



I've got to get back to the  
land of the living



CANCER PREVENTION & RESEARCH  
INSTITUTE OF TEXAS

## TOPICS

# Welcome to Week 10

Click the yellow “Next” button [NEXT ►](#) above if you want to go through the entire Week 10 step by step, or click on a button below to jump directly to a topic of interest.

**Watch this video of Dr. Eileen Shinn, Assistant Professor, MD Anderson Cancer Center, as she introduces the topics this week.**

[Quote from a Former Patient](#)[Tell Us What You Ate](#)[Program Wrap-Up:  
Managing Your Health](#)[Patient Stories and Tips to  
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# Quote from a Former Patient

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[Click here to read more.](#)



## QUOTE FROM A FORMER PATIENT

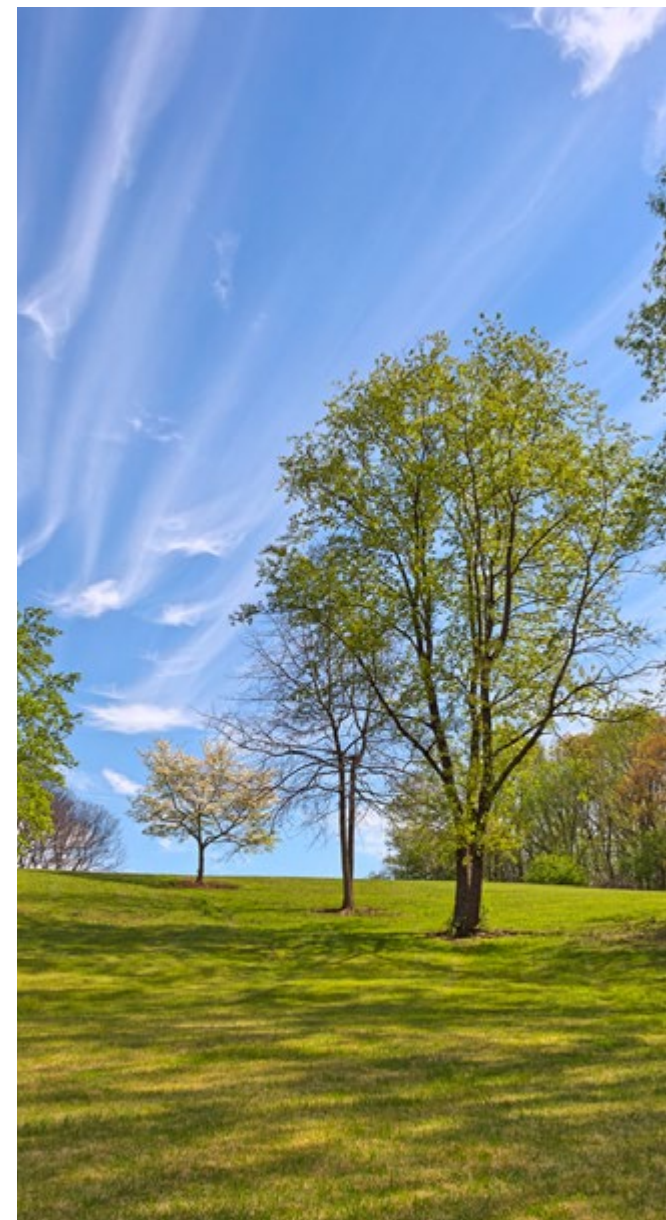
## “There is a time when it’s real. ”

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“You really cannot move, you really cannot swallow anything, you really do need the morphine, you really do not feel like doing anything. That’s a given. But you come to a point where you realize, ‘I want to get back to the land of the living.’ You say to yourself, ‘Okay, I’ve got to do something.’

You get to this bridge and only you can cross it. That’s when you have to push yourself. I really did not want to get out of bed and it was easier to stay on the feeding tube than forcing myself to eat. Everything tasted like cardboard and plus I was nauseated. But I forced myself to get out, take a short walk, try to swallow something. It doesn’t happen overnight. You just got to keep at it, you may not even see a change from week to week. But month by month I get a little better, closer to where I was before it all started. As long as that damn cancer stays away, I don’t really care, as long as I don’t have to go through that again. Because it was really rough, it was the hardest thing I ever did.”

Former Patient



# Tell Us What You Ate

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TELL US WHAT YOU ATE

## Recovery is a Gradual Process

Now that you have made it to Week 10, take the opportunity to look back to Week 7 and see how far you've come with your eating. You may still not be able to eat a variety of foods, but you are taking steps each week to getting closer to your goal of eating your favorite things again. Remember, recovery and getting back to health is a gradual process, so keep this in perspective. You are doing a GREAT job!



TELL US WHAT YOU ATE

# What did you eat this week?

## List of Foods for the Week

- 1.
- 2.
- 3.
- 4.
- 5.
- 6.
- 10.



# Program Wrap-Up: Managing Your Health

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[Click here to read more.](#)



## PROGRAM WRAP-UP

# Managing Your Health

Now that you are in your 10th week, think of all the new things you have learned in the management of your health. You should now be able to:

**Chart your swallowing exercises** each week. This is a great method of tracking and accountability that you can apply to help yourself stay focused and encouraged.

