

**Despina's Helpful Hints**  
**by Despina Spencer**

**Editor's Note: Despina has kindly contributed her wisdom and experience to this article.  
As Despina notes, please be aware that treatment and doctors' recommendations vary.**

In October 2007, I noticed a peculiar lump in the front of my neck. After both ultrasound and biopsy came back indeterminate, I decided on a partial thyroidectomy in hopes that the nodule was benign. Unfortunately, it was malignant and I underwent a completion thyroidectomy two months later. This journey has certainly been a tough one, with twists and turns along the way. I have learned so much, and these helpful hints were written in hopes of helping others with their thyroid cancer journey, just as I have been helped along the way with the kindness, knowledge and support of Thy'vors members.

\*\*\* Please remember that these are only my experiences and suggestions, and in no way should they replace your medical care! \*\*\*

Medical Appointments

- Ask for copies of all results, biopsy, blood work, pathology, whole body scan (WBS). You have every right to copies of your results. Keep all your records in a folder.

Research and Education

- Although information on the web is plentiful and informative, sometimes it's also misleading. I found that searching the internet for information almost always upset me. Research thyroid cancer and educate yourself as much as possible, but be careful not to jump to any conclusions or worse, self diagnose – leave diagnosis and prognosis to the doctors!

Biopsy

- Some biopsies are done in the endocrinologist's or surgeon's office; others are done at the hospital with a local anaesthetic. However, I found that this procedure was not all that painful. Mostly it just feels like a needle with some pushing and pulling. There will be a few samples taken, with a new poke each time.
- Papillary cancer can usually be diagnosed with a biopsy, but many biopsies come back indeterminate or inconclusive. In this case, the doctor will suggest watchful waiting with another biopsy in a few months' time, or a surgeon may discuss surgical options. This is the route I took. I had a partial thyroidectomy and when the pathology showed papillary cancer, I had the completion thyroidectomy two months later.

Diagnosis & Anxiety

- I found that NOTHING can prepare you for a cancer diagnosis. Although you will hear that thyroid cancer is the "good cancer" many times, with a good prognosis in almost all cases, you may still feel completely shocked.
- Give yourself time to "grieve" and accept your diagnosis.
- When my spirit was shattered, I found relying on my friends at Thyroid Cancer Canada (Thy'vors) most comforting. Receiving support from someone who knows exactly how you feel is irreplaceable.

- I called Wellspring<sup>1</sup> a few times as well. Although I never actually made it into a centre, I still plan to. The phone support, I will say, was fantastic and it lifted my spirits. I can imagine that in person support would be great too!
- Remember that friends and family are most likely shocked too, and don't be surprised if they "don't know what to say".
- However, absolutely accept all help that is offered. Diagnosis may come before surgery or after, but either way, you may be exhausted and stressed and should concentrate on getting well, not cooking dinner or cleaning the house!
- Even after you feel good, depression, anxiety and stress may rear their ugly heads again. I find that I'm constantly on a roller coaster ride of emotions, up down and all around. Lean on those around you, and don't be afraid to seek professional help, including medication, if needed.
- My children were surprisingly not terrified when I told them I had cancer. I explained that I was going to be busy with surgery and treatment, and that there would be times when I couldn't do everything I wanted to do with them. They were far calmer than I expected them to be, and certainly not at all traumatized. The key for us was open communication, honesty and reassurance.
- A thyroid cancer diagnosis means a lifetime of appointment and follow up scheduling. I found being upfront with my employer about this helped a lot. I simply explained that I would need time off - perhaps weeks at a time for RAI, or just hours for Endo appointments - and asked for their understanding.

#### Thry'vors -- Thyroid Cancer Canada's Online Forum

- Just a little bit more about being part of an online support group. I have never belonged to a forum before. I didn't understand how it worked (technically) and initially was afraid to pour my heart out into the web.
- However, once I did, I opened myself to a world of kindness, support and even love that I never could have imagined. I was honest with my posts (sometimes crying while typing, other times laughing while typing) and found that the responses were just as heartfelt.
- To me, Thry'vors is like a group of friends, coming together to offer support and comfort at times when the road seems long and dark. We often even laugh together!
- As a forum moderator volunteer, I have found that some people want "just the facts" and others want a shoulder to lean on. Whatever one's needs, the Thry'vors Forum members have a wealth of information and hearts of gold.
- "Giving back" with Thry'vors has been far more of a reward than it has been a challenge. I truly love helping others. If I could relieve one person's fear and anxiety in the least bit, then it's all worth it.

