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Editor's Note

Greetings,

In this issue, I examine the experiences of young women diagnosed with thyroid cancer. I am sure many of you will be able to relate to some of the stories they tell.

Charna summarizes the results of a study undertaken to examine the relationship of pregnancy in thyroid cancer survivors, and whether there is a risk of recurrence in this population.

Hope you can join us for one of our fall events.

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Too Young For This:

Young Women and Thyroid Cancer

by *Stephanie Wylie*

From the age of 15 or 16, Grace noticed she was having trouble keeping up physically with her peers and had started having unusual food sensitivities; by the time she was diagnosed (at age 19) with stage II papillary carcinoma, the oncologists determined that her tumour had been growing for approximately three years.

18-year-old Shalima never noticed anything wrong with her thyroid gland. She had none of the symptoms typically associated with thyroid issues and after her annual physicals, her bloodwork always came back normal. It wasn't until her mother pointed out the prominent lump on her daughter's neck when she swallowed, that Shalima thought something might be wrong. She was eventually diagnosed with stage II papillary cancer.

The diagnosis of cancer of any kind in a young person is difficult for everyone involved; the doctor, who all too often believes what he or she was taught to think in medical school, that "cancer only happens to older people"; the individual diagnosed and their family who are often conditioned to believe the same thing, and that young people just don't get cancer.





This myth, and the subsequent diagnosis of thyroid cancer often results in confusing emotional reactions from the families and friends of the patient. Katie's experience is not at all unusual. Post-diagnosis at age 27, "Everyone had mixed reactions and A LOT of questions. While my family stuck by me, a few friends stopped talking to me and avoided me at all costs. After my thyroidectomy and one round of RAI, some of my family thought I should have been back to 'normal' right away". Grace describes "...friends who showed up right after surgery, and others who just pulled away...some family members who were stoic and expected me to be equally stoic and unreactive... and when the 'I-Have-Cancer' anger started to show up, (people's) patience started wearing thin".

"It's very different for young people with cancer because it's hard to believe they face a life threatening illness when their "life" hasn't even started yet. It's difficult to concentrate on things like university and building a career while visiting doctors and constantly worrying about being healthy. We also face different kinds of social pressures, like not being able to hang out with friends or being able to talk to anyone about what (we're) going through".

While Nina (who was diagnosed at the age of 40) relates that she had tremendous support from her husband, friends and most of her immediate family, one of her sisters, to whom she was extremely close, seemed to shut down: "Her way of reacting was to ignore my diagnosis and even avoid me, which was very upsetting. When I told her I was hurt and disappointed that she had retreated from me between the time of my biopsy and surgery, she broke down in tears and admitted she could not face the 'C' word being in our lives again, since we had lost our mother to breast cancer only four years before".

Clearly, young women diagnosed with thyroid cancer also face huge challenges on several fronts – entering adult society, joining the work force, contemplating relationships and the possibility of marriage, starting a family – all of which can be overwhelming even without the looming spectre of disease. These younger women are also likely to be stigmatized, since fewer of their peers have had a personal experience with cancer.

As Shalima conveys: "It's very different for young people with cancer because it's hard to believe they face a life threatening illness when their 'life' hasn't even started yet. It's difficult to concentrate on things like university and building a career while visiting doctors and constantly worrying about being healthy. We also face different kinds of social pressures, like not being able to hang out with friends or being able to talk to anyone about what (we're) going through".

"A worm-hole to another stage of life and maturity" is how Grace explains the emotional reaction to her diagnosis of thyroid cancer. She goes on to say that "it's a bit like being ripped out of teenage life...put through a ringer-washing machine of experiences where my companions were a generation older than I was, then spit back out and expected to re-join my young adult life. And when she did re-join that 'life', "...I felt somehow behind my age group because of the time that I had lost while I was busy not dying and getting