**Recognize side effects** and monitor infection. If you have any other problems in the future, you now know when to call the doctor and when and how to care for yourself or your loved one at home.

**Manage nutritional needs.** The healthier you can eat, the more energetic you will be.

**Establish new healthy behaviors**, such as getting more rest, reducing your stress levels, and being positive about your life.

**Communicate more easily** with one another. Keeping the lines of communication open and realizing how the other person feels about a situation will aid you in all areas of your life.





PROGRAM WRAP-UP

# Congratulations

You have done a phenomenal job during this entire process and you should be VERY proud of yourself. YOU DID IT!!



## PROGRAM WRAP-UP

# Caregivers, you deserve a reward too!

You have done a phenomenal job, and we know this has required a lot of work and effort from you.



# What do I do now?

**Exercise of course.** No, you're not off the hook. You may be done with radiation, but your face and neck muscles still need the workout to continue functioning, and to regain some of the strength they've lost during treatment. Keep doing your swallowing and trismus exercises to prevent scarring and late term swallowing problems.

**Life beyond radiation.** Plan some fun! Once you feel up to it, be sure to reward yourself. You've gone through a very difficult time, and you've worked very hard. What are

some of the goals you chose in Week 6? Which of them can you do, or at least start on, today?

**Keep your follow up** appointments with your doctor.

**Track and monitor** your progress with your swallowing.

**Identify any side effects** and follow the appropriate steps to cope with them.

**Create new** healthy behaviors.

**Be patient** with your spouse and caregivers, this is a stressful time for them.



# Patient Stories and Tips to Encourage You

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[Click here to read stories and tips from other patients.](#)

## PATIENT STORIES AND TIPS TO ENCOURAGE YOU

“It’s like taking baby steps. Not leaps and bounds. It’s a slow process, but I’m going to make it.”

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“Sometimes I feel I am going stir crazy. I feel I need to get up and do something. Plus I want to freaking eat! But I still have a lot of healing to do.”

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“I’m still in a lot of pain.”

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“I feel a little better every day.”

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“Patients have to listen to their bodies.”

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“Make a calendar. Use visuals. Keep the days moving and marking them off.”

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“Be the well person. Don’t be the sick person who’s always staying in bed.”

Former Patients



## PATIENT STORIES AND TIPS TO ENCOURAGE YOU

“Everyone’s story is different.”

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“Have friends. Be involved. Be part of your life.”

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“You should look outside, do something.”

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“Discover your possibilities.”

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“At least once a day, think and dream for yourself.”

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“Believe it! High expectations are the key to everything.”

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“To get from point A to F there are a lot of regulated steps in between.”

Former Patients





## “You Can’t Look Back, You Can’t Change What’s Been.”

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“You know you wonder what you could have done, but if you do that you’re looking back and you are not looking forward. You can’t change anything that has happened. Sometimes, stuff just happens. There is nothing you can do about it. You didn’t do anything wrong.

You can’t beat yourself up. You’ve got to stay focused on battling this thing now and beating it. You’ve got to stay strong. If your mind is weak and your spirit is weak, it’s hard for your body to be strong. So my advice to anybody that goes through this is to accept things as they are. Try to be more healthy. Don’t fall into that trap of second guessing and looking back because that is counterproductive. You can’t change what’s been.”

Former Patient





## Michael's Story

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“After the radiation and the scare something else changed too. I have a new baseline and definition for pain and for fear. The threshold for both has been forever reset. I have new courage and tolerance that I never had before. I quit my well-paying job in a large company. No fear. My wife thought I was out of my mind giving up the income and the security, but I wasn't happy. I hated working for a group that cared only about making money and not much about the customers or the employees. It

took me quite a while to figure out my new path but now I am a business owner and have replaced all of my former income plus some. I have independence and I love what I do. Don't get me wrong, I'm not advocating for crazy decisions and quitting your job because of cancer, but I am saying there is no good reason to be miserable in your life and you shouldn't underestimate yourself and what you can accomplish. It's your life, you get just one of them.



## PATIENT STORIES AND TIPS TO ENCOURAGE YOU

It's your time that you earned going through what you are right now and you should use it the way you choose to.

I have to be totally honest and recognize I still have challenges in life. I always will. It's life after all. There are times I still feel sadness or despair, but they don't last long. I still get frustrated but it takes a lot more than it used to. I can feel pain still but it's not really much of anything compared to the pain I felt from radiation in my throat. I can get tired but not tired like radiation-tired. I can feel alone at times (rarely) but not like I was alone in the chemo room, by myself with a cold IV in my arm.

I wish you the very best outcome and truly hope your path will be

similar to mine. Whatever your time is and our time is – none of us ever really know - make sure you relish every minute of it. It's so precious and your family is such a gift to be enjoyed.

Good luck to you – you've got what it takes - and you can do it! There's a strength in you that you didn't know was there before. I know you feel it. There's a resolve to survive and live. There's so much depth to your strength – feel it and trust it. It will carry you to the finish line no matter how hard that seems. When you come out the other side of this like I did the rewards are enormous. Look forward to that – you will have earned it.”