#### Surgery

- Don't be surprised if you are nervous about surgery – although thyroid surgery is not high risk, all surgery has some risks and with that fear comes stress. Just try to relax as much as possible pre-surgery, and spend lots of times with loved ones.
- If applicable, explain to your children in simple terms what is happening, and you'll feel a sense of relief once everyone understands. Also, having a plan in place for the kids helped me feel more relaxed, knowing they were well taken care of while I was "out of commission".

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<sup>1</sup> Wellspring Cancer Support Centres offer support of various types in Canadian locations. To view their locations see [www.wellspring.ca](http://www.wellspring.ca)

- After being horribly ill from the anaesthetic from my first surgery, I asked for anti nausea meds in my anaesthetic the second time around – you do not want to be vomiting after neck surgery
- Bring V-neck jammie tops to the hospital – you don't want to be wearing anything near your incision

### **Suggestions for preparing for your hospital stay:**

1. **Prepare.** Stock up on easy-to-prepare foods and comfort foods for your return home after surgery.
2. **Find a driver.** Make arrangements for someone to drive you home.
3. **Lighten your workload.** Make arrangements for a babysitter, dog walker, etc. Be aware that it may take a few weeks to resume your employment.
4. **Use a special pillow.** A 'dog bone' or curved pillow may be helpful. Some people find these pillows comfortable during to support the neck during recovery time. Others use hot or cold packs to minimize the swelling.
5. **Pack for the hospital stay.** You may need: medications, curved and/or regular pillow, toiletries, slip-on slippers, rope and sleepwear (pyjamas or nightgowns that open in the front).
6. **When you are released,** keep track of the notes and prescriptions given to you. Eat soft high-fibre foods. Don't sit hunched over.
7. **Minimize your scar.** Follow your doctor's instructions for keeping your incision covered and or the use of ointments.
8. **Rest.** Recovery usually takes several weeks.

### Hypoparathyroidism

- Your parathyroid glands are four tiny rice sized glands that are solely responsible for the calcium regulation in your body. They are very delicate glands that may become "stunned" or damaged during neck surgery.
- Temporary hypoparathyroidism is a common temporary complication of thyroid surgery, with function returning usually within a few weeks to a few months. Permanent hypoparathyroidism is very rare.
- Your calcium levels will be monitored after surgery, as low calcium is a sign of parathyroid stunning or damage. If you feel any facial tingles or numbness in your hands and feet, let the nurse know immediately as those are also signs of the effect. You may need additional calcium. This may delay your release from the hospital by a few days.
- If you do have temporary or permanent parathyroid damage, you will need to take prescription vitamin D (Rocaltrol) or over the counter vitamin D and calcium several times during the day until your parathyroids start to work again.
- It is important that you have weekly or biweekly blood work done during this time, as you need to stimulate your parathyroids into working as soon as you show some parathyroid hormone in your blood tests. Your endocrinologist will adjust your intake of calcium and vitamin D because if you remain on high levels of calcium and vitamin D unnecessarily, your parathyroids could become lazy -- you want them to start to work again, slowly and patiently!
- Do not adjust your medicines without your endo's approval

### Incision

- Keep your incision clean and dry.

- Steri strips will either come off on their own or your surgeon will remove them at your post-op appointment
- Ask your surgeon how to care for your incision. I didn't use anything prior to the steri strips (and stitches) being removed. I then started using Bio-Oil every morning and night, gently massaging the area in a circular motion for a few minutes during application
- ALWAYS use sunscreen on your incision. Carry a lip balm with sunscreen in your pocket for midday application.

#### Choosing a Surgeon / Endocrinologist

- Don't feel obligated to go with the first doctor that you are referred to. You have to feel very comfortable and confident with your specialist. Go armed with a list of questions, and don't leave until they are all answered.
- Someone suggested faxing your questions ahead of time, so that your specialist is prepared for them.
- Or, instead of faxing, you could bring 2 copies of your written questions to your appointment so that you can go through them with your doctor.

#### Staging

You may want to use the following link from the American Thyroid Association to help you better understand your thyroid cancer 'stage' and general prognosis (see Table 4):

<http://www.liebertonline.com/doi/pdfplus/10.1089/thy.2009.0110?cookieSet=1>

- However, don't forget that having thyroid cancer means a lifetime of follow up, with no room for errors. If thyroid cancer recurs, you want to know about it right away so that it can be properly and immediately treated.

