

Tim's Tips

for Children and Teens with Thyroid Cancer

Part of the Pediatric Backpack Project

Created in 2007 by Tim C. of Maine, a Teen with Thyroid Cancer

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Distributed free of charge by

ThyCa: Thyroid Cancer Survivors' Association, Inc.SM

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Disclaimer: This packet and all contents of the backpack are intended for informational purposes only. I have no medical training. I am not engaged in rendering medical advice or professional services. The information here should not be used for diagnosing or treating thyroid cancer or any other health problem or disease; it is not a substitute for professional care. Always consult your medical doctor.

The Pediatric Backpack Project

Hello, my name is Tim,

It was my idea to assemble this backpack for you. I want you to know that I was really surprised how many people really wanted to help with this project. Being a part of my project made it possible for them to help you as well.

I also want you to know that in January 2005, I too was diagnosed with thyroid cancer. Because of this I have already gone through what you are probably going through now. I know the procedures may seem endless, and the diet is harder than most people think. However, if you take it one step at a time and focus on what is next, it will all seem a little easier!

I really hope you like this backpack. I have tried to put in things that I thought would make this a little easier for you and your family.

With Best Wishes for a quick recovery,

Tim

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1. BEFORE Your Treatments

PLEASE START HERE!!!

Hello! My name is Tim and I'd like to share information from my experience with papillary thyroid cancer. I hope it will help you and your families get through this experience more easily. Your experience may be different from mine. If you would like further information, please e-mail ThyCa's Pediatric Support Group Coordinator at pediatric@thyca.org.

Here are some things I learned about thyroid cancer:

- Thyroid cancer is a cancerous growth or tumor in the thyroid gland.
- The thyroid gland is an endocrine gland that's shaped like a butterfly at the base of the neck.
- Thyroid cancer is one of the few cancers that is becoming more common, especially in adults. It's the most common type of endocrine cancer. There are several types, but the four main types are papillary, follicular, medullary, and anaplastic. Papillary and follicular are the most common.
- Thyroid cancer occurs in all ages, but mostly adults. Thyroid cancer in kids is rare. The resources and web sites listed with the mailed packet have a lot more information available!

MY STORY

For me, it started with a check-up at my Doctor's office when I was 12. He found a lump when he checked my neck. Then I had blood tests and found that I had low thyroid function or hypothyroidism. This was news to me and my family!

I had to take medicine to help my thyroid function, but the lump kept getting bigger. So, they changed my dose, but it still kept getting bigger.

Next, I had an ultrasound done. It was like rubbing a microphone and cold jelly all over my neck while they took pictures and measurements.

I also had a needle biopsy, which to me was the worst part. They took out some tissue from my neck with a very small needle. They didn't let mom stay, but they were nice and talked me through it. It was kinda scary and hurt, but I got through it all right and so will you!

These tests helped my doctors decide I had thyroid cancer and that I would have to have surgery and radioactive iodine treatments to fix it.

There are other tests and treatments, depending on in part what kind of cancer is found. Your doctor will decide the kind of tests and treatments that are right for you.

THE HELP DESK

This affected everyone close to me. They wanted to help but didn't always know how. By helping me, it helped them, too.

Here are some ideas of ways to help out:

- Go to appointments for support & extra ears... it was a lot to hear and try to learn at one time! It was also helpful to take notes, which was ok'd first by my doctor!
- Cook for us. Grandma made all of my bread & kept me well supplied in cookies!
- Make ahead recipes or meals & freeze them for when you are really on the diet.
- Let someone search the web sites listed through www.thyca.org, to filter out what you don't really need to know or worry about.
- Help find low-iodine items or recipes.
- Make phone calls for us to tell family and friends what is going on.
- Send flowers, cards, or small gifts.
- It's OK to talk about thyroid cancer with us; we are all a little worried!

2. DURING Your Treatments

THE BIG PICTURE

I don't want to make it sound like my path through this will be the same as anyone else's. It will be different for everyone.

If you want more info on stuff you read here, there are more details in the specific topic sheets in this section.

To make it more interesting, I used cooler names rather than just calling the info sheet "surgery," for example, but to make it easier, I'll list some here:

- The Cutting Edge: surgery
- Kid's Menu: diet tips that worked for me
- Got That Healthy Glow? Radioactive Iodine
- My Two-Day Vacation: isolation afterwards

If your experience is anything like mine was, that is the big picture. Once I was diagnosed, I had surgery and a recovery period for that, then the diet, the radioactive iodine, a couple of days of isolation and some tests. That's it, but then again, that's enough.

