

Rob's Story: Lessons in Becoming an Informed Medullary Thyroid Cancer Survivor

**Wally Patching Memorial Presentation 2007 Series
Thyroid Cancer Canada**

by Jody Smith



Smith Family, Christmas 2005

My husband, Rob, was diagnosed with medullary thyroid cancer sporadic variant in 1996, at age 42. Medullary thyroid cancer (MTC) is a rare malignancy of the thyroid C cells. It occurs in two forms, hereditary (25% of cases) and sporadic (75%). Medullary is a poorly differentiated type of thyroid cancer that is more difficult to manage than the more common papillary and follicular variants, because there are few effective treatments for metastatic disease.

When we met Diane Patching at a TCC forum in May 2004, she explained how important it was for "Everyone be their own best advocate and take their health into their own hands!!" I'll never forget her words because Rob had just been diagnosed a week earlier with liver mets. We took her advice to heart and decided to "take charge" of his health care. I feel that everyone needs to get as much information as possible in order to not fall thru cracks in the healthcare system and get the best treatment. By sharing Rob's story as part of the TCC Wally Patching Memorial Lecture 2007, I hope others can learn from our experiences.

Importance of initial surgery

After Rob's 1996 diagnosis of medullary thyroid cancer (MTC), he had a total thyroidectomy. Sporadic MTCs frequently metastasize to cervical lymph nodes and with few treatment options for metastatic disease, it is very important to remove as much of the cancer as possible with the initial surgery. Initial surgery for MTC can involve both a thyroidectomy and neck dissection to remove lymph nodes. It is important to consult with your surgeon on how to nip as much of this disease in the bud as possible, right away to minimize your risks of recurrence.

Understand your post-treatment monitoring plan and follow-thru with all testing and appointments, even years after your initial treatment

After your treatment is complete, your monitoring plan should be reviewed with your medical team. Learn about imaging methods and the measurements of serum calcitonin and CEA levels in post-treatment monitoring for persistent or recurrent medullary thyroid cancer.

Rob had no sign of persistent or recurrent disease for six years after his initial surgery. I remember vividly toasting his health on New Years Eve after five years.....thinking he was cured and cancer free.

Stay vigilant – stay on top of things.

Follow up on suspicious or inconsistent information in scans and biopsies. If needed, get a second or even third opinion.

Rob ended up having surgeries in 2002 and 2003 for a nodule in his neck that kept showing up on scans, but could not be found when the surgeon went in. It was decided that it was probably scar tissue and we were guaranteed that no cancer was there. However, in 2004, he needed a liver resection when a large tumour was found after 5 out of 6 biopsies (at two different hospitals) showed NO cancer was present. Our doctor kept hunting for it though, since he knew MTC was present due to Rob's calcitonin levels.

Please follow up on those scans and biopsies. DON'T always trust the first one. Rob also had a clear scan in November 2004 (five months after his liver surgery), but by Oct 2005 we were told that his MTC was back again--this time in his femur, sternum and three ribs. We were told the liver scan was CLEAR. However, on second viewing, over two-dozen mets were found in his liver and by that time, surgery was no longer an option. What can I say ???!! If needed, get a second or even third opinion.

Keep good records and know your health history.

Managing medullary thyroid cancer involves working with multiple specialists such as a surgeon, endocrinologist, oncologist, and nuclear medicine specialist. It is important to document your appointments, keep track of tests and the results. Make sure the physician who is your treatment manager is copied on all tests and correspondence.

Make sure your family knows your health history, physicians and after-hours contact information.

Know the phone numbers of your physicians and other key medical personnel involved in your care, the hospital, the ambulance services that are in your area. Not only should you have these numbers handy, but your other family members need to be informed of where to turn in case of an emergency.

Know the medication you are taking and the potential side-effects.

As you undergo MTC treatment and monitoring, understand any medication you are taking, how it works and how it may have side effects that should be immediately reported to your doctor.

Rob was put on steroids (*Dexamethazone & Prednisone*) in February 2006 to help reduce his spinal tumours. In August, his health suddenly took a turn for the worse. He was extremely tired, totally confused, up every hour going to the bathroom, shaking, vision changes, food tasted "dry", swollen feet and mobility problems. It turned out he had a blood sugar reading of 36 (which is off the scale!) and was now a diabetic! He had "steroid induced diabetes", which was VERY difficult to manage with everything else he had to deal with. We were never told that *Dexamethasone* and *Prednisone* both affect the glucose and can cause diabetes. We didn't interpret his symptoms properly.

Reach-out for support and share support.

At this point, I'd like to say a huge thank you to everyone involved in providing MTC information and support. Rob and I participated regularly in the on-line medullary support group of the US Thyroid Cancer Survivors' Association to share experiences and support with others battling MTC. There are medullary conference sessions offered as part of their annual international thyroid cancer conference.

These are some sources of MTC information and support that we found helpful:

Annual International Thyroid Cancer Conference, Medullary Workshops.
<http://thyca.org/conferences.htm>

Medullary Thyroid Cancer Support Group. <http://health.groups.yahoo.com/group/medullary/>

National Cancer Institute International Database of Clinical Trials (current, closed and past clinical trials). http://www.cancer.gov/search/clinical_trials

Ontario Cancer Trials. <http://www.ontariocancertrials.ca>

US Thyroid Cancer Survivors' Association. Ten Things to Know About Clinical Trials.
<http://www.thyca.org/knowabouttrials.htm>

Live well

Rob dealt with all his health issues beautifully. In spite of having MS, cancer and diabetes, no one would have known he was sick until the last few months. He skied all last winter (2006), continued working through most of the summer, and never gave in to any of his illnesses.

Rob was the eternal optimist and definitely didn't live his life as a "sick" person. In fact, our three daughters (ages 23, 21 & 19) didn't even know about his MS until 4 years ago. He didn't want them to "worry" ...plus he never wanted to be defined by an illness. He never complained and thought of his illnesses as mere occurrences in his life, to be dealt with like anything else. He was truly an inspiration to all our friends and family. He kept his hope and positive spirit right to the end.

The nurses expected Rob to pass away on December 18th, 2006 but he waited for all the girls to get home from university (the last was back on the 20th) and then he waited for Christmas to pass. He was constantly asking what date it was!

We had a wonderful Christmas, gave him a "spa day" at the hospital on Boxing Day, then on the 27th he got extremely restless and wanted out of the hospital. We're skiers and this was the first day it had snowed, so it was perfect that he got to go out in it (4 times) before settling into bed that afternoon and just falling asleep. He passed away so peacefully, with the girls and me with him... not one second of distress, thank goodness. He couldn't have planned it any better.

This might sound strange, because cancer is terrible, but the last two months were probably the most precious in our thirty-year marriage. I hope everyone is able to experience what we've been able to when you cherish every second you have together and feel truly loved and appreciated. As a posting on the medullary online support group described, "this experience makes you appreciate the value of life, your family, and your support group". This is so true.

Support medullary thyroid cancer treatment research

The research continues for new medullary thyroid cancer treatments. Newer treatments with agents that target abnormal RET proteins hold promise and are being tested in clinical trials for patients with metastatic disease.

Good luck to all of you and I hope and pray that a cure comes soon.
