



## ASK THE DOCTOR: MELISSA'S STORY

From our Thyroid Cancer Patient Panel, with Dr. Sana Ghaznavi

**Melissa:** Thank you so much for having me today, it's a pleasure to be here to share my story. As young

women we're constantly reminded to check our breasts for lumps, to be suspicious of moles in our bodies and to check our menstrual cycles for irregularities. While each of these checks is extremely important, we're not often advised to check our necks for lumps or enlargements that may help in the early detection of thyroid issues.

I was completely unaware of this neck check; fortunately for me my family doctor is incredibly thorough and during my physical in March 2013 he noticed a significant enlargement of my neck. Within a few weeks of this finding, I did the ultrasound CT scan and had my first visit with the ENT and during this time my blood work was quite normal so there wasn't really an indication that something was amiss.

As it turned out, I had a large mass in my neck that was over 8 centimeters and it had grown inward, so it's not that I completely missed this neck growth, but rather it was through his check that he felt the enlargement and that was confirmed through a CT, and then the ENT performed a Fine Needle Aspiration biopsy which resulted in the diagnosis of papillary thyroid cancer. Following that I had a total thyroidectomy and a lateral neck dissection to remove the affected lymph nodes and I have a good scar from behind my ear all the way across to the other side of my neck. When the pathology came back, over 22 of the 40 lymph nodes were also cancerous.

Fortunately, I healed really well and most people don't even notice my scar, which is a testament my amazing surgeon and how our incredible bodies can heal.

Following my surgery, I was scheduled for radioactive iodine (RAI) treatment. I remember it was July, everyone was enjoying barbecues in the summer and I was on a low iodine diet getting ready to drink my toxic cocktail – not the same kind of cocktails everyone else was enjoying that summer! I was fortunate I was able to isolate following my treatment at home and my husband stayed with my parents just to make sure that we had enough distance.

To prepare for that RAI treatment, I had a thyrogen injection. At that time it wasn't in short supply, it was easier to come by although quite expensive because it's not covered by public health in Ontario, but thankfully we both had benefits through work and so it made it accessible and certainly easier to prepare for the treatment.

Unfortunately, my post radioactive iodine scan showed that the thyroid tissues had spread outside of my neck into my chest and both my lungs. That was an unexpected outcome for my age, and given that I really didn't have any symptoms. My thyroglobulin levels were also quite high, well over 300 at that time, and I also had thyroglobulin antibodies making it a little bit more complicated in terms of measuring. I'm sure many of you have heard that thyroid cancer can be coined the 'good cancer' (although I don't there really a good cancer). I certainly realized at that point that the so-called good cancer can misbehave!

I had to wait a couple of months before I could have another round of RAI. I started seeing a naturopathic oncologist in Ottawa. We were lucky, we actually had an integrative cancer centre, it's since been rebranded. I started to take various supplements, doing acupuncture, all the things that I could to help my body to heal from the treatments I had, the treatments I was about to have, and to improve the immunity in my body. I received my second dose of RAI in November 2013. This time though, the doctors thought that I should not use thyrogen to prepare and so it wasn't so much because I couldn't access it or that it was not financially feasible but rather using a bit more of an old school way to put the body into a more susceptible state to uptake that RAI treatment. So I was removed from my Synthroid for several weeks.

I can't tell you how tired I became but the time went by really fast actually because you're in a state of, not necessarily confusion, but just you're just really tired, really lethargic and so for someone who's pretty highly

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active and high energy, the time actually passed pretty quickly, just sort of staring outside the window and watching the snowfall and whatnot. I also couldn't drive during that period because they consider such a state of hypothyroidism an impairment.

And so for those of you who are familiar with TSH, my TSH ended up going over 90 which I guess was what they were hoping for prior to the dose and I was also on the low iodine diet during that period.

Thankfully it was effective and it was as the doctors had hoped. When they did the follow-up scan, most of what 'lit up' for lack of a better term, for the first time on those scans was dark which is a good thing. Where there was a little bit of uptake, the radioactive iodine was doing its job. My thyroglobulin levels for my blood work that followed had dropped from well over 300 to around 20 which was pretty significant.

So, since then, fast forward 10 years, my blood markers have been stable. Someone mentioned earlier that their thyroglobulin levels are still quite high, it took time for them to normalize, and my endocrinologist likes to say that they're a long term game, so not getting too worried when you see little blips but rather seeing sustained patterns. Since my diagnosis, I've traveled to over 30 countries, I have a successful career, a fulfilling life, I continue to have ultrasounds to monitor things. I see a naturopath regularly, I still do acupuncture, all the things that just help me to feel like I can be my best self. I don't know if I can blame my thyroid, but losing weight has been a challenge over this decade, however just trying to feel your best and look at all the other factors that give us indications of health.

What I found challenging at the time was that lots of women in their 30s have thyroid cancer but not a lot of them had the extensive case that I had and it was really hard to find stories that inspired me at that time. Looking back on that period, I can appreciate how it really has transformed me to appreciate the little things that I definitely took for granted at 29 and 30 that I find myself now at 40 helping people who are much older than I am get perspective in life.

I am grateful for the opportunity to hopefully bring some peace of mind to others and share that life is still very full following my diagnosis and treatments. Thank you for letting me share my story.

