixes at GNC stores.

**Remember to try foods again that you may not have liked in the past.
Everything tastes differently now.**

- I tried being creative with my menu. As soon as I could eat something, I'd think of the next food group to master.
- Grilled pork tenderloin and tri tip (medium rare) tasted pretty good at this stage.
- I tried pita bread warmed in a pan with cucumber, tomato, sprouts and mayo—it was light and tasty.
- Sautéed mushrooms and onions with some leftover pork tenderloin in a pita was great.
- I found that flat breads had more options than baked breads, as they are a dense texture and don't absorb as much saliva as baked breads.
- French fries worked for me again at this stage but with NO ketchup.
- Low-sodium deli meats from the butcher in pita pockets were also good sometimes.
- I enjoyed fried egg over a lightly toasted English muffin. Yum!
- Grapes and nectarines took a while but work well now.
- An ice cream sundae with caramel instead of hot fudge tasted great.

Taking Chances

I had to stay away from Lay's potato chips. One bite and I was crying from pain. Tortilla chips seemed to be an option for me though, with pico de gallo and homemade salsa without jalapeno.

I went easy on spices, but Italian seasoning, salt and paprika seemed to be pretty forgiving.

I made sure to balance my meals with protein and carbohydrates to help my muscles recover properly.

BBQ pulled pork from Trader Joe's is a bit spicy but I tried it and it was good. Dark meat from chicken was all I could process; white meat was instantly dry and hard for me to eat, with the exception of freshly cut rotisserie chicken in the juice.

I stuck with dark chocolate. It's not nearly as sweet as milk chocolate.

The worst food mistake I made in the last year was
trying to eat a Twinkie! Don't do It.