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### Altered Taste/Dysgeusia

- Strategies to help you (week 3)

## A note to caregivers (weeks 7 and 9)

### Bowel management

- Do not take Metamucil or Citrucel! (week 3)
- What to do if you're constipated (weeks 3, 4, and 7)
- Summary of constipation management (week 7)

### Caring for your skin

- Sunscreen products (weeks 1 and 2)

## Checking for trismus (weeks 1, 2, 3, 4, 5, 6, 7, 8, 9, and 10)

## Constipation management (week 8)

## Communication at home (week 2)

## Congratulations! (week 6)

## Create Eat/ Don't Eat Lists (week 3)

## Dealing with fatigue and nausea (week 7)

## Dehydration (weeks 1, 2, 3, 4, 5, 6, 7, 8, 9, and 10)

### Dental care

- Strategies for dental care (week 2)

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## Fatigue (weeks 5, 6, 8, and 9)

### Feeding tube

- Help (week 1)
- Introduction (week 1)

## Feeding tube weaning (week 8)

## Fighting with your caregiver (week 2)

## General advice from patients (week 3)

## How to throw up through your feeding tube (week 5)

## Hydration (week 1)

## Importance of hydration (week 1)

## Improving your oral intake (week 3)

- Foods you may enjoy
- Products to increase calorie intake

## Information for caregivers (week 5)

## Instructional videos for swallowing and trismus exercises (week 1)

## Keep swallowing by mouth (week 4)

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## Making a commitment to do your swallowing and trismus exercises (week 1)

## Managing your energy (week 1)

## Mini-relaxation exercise for both patients and caregivers (week 5)

## Mucositis (week 9)

### Nausea

- Commonly prescribed anti-nausea medications (weeks 3 and 5)
- General information about nausea (week 9)
- Thick saliva can cause nausea (week 5)
- Try to determine what is causing nausea (weeks 3 and 5)

## Nutrition (week 1)

## Pain/dryness in radiated skin

- Products for dry and radiated skin (week 3 and 7)
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## Pain from radiation burn (week 9)

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### Patient Stories

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- Difficulty swallowing due to pain and mucus (week 9)
- Frank's story (week 7)
- Gary's story (week 6)
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- Macho story (week 9)
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- Michael's story (week 1)
- Steve's story (week 2)
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# Index of Topics with Week Numbers

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- Skin care (week 3)

## Preventing constipation

- Do not take Metamucil or Citrucel! (week 2)
- Managing constipation (week 2)
- Medications that cause constipation (weeks 2 and 4)
- Products to combat constipation (weeks 2, 4, and 7)
- Strategies to combat constipation (weeks, 2 and 4)

## Program Wrap-Up: Managing your health

- Congratulations to caregivers! (week 10)
- Congratulations to patients! (week 10)

## Pureed diet

- Foods to avoid on a pureed diet (week 4)
- How to make pureed food (week 4)

## Recipes

- All recipes (week 4)

## Reminder: 6-Month follow up (week 9)

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## Setting goals for yourself (week 6)

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- Foods to avoid on a soft diet (week 4)

### Some reminders as you recover at home (week 7)

### Stress relief for patients and caregivers

- A note to caregivers (week 8)
- Breathing Awareness (weeks 2 and 8)
- Diaphragmatic Breathing (weeks 2 and 8)
- Guided Imagery (weeks 2 and 8)
- Progressive Muscle Relaxation (weeks 2 and 8)
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### Swallowing exercises (week 1 and swallowing and trismus exercises PDF)

### Taking care of your skin during treatment (week 2)

### Taking medications through a feeding tube (week 5)

- Taking liquid medication through a feeding tube (week 5)
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### Tell us what you ate (weeks 7 and 9)

### The importance of swallowing exercises (weeks 1 and 2)

### The importance of trismus exercises (weeks 1 and 2)

### Thick saliva and dry mouth (week 2)

- Strategies to fight thick saliva

## Thrush (Candida) vs. Mucositis (weeks 3 and 5)

### Tips and products for mucositis

- Explanation of mucositis (week 3)
- Products for mucositis (weeks 3 and 7)
- Strategies to combat mucositis (week 3 and 7)

### Tips and products for thrush

- Explanation of thrush (week 3)
- Medications to treat thrush (week 3)
- Strategies to combat thrush (week 3)

### Tips for dry mouth

- Explanation of dry mouth (week 3)
- Products for dry mouth (weeks 3 and 7)
- Strategies to combat dry mouth (week 3)
- Tips for dry mouth (week 9)

### Tips for improving oral intake (week 4)

### Track your fluid intake (weeks 1, 2, 3, 4, 5, 6, 7, 8, 9, 10)

### Track your weight (week 3)

### Trismus exercise (week 1 and swallowing and trismus exercises PDF)

### Unrealistic expectations (week 6)

### Quote from a former patient (week 10)

### What do I do now? (weeks 1, 2, 3, 4, 5, 6, 7, 8, 9, and 10)

### When is my taste coming back? (week 9)

### You can do it! (week 1)

### Your progress (week 9)

- Don't stop your exercises now!