Don't worry; if you take it one step at a time, it's really quite do-able. We always just tackled the next step and kept focused on it while we got through it!

You can also have your family sign up for the Pediatric e-mail listserv at www.thyca.org to get more info and share stories with others who have already been through this. It's a good way to feel like you are not going through this all alone!

THE CUTTING EDGE

My surgeon did another ultrasound. He told me on the spot that I had thyroid cancer and I would have to have an operation to take my thyroid out.

I couldn't eat or drink the night before my surgery, but that was easy for me as mine was first thing in the morning! They prepped me for surgery, and I got an IV. That's a needle in my hand for different meds for both the surgery and afterward.

I got a drug to relax me.... boy that worked! I don't remember anything after that! Later I was told that I was in recovery a couple hours, and I threw-up while I was there, but I don't remember it!

The next thing I knew I was back in my room. I had some visitors that I talked to some but don't remember because of the meds.

The worst part was after the catheter came out. The first couple times it “burned” a little when I went to the bathroom.

I spent one night in the hospital. There were little strips and a bandage on my incision. When it closed, I put vitamin E on my scar to heal better. I also had a couple follow-up visits with my surgeon.

I wore turtlenecks for a little while after that but not for too long. Kids at school thought it was cool... and get this, even some of the girls!

LET’S GET COOKIN’ !!!

Before I had radioactive iodine (often used for my type of cancer) my doctor told me I had to follow a low-iodine diet for a while. This diet would help eliminate as much iodine from my body as possible. When my body was low in iodine, it could absorb the radioactive iodine better. Hopefully this would make my treatment more effective.

This is different from a low-sodium diet. The sodium isn’t really the problem; it’s that salt can be iodized. And most processed foods have salt in them. Unfortunately, you don’t have any way of knowing whether they are made with iodized or non-iodized salt. Sea salt and things from the sea also tend to be high in iodine. So were other foods my doctor told me about.

We started eating foods with less iodine before it was time to really go on the diet. This helped to know what foods we liked & made it easier for all of us once I HAD to be on the diet. To support me, my whole family followed the diet!

We also experimented early with different recipes. It was less stressful when we were only practicing. It was also a good time to start looking for things like no-salt ketchup, peanut butter, pasta, and non-iodized salt. There are more ideas in the next diet section, too!

KID’S MENU

My favorite food was what I had last, Shish-ka-Bobs. It was great! Another favorite was Smoothies; I mixed juice with fruit & ice in a blender. Too bad it was winter when I was on the diet; those are cold!

We made nacho chips out of corn tortillas cut smaller and deep fried. Salsa made from scratch was great! I used ThyCa’s recipe for mayonnaise, but it was better without paprika.

We had a lot of salad, with croutons from the salt-free breads my Grandma made for me.

We got no salt/no-yolk pasta & made spaghetti sauce and froze it in smaller portions. Meatball subs were good too! My no-salt yeast bread was also made into rolls!

I LOVED the chocolate cake recipe ThyCa had; and added powdered sugar to each piece!

There are lots of food choices available. The backpack has a cookbook from ThyCa: Thyroid Cancer Survivors' Association and a different one from Light of Life Foundation. You can also try the Low-Iodine Diet "LID for Kids" compliments of Melissa L. on the ThyCa web site.

You can also get extra copies of the ThyCa cookbook for others free by downloading it from their website, www.thyca.org like we did!

GOT THAT HEALTHY GLOW?

Radioactive Iodine treatment is a big part of treatment in the papillary type, like I had. Thyroid cells hold iodine and use it to make hormones that we need. Cancer cells act like thyroid cells. With my thyroid gone, doctors are able to test to see if there was any residual cancer.

Think of a dry sponge, ready to soak up water. The diet makes any remaining thyroid tissue crave iodine, and like the dry sponge the tissue is then ready to soak up more of the radioactive iodine! The radiation then destroys any thyroid tissue left and hopefully destroys any more thyroid cancer cells with it.

All the details of my treatment were decided by my doctor. I just went to the doctor's office, but many people get their treatments in a hospital. I was alone in a special room, opened a lead lined canister and took out a vial. I read the label out loud to my doctor to make sure the pill was mine before I took it. The doctor stayed back from me as he is around this a lot.

It seemed like a big build up to just simply swallow a pill, but I for one think simple is good!

MY TWO-DAY "VACATION" AT HOME

Many people stay in the hospital for this, but I was at home. Either way, this is the boring part.

During this time, the doctor had people stay away or limit time with me. My parents could visit 10 minutes each hour but 10 feet away. My brother couldn't get close the whole 48 hours! I had to use my own bathroom and flush twice.