#### Low Iodine Diet

- Thyroid Cancer Canada recommends that patients stay on the LID for two weeks, although some research indicates that one week is sufficient if they are absolutely strict!
- The LID is not that difficult, it's actually more like the way we SHOULD be eating. Lots of fruits and vegetables, small portions of meat, homemade breads, no fast food...MOST find that they even lose a few pounds. I however, gained a pound!
- Prepare as much as you can ahead of time – you don't want to be hypo and hungry or cooking all of your meals from scratch. Even if you are using Thyrogen for your ablation, LID is much easier if you have plenty of meals prepared ahead of time.
- Utilize the ThyCa cookbook (you can download it for free at thyca.org) and recipes from the TCC website or TCC Online Forum files
- Ensure all salt used clearly states "not a source of iodine", otherwise, do not use it!
- Read every label carefully
- Have your pharmacist check the medicinal ingredients of your supplements and medications
- Remember, when in doubt, leave it out!

#### Radioactive Iodine

- If you are at all doubtful about RAI treatment for your thyroid cancer, please consider a second opinion
- If you go hypo for your treatment, ensure TSH is tested prior to RAI administration to confirm that TSH is high enough for RAI to be effective.
- To read about my SPECIFIC experience at Credit Valley Hospital in Mississauga, read my Thy'vors Online Forum message #27528, which is copied below.

- I received an RAI is 100 millicuries(mCi), which is quite a standard dose. This is the minimum dose when Thyrogen is used. Higher doses (up to 300 mCi) are not uncommon.
- I was given my RAI dose (a pill) and then left alone for three days in a hospital room. However, some facilities have an outpatient RAI program and will send you home.
- After plenty of research about whether one should drink water post treatment, I drank just slightly more than normal amount of water. You want to drink enough to be peeing quite regularly, but not too much so that your flush the RAI out of your system before it has a chance to do its job!
- See below for a copy of my Thy'vors Online Forum message #27565, a list of suggested items to bring to the hospital, including food. Check the policies with your hospital to confirm what you can and cannot bring into your hospital room.
- I stayed on LID for 48 hours after RAI was administered – ask your Doctor for their specific recommendation
- If you bring your own food to the hospital for your isolation period, ask the nurses to not bother you with food for the time while you will remain on LID – the food they bring you is NOT LID and it will only stink up your room.
- I did not have any nausea or pain or salivary gland issues.
- My teeth / jaw were a little achy, and my throat was quite dry.
- My biggest complaint was boredom and sadness from being isolated.
- My children were able to stay with my parents for 10 days. Although I thought they would suffer severe separation anxiety, rather, when it was time for our reunion, they asked if they could stay a few extra days at Grandma and Grandpa's. Children certainly are resilient and adjust well!

### Thyrogen

- There is still some debate regarding whether Thyrogen is acceptable for ablation, however, my Endo completely supported its use and I'm so thankful, and I cannot imagine going "hypo" with everything else that I was dealing with (two surgeries, diagnosis, HPTH.)
- Take your Thyrogen prescription to your pharmacist well in advance of your injection appointments, and discuss how far in advance it should be ordered (it is expensive and so most pharmacies do not keep it in stock)
- Thyrogen is available in packages without sterile water. If your package does not include sterile water, ensure the pharmacist orders two viles of sterile water for you. These usually cost between \$2-\$10 each.
- I was told to keep the Thyrogen refrigerated, and travel with an icepack to ensure the Thyrogen stays at the proper temperature of between 2 and 8 Celsius.
- My injections were given in alternate butt cheeks, one day apart at the approximate same time each day.
- Most extended health benefits of private medical insurance cover the cost of Thyrogen, or a portion of Thyrogen (if your province doesn't cover the cost). Call the Genzyme Support Centre for assistance with this.
- Most provinces cover the cost of Thyrogen. If you do not live in a province that covers the cost, or have private medical insurance, you will have to pay about \$1,600 for Thyrogen.
- Please see Thyroid Cancer Canada's Information Sheet on Thyrogen for cost-coverage information.

### Whole Body Scan (WBS)

- The WBS is a procedure that follows ablative or diagnostic doses of RAI. The procedure takes between 40 minutes and an hour and is not painful at all.

