



Be Proud of Every Little Thing



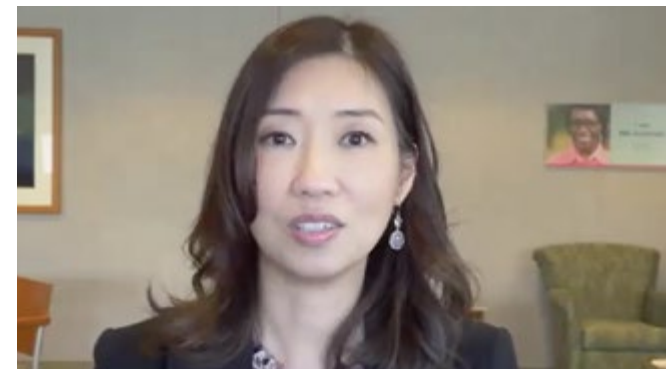
CANCER PREVENTION & RESEARCH
INSTITUTE OF TEXAS

TOPICS

Welcome to Week 9

Click the yellow “Next” button  above if you want to go through the entire Week 9 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.

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Your Progress

[Click here to read more.](#)

YOUR PROGRESS

Your Progress

The radiation side effects are peaking during these weeks.

It is normal to feel fatigued.

It is also normal to experience symptoms such as loss of taste, mucositis and dry mouth at this stage.

Try to focus on the ways you have improved since your treatment ended.

As one patient put it:

“Be proud of every little thing you can accomplish.”



YOUR PROGRESS

Don't stop your exercises now!

Now that you're home and comfortable and not reminded of your radiation treatment, don't let all your hard work go to waste! Keep up the good work with your swallowing exercises. Like any exercise program, it's much harder to stop and start again than to never stop at all.



When is my taste coming back?

[Click here to read more.](#)

WHEN IS MY TASTE COMING BACK?

When is my taste coming back?

Your taste may begin to return 4-6 weeks after treatment, and continue to improve for the next 2 to 3 years.

Your taste may not return to exactly the way it was before treatment.

You may not enjoy certain foods anymore, but on the other hand, you may discover that you love new foods you hadn't liked before.

Your taste may be different, but different is not always worse. Just keep trying to find foods you enjoy!

If you try something today and it doesn't taste good, try it again in a couple of weeks.



A Note to Caregivers

[Click here to read more.](#)

A NOTE TO CAREGIVERS

Communication: What to Expect

This can be a difficult week for caregivers as well as patients. If you become angry with your partner remember to express your feelings at an appropriate time, when the two of you are alone and have time to talk. Express your feelings calmly, and use I statements instead of accusations. It is also important to communicate with people besides your partner.

We all need to vent to someone from time to time.

Do not expect your loved one to return to normal activity levels at this point. It is perfectly ok if your loved one is still sleeping most of the time. The radiation is still active in the patient's body and the patient is still working hard to fight the cancer. However, if you notice that your loved one's energy is not starting to improve 4-6 weeks after treatment has ended, then make an appointment to see the doctor. Don't forget to sleep and eat and to take care of yourself.



Pain from Radiation Burn

[Click here to read more.](#)

PAIN FROM RADIATION BURN

Pain – Radiation Burn

Change neck dressings regularly.

Splash lukewarm water on the area.

Apply moisturizer regularly.

Wear sunscreen on burned areas whenever you plan on being outside for more than a few minutes.

If you are in a lot of pain, make an appointment to see the doctor.



PAIN FROM RADIATION BURN

Should I put cream on my neck before my radiation session?

You can and should apply cream to your neck continually throughout the day except for the 4 hour period before your radiation treatment.

Studies have shown that the cream would need to be a quarter of an inch thick to affect the beam's scatter.

The beam would still be effective in reaching your tumor, but the surrounding neck skin would receive more of the scatter

Do not use creams with zinc oxide as this may inadvertently lead to more irritation on your skin.



Fatigue

[Click here to read more.](#)

FATIGUE

Fatigue

Fatigue can be pretty bad this week.

Get LOTS of rest and don't push yourself!

Eat a nutritious diet to help reduce fatigue.

Try eating small snacks if you cannot finish a meal.

If you can only tolerate liquids, make sure you are getting enough calories and protein every day.



Nausea

[Click here to read more.](#)

NAUSEA

Nausea

Nausea may become especially bad the next couple of weeks.

If you have trouble keeping medication down, try crushing it up in apple sauce or custard.

Avoid using caffeine, alcohol or tobacco.

Try natural solutions to nausea such as drinking lukewarm water, cool thyme or chamomile tea.

Sip Ensure/Boost slowly.

Try smaller servings (1/4 or 1/2 can) throughout the day.



Mucositis

[Click here to read more.](#)

MUCOSITIS

Mucositis

Gargle with baking soda solution.

Use oral rinses/gels throughout the day (talk with your doctor about getting samples).



Dry Mouth

[Click here to read more.](#)

DRY MOUTH

Tips for Dry Mouth

It may continue to be a problem for a year or longer, but don't let that discourage you.

Keep water with you whenever you can.