I had a setup with a microwave, cooler, food, and paper goods. I kept laundry and trash separate from my family's. Because of my particular dose, I had to throw away my

toothbrush after the first day, & another one after the first week. Radiation comes out in body fluids, so we had to throw out or wash everything I used when I was done isolation.

I had a TV, VCR, DVD, Game boy, and an Xbox set up in my room. I used a walkie-talkie or a cell phone to talk to others to help pass the time. I had music, cards, and books to keep me occupied. Mom and I even played chess and Battleship (with the paper removed) over the walkie-talkie.

Even so, it was pretty boring. I slept a lot, and even got out of some school and homework... That was the best part!

3. AFTER Your Treatments

TIME TO CRASH THE DIET

After the diet, radioactive iodine treatment, AND two days of isolation, it was finally time I could eat “anything I want...”

I’d been planning for this a long time, ever since we started “practicing” before I even had to start the new diet.

There were many options I thought about, lots of my favorite foods to pick from, but I had it all figured out! But please take my word for it, be careful! You’d better take it slow and easy! (I wish someone had warned me...)

First, I had a big breakfast with whole eggs, sausage, AND bacon, and I loved every bite.

Later we celebrated with dinner with my family & friends at my favorite pizza place. That was a mistake! By the time I got home, I felt awful because of eating all that salt at once.

Since Dad and my brother cheated on the diet when they were not at home, they didn’t even notice it. But Mom and I both felt it, eating too much salt too fast. If I had to do it over again, I would start back slower.

A few people suggested we stay on the diet since it was healthier and we were used to it anyways... well, I wouldn’t want to go THAT far!!

THE NEXT STEP

Just because I was through my surgery and radiation and I was off the diet, I was NOT really off the hook....

It seems like I am always at some lab or doctor’s office, but really, it’s not that often. It just seems like it, since I didn’t need to go to see the doctor much at all before all this happened.

Once we were back on a regular diet the only thing we had to do was follow-up tests like blood tests and a total body scan, but not everyone has this test!

This was pretty cool. They had to time the radioactive iodine just right so that there was a specific time between the radiation and when we were able to get a body scan. This test let me doctors know if there were areas left of either thyroid tissue or cancer cells.

For me, it was only my neck and chest. I had to be very still on my back, and the machine slid me into the part that did the scanning like sliding in a drawer, only a lot slower.

There was a lot of clicking and humming noises, but except for having to remain very still while they did the test, it was easy.

A NEW DAILY ROUTINE

Once my doctor found a lump in my neck because I had a problem with my thyroid, I had to take a pill to support its function.

Since then my dose has changed a lot. I have grown quite a bit and with the surgery I went from having poor thyroid function to NO thyroid function.

My doctor prefers that I take the brand name of my medicine and stay on the same brand.

A few things I have learned are:

- Follow all instructions I have been given. I need to take my thyroid medicine on an empty stomach and at the same time every day. I'm also supposed to drink an 8-ounce glass of water with my medicine.
- We found it helpful to set up a couple of 7-day pill boxes to be sure I didn't miss any doses of my medicine, and so we knew when we needed to get it refilled. There are 2 included in your backpack if you want to use them too!
- You should also check out the "Know Your Pills" that's in the ThyCa information packet and on its web site.

TESTS YOU DON'T STUDY FOR!!!

One of the things about Thyroid cancer is that the doctors will have to monitor me now for the rest of my life.

Most of the follow-up tests are the same ones I had before they decided I had thyroid cancer in the first place.

Since I've been through most of this already, now I'm just about a pro!

The type and severity of Thyroid cancer I had, among other things, will decide which tests I'll have and how often.

Testing tends to be more frequent for kids than adults since our needs change as we grow.

As time goes on, the amount of testing I'll have to have will probably become less.

Tests used to monitor my condition:

- Physical examination
- Neck check
- Blood tests
- Ultrasound of the neck region
- and maybe other tests if I need them.

That's okay, I'm not gonna study for any of them anyway!

STICK YOUR NECK OUT...

After you go through all this, both you and your family will be very knowledgeable about the things you went through. You'll relate better when other people are going through a similar situation.

Maybe you can find a way to reach out and help others since you've been through it too.

Maybe you can be part of a support group in your area, find events that help raise awareness, or help raise money for organizations that are researching better treatments and trying to find cures.

See what's out there, decide what interests you and do it!

That's what I am doing, and why I am also offering to help even more if you would like to contact me through e-mail. Contact ThyCa's Pediatric Support Group Coordinator at pediatric@thyca.org.

Remember when I said that when my family and friends were helping me, it seemed to help them?

It works the same when the survivor gets involved!