**Dr. Ghaznavi:** Melissa, honestly I don't know if I can follow that up, that was beautiful. It was really nice, you know this is my favorite part of my entire job, I feel very grateful to be in a career that I find really fulfilling, but by far the most fulfilling part of my job is conversations like this. I'll have those on a



a weekly, bi-weekly basis with patients who are diagnosed or they're 10 years out through their Journey or at the end of their Journey or whatever it is and it is really, really nice. I think it gives perspective, you started by saying finding beauty in those small things and I think this is a huge part of healing, it's not just the radioactive iodine and all that stuff but it's actually understanding that this thing has happened and it's not going to define you, but it is going to focus you and give you perspective and all of that and I find it incredibly inspiring. I've been known to cry more than once in my in my clinic with patients and also I haven't been through this adversity but having been through adversity I think that's what makes you human and makes you relatable to other people. As a doctor, I feel grateful for those things because it helps me actually connect with with others so one is, thanks for being just open and honest about that and honestly it is a really nice part of of this whole patient journey thing for both sides, is to be able to connect and understand one another just as humans. Yes I'm the thyroid specialist and you're the patient or whatever but at the end of the day we're just humans trying to figure this out.

We had talked about this before the webinar had gone live, the fact that a lot of patients do integrate naturopathic remedies or treatments or that sort of thing in the oncology world specifically and that for me, I don't see that as something that has to be an either or thing. It's not like either you take my treatment, you do everything I say in conventional medicine and randomized control trials, or you're doing this other thing. I think what we should be working towards is everyone that's a part of the care team has to actually be working together towards the healing of the individual right, so I would love to see more integration of that even into our Cancer Centre because I think that's what patients are doing and that's what they want, is a combination of conventional medicine and naturopathic medicine and two is, I think there are things to be learned from both sides absolutely. So it definitely should be something that we can work towards as a model of care where it's more integrated.

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So a couple of medical things that I'll comment on, one, you talked a lot about your journey with the low iodine diet and thyrogen stimulation and then the second time around how they didn't think that you should prepare with thyrogen but you should instead prepare by withdrawing your thyroid hormone and that is because in Canada, by Health Canada as well as the FDA, thyrogen is not approved for the indication of treatment of metastatic thyroid cancer, so when you're going to give Radioactive iodine in the metastatic setting it's not technically approved. I will say that probably 95% of centres and clinicians will still go ahead and treat people with thyrogen and that's because even though the trial was never done, there's a lot of real world data that came out, meaning that we treated a bunch of people using thyrogen, it still worked, and prepped them appropriately and we were able to get radioactive iodine to treat the tumors that they have that are metastatic and then, eventually those were published and reported and so we have a lot of real world data, not a lot of trial data. Most of us now, because of how unpleasant it is described, the energy and the challenges, the fact that you're not allowed to drive for example, all of that, it's just very unpleasant to be withdrawn from your thyroid hormone and purposefully made to have a TSH over 90, I can't imagine, most of us now do treat with thyrogen.

The other thing to talk about is just both the natural history of both pulmonary metastases which means your thyroid cancer has spread into the lungs as well as lymph node metastases, so at the very end you said what's happening now is you've got a funny lymph node on the ultrasound, it has this characteristic where it's lost the fat, the ribbon of fat that runs through normal lymph nodes and that makes it suspicious so they're monitoring it and so a couple of thoughts: one is the natural history, so what happens to these things over time if you just watch them; what we see is in lymph nodes at least about 80% of lymph nodes that actually are thyroid cancer, they don't grow and they don't change, and so again it comes back to what I had actually said with Kim's story, which is you have to balance the risks of doing nothing and monitoring, and what the disease will do, versus the risks of doing something and what the treatment itself would do. For example, the risk of doing a second neck dissection, going in there again and the general anesthetic risk, and the risk that you could have surgical complications and that sort of thing, versus the risk of what would happen if I simply monitor this and for lymph nodes that are papillary thyroid cancer, we know that with 80% of those patients it's actually just going to sit there and it won't do a whole lot, so our principle whenever we discuss any cases is,

is it progressive. Progressive means it's growing and changing or spreading, something is changing over time, and if it's not progressive then most of the time our recommendation is active surveillance, you're monitoring actively and you're ready to intervene but you won't intervene unless you tip the scale in favor of doing something.

So that's the natural history of lymph nodes, of pulmonary metastases in young people, specifically it's also quite reassuring in that most patients will have some initial growth, and then lymph or pulmonary nodules tend to get stuck around the 1 cm or 10 millimeter mark and they tend not to grow much past that. So again, the question about further treatments is always about whether it's progressing, so is it changing on the CT scans over time, is the thyroglobulin rising and that sort of thing.

One final thing I'll say about the thyroglobulin, because this is a very objective marker that you can use, is that there's always some variability in the thyroglobulin. It's sensitive to your TSH which means that if your TSH has gone up, say your doctor just reduced your dose of Synthroid and your TSH goes up, you can expect that the next time you have your bloodwork, your thyroglobulin will also go up a little bit because as the TSH goes up the thyroglobulin goes up. As the TSH goes down the thyroglobulin goes down, so there is a significant amount of variability that you can get from day to day in the thyroglobulin.

Why I mention that is because, at least in Alberta, we have something called Connect Care which is our EMR system, and patients often have access to their tumor marker results and even their CAT scan and PET scan and ultrasound results even before I've seen them and discussed it with them. So they're looking at this number and thinking oh my goodness it was six before and now it's 8.5 or whatever, and they're worried and I just want to caution that there's a normal kind of variance that can happen and what I'm looking for is consistent rise, so a pattern where every time I measure it it's a little bit higher rather than, yeah this person sort of bounces around in this range. In that case I don't give patients their tumor marker number, I give them the range that they exist in. I usually tell patients your thyroglobulin usually is in the two to three range and then they know that if they see any number within that, that it's not a marker necessarily of a recurrence right, so I thought that was an interesting thing to talk about.