Oasis spray/Biotene products are helpful.

Chewing sugar-free gum can help to relieve dry mouth.



Reminder: 6 Month Follow Up

[Click here to read more.](#)

REMINDER: 6 MONTH FOLLOW UP

Reminder: 6 Week Follow Up Appointment

Your next appointment will probably be the 6 week follow up with your oncologist.

Begin thinking about some questions and writing them down. Then, when you get to your follow-up, you'll be ready and the doctor may address your concerns right then.



What do I do now?

Remember, it's normal to be feeling bad.

It is normal to not have any taste.

Caregivers need rest and support too.

Go easy on yourself. You need time to recover.

It may be hard, but try to keep doing your swallowing exercises.

Refer to the quick tips for pain, nausea, and dry mouth.

You need at least 8 cups of water every day to avoid hospitalization.

If you are on pain medicine, keep track of your senna schedule and bowel movements.

See your local doctor and jot down questions for him/her as well as for your cancer team.



Patient Stories and Tips to Encourage You

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

PATIENT STORIES AND TIPS TO ENCOURAGE YOU

“I kept telling myself that my taste would eventually come back. I tried coconut cream pie 5 or 6 times, and every time it was bland, but I just kept trying everything else.”

“Be proud of every little thing you can do.”

“You got to manage your diet even if you’re not hungry.”

“You have to make up your mind – you’re stronger and tougher than it is.”

“You got to make up your mind you’re going to beat this”

“You know what your own limits are. Do a little bit. You don’t need to do it all.”

“I just kept telling myself “I’m going to survive this. I’m going to be ok. And now, 5 years later, I am. I’m playing ball with my sons, I’m mowing my grass, I’m working again.”

“I told myself there is an end to this.”

“One of these days is none of these days”

“Set little goals during the day like folding towels. Be proud of getting up and accomplishing little tasks.”



Former Patients

Patient Quotes and Tips

“Another challenge I faced going through radiation was difficulty swallowing because of pain and mucus.

I couldn't believe that my body could produce that much mucus. It really was a challenge to clear it out so that I could swallow food. I would swallow so much mucus that I got nauseated, and there's just nothing worse than throwing up. Everything I did was to try and keep from having to throw up.”

Former Patient



PATIENT STORIES AND TIPS TO ENCOURAGE YOU

Patient Quotes and Tips

Macho Story

“Coming from the military, I felt a little bit macho going into this and it was hard for me to ask for help. It’s still hard to admit when I’m having problems dealing with something. But, the fact of the matter is that you can be so macho that you can send yourself to the grave. So don’t try and tough things out. If there is a pain response or if you need some help, then get the help that you need. Don’t try to tough this out thinking, ‘Oh it’ll get better on its own.’ The fact of the matter is, it won’t. And you can actually do some permanent damage to yourself if you don’t get help.”

Former Patient



Jake's Story

The first thing I wanted to know after I got diagnosed was, am I going to live? Although no one can answer that question with certainty. They might say that your chances are quite good, or that you will probably live, but there are never any guarantees. What I wish I could tell patients is, they may have to burn the hell out of you with radiation, but you will eventually recover from it.

I will never forget what radiation was like. I lost my taste, everything tasted like Kleenex or wet cardboard. I remember saying to myself, “is there anything I can taste?” and I tried everything in sight, and the only thing that worked was cherry Kool-

Aid. I still have little packets of it everywhere around my house. I don't even like that taste now, but at the time I remember saying to myself, “I can taste this! I can taste this!” One night, about a month after radiation was over, I dreamt of green beans. I woke up and asked myself, I wonder if I can eat that? I stumbled to the kitchen, opened up a can of green beans and I could taste it! I ate the whole can right there, like a starving man.

It's been 14 months now since my diagnosis, and in the last two weeks, with the weather being so mild and cool, I've put over a 1,000 miles on my motorcycle. I can eat everything; I'm eating like a hog now. I look back on



that time in my life, and I can't believe how difficult it was. I did go to all of my radiation. That last week, I really wanted to skip the last treatment. My neck was so raw, and I felt like I was too sick, but I did go. I did all of my swallowing exercises, even the complex ones, and I did my dental work to a T. I don't see why anyone wouldn't. If someone were to tell you, “do these exercises, they will help you have a normal life after this is over,” then why wouldn't you do it?”

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Altered Taste/Dysgeusia

- Strategies to help you (week 3)

A note to caregivers (weeks 7 and 9)

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- 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)

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- Strategies for dental care (week 2)

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- Introduction (week 1)

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Importance of hydration (week 1)

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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)

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- Products for dry and radiated skin (week 3 and 7)
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Patient Stories

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- Difficulty swallowing due to pain and mucus (week 9)
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Index of Topics with Week Numbers

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- Managing constipation (week 2)
- Medications that cause constipation (weeks 2 and 4)
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Program Wrap-Up: Managing your health

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- Explanation of thrush (week 3)
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- Explanation of dry mouth (week 3)
- Products for dry mouth (weeks 3 and 7)
- Strategies to combat dry mouth (week 3)
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- Don't stop your exercises now!