- I am claustrophobic so I took an anti anxiety medication sublingually immediately before the procedure.
- I kept my eyes closed, but when I did take a tiny peek, I was alarmed to see how close to my face the machinery came (a few centimetres!).
- After the procedure, the technician will review the pictures and may ask to repeat an area. Don't be alarmed if this happens, as it happens often.
- Also common is being asked to come back in a few days once the RAI has passed through your abdomen more thoroughly, for another scan.

In September 2008 the results of my whole body scan came back "clean", with uptake only in the thyroid bed. What a huge relief! However, I know that my thyroid cancer journey will not end any time soon. Regular checkups and continuous follow ups will be a part of my life. I try to hold onto the fact that whatever may come, I am strong. I have an amazing support group of family, friends, and online friends, who will help me along this sometimes bumpy road. I hope these Helpful Hints helped you with your bumpy road. And don't forget to pay it forward!

Thy'vors Patient Resources available at [www.thyroidcancerCanada.org](http://www.thyroidcancerCanada.org):

[Patient's Guide to Thyroid Cancer](#)  
[Thyroid Cancer Resource List](#)  
[Low Iodine Diet Pamphlet](#)  
[Thyrogein Information Sheet](#)

[Despina's Message #27528 posted to TCC-Thy'vors Online Forum \(updated Jan 2010\)](#)  
[RAI at Credit Valley Hospital \(Mississauga\)](#)

I made it - I'm home - YIPPEE! HaPpY DaNcE!

Here is a bit about my experience:

I arrived at the hospital at 10am on Friday morning. Had bloodwork (TSH, thyroglobulin and anti tg?) and then went to the Emerg Dept to be admitted. After that, I was off to Nuclear Medicine, where they did a short Information Session, where they reviewed the protocols for when I was in the hospital and for once I left.

I was shown my room and asked to change into a gown. I said good bye to my husband (and of course, the tears started flowing). Dr. Cheng arrived at 12:30pm and we reviewed the procedure. . She opened the lead container; I reached in and took out the little plastic bottle containing the RAI, popped it in my mouth and swallowed it down. She took a measurement with some box like meter, mumbled something like "11", said "have a good weekend", and closed the door behind her. (more tears follow - and I often thought of the poem RADIOACTIVE TEARS that someone recently posted)

Thank God for the "have someone that you love write you daily letters" idea, because I had four letter to read (my two sisters, my best friend and my husband) for each day I was "locked up". What an incredible suggested, as these were surely the best part of my four days in isolation.

I did not feel anything when I took the pill. I immediately started drinking water, but not TOO TOO much. I was happy if I was peeing once an hour the first day. A bowel movement was also necessary to have the first 24 hours - otherwise they tell you to buzz the nurse for a laxative. (sorry if this is too much information)

On Friday night, I couldn't sleep, so I took half an Ativan. I've never taken one before and didn't know what to expect. It did nothing for me. I'll have to remember to take a whole one before my WBS, because half did absolutely no good - I was awake pretty much all night. I slept a bit better Sat and Sun - but not much.

The meals (one of which arrived immediately after the door was shut) were not LID at all. Milk and cream soup and a cheese block - no thank you. I told the nurse to please not give me any food at all until Sunday as I didn't want it stinking up my room - all food stays in the room with you, albeit they give you a plastic container with a lid for food scraps. I just ate my food from home and drank my water.

I read my books, wrote in my journal, watched tv, did Soduko puzzles, and talked on the phone. B O R I N G. My God it was boring. I also got quite claustrophobic in that little hospital room which was made smaller because of the shower stall that was installed beside the bed. There was a window that overlooked the garden, but no one was ever out there to wave to! No one came in my room, and the nurses opened the door twice on Sunday just to pass me my food - that's it. They did call maybe once or twice a day to ask if I needed anything (Yes - to get outta here!!!) but I had no human interaction other than the phone.

All I felt was bored. A couple of times, the water tasted funny (maybe a bit metallic) and maybe once or twice my stomach was a bit upset for an hour or so, but otherwise, I felt nothing.

At 8am this morning (Mon), the nuclear medicine tech came in and took my reading and told me I was free to go, but my husband (who I told to be IN THE HOSPITAL at 7:30am!) was nowhere to be found - argh!!!! I used the time to clean up the room (put everything in the big bin labelled RADIOACTIVE) and watch more (gag!) Olympics. He showed up at 8:30am and I changed into clean clothes and shoes (that he brought with him) and I was outta there. OMG - I cannot tell you how fantastic it was to breathe in fresh air. I sat in the back of the car (two rows behind him) with all the windows open and my hair flying around like crazy!

I still feel fine, except maybe my throat is a bit dry this morning. I have to remember to continue to drink plenty of water. I am not sure if I can expect any side effects to start now (three days later) or at a later time, but if I feel anything, I'll be sure to ask you all!

I am all alone at home (hubby and kids are at my parents being spoiled no doubt)

until Friday. Hubby comes home then and is taking me to my WBS (wish me luck!) and then kids come home Monday (God, I miss them soooo much!) I was told that all safety procedures end this Friday (one week post RAI) but I'm going to have my husband sleep in a separate bed until Monday anyway, when my kids get home. I'm going to use this time to relax and sleep and enjoy being home. I'm going to sit outside and enjoy the beauty of nature. I'm going to enjoy being spoiled by my family and friends (who promise to bring me anything I'd like - and I assure you, after two plus weeks on LID and this entire ordeal, which I know isn't quite over yet - anything I'd like? the list goes on and on...mmm....pizza and ribs and coffee with cream and fruit with whipped cream and cheesecake and quesadillas!!!) Needless to say, I'll gain weight this week and I don't care!!!! I did do some soul searching while I was alone, and found myself quite worried about the long term side effects of RAI. However, I've decided that (after this week) I'm going to lead a completely healthy lifestyle. That means, being as stress free as possible, lots of exercise, healthy eating (which I'm pretty much accustomed to, with my parents who think boiled greens with beans is a delicious meal) and of course, lots of love and laughter.

I feel like crying because it just feels sooo good to be home. But I've cried enough this weekend, and now, I'm off to the backyard with my new book "The Secret" to enjoy the beauty that surrounds me.

I cannot thank you all for your kind words and best wishes (okay, now I am crying). You have been so wonderful to me, and I know, that your kindness has made all the difference.  
Despina

#### Despina's Message #57565 RAI Isolation Packing List

Hi,

**For those preparing for RAI**, I thought I'd prepare a list of things you may want to take with you to the hospital:

#### **Clothing** (that you don't mind throwing away if need be):

- \* bras (sorry men!) and underwear
- \* slippers
- \* pillowcase, sheet and pillow
- \* comfy clothing (unless you don't mind hospital gowns for three days)
- \* discharge clothes to be put on after you shower the day you are discharged (I had my husband bring my already prepared bag with him when he picked me up on Monday)

**Food** (remember, you should stay on LID for 24 to 48 hours after the RAI dose is administered) - here are some things that I brought with me in a Styrofoam cooler:

- \* ginger ale
- \* water
- \* rice cakes, rice crackers
- \* unsalted nuts
- \* dried fruit
- \* fresh fruit

- \* fruit bars
- \* sesame snaps
- \* homemade LID muffins
- \* fresh salad and LID dressing
- \* all natural nut butter

**Prescription type stuff** (just bring enough for the time you are in the hospital):

- \* thyroid meds (if you had a stimulated preparation (ie. used Thyrogen)
- \* other prescription meds
- \* Gravol
- \* sour lemon drops
- \* dry mouth spray (just in case)

**Toiletries** (remember, you are going to throw these away before you leave the hospital):

- \* shampoo and conditioner
- \* soap
- \* body wash
- \* toothpaste and toothbrush
- \* mouthwash
- \* body cream
- \* brush or comb
- \* hair elastics (to keep that constantly wet hair away from your face)

**Sanity items:**

- \* letters from those you love (a real sanity saver!! Thank you Sharon D.!) for each day you are away
- \* books
- \* magazines
- \* puzzles (thank you Joanne for this great idea!)
- \* soduko (this will keep you busy!) or is it sudoku?
- \* journal
- \* pencil and pen
- \* people's phone numbers

I went to the hospital with a big cooler of food, six 1.5L bottles of water and two big paper bags of clothing and toiletries, and left with the clothes I was wearing. In some hospital isolation rooms, the personnel do not allow patients to take home items that they brought with them at the beginning of the stay. Check with your nuclear medicine department for their policy on this issue.

I hope this will help you if you are preparing for RAI.

Good luck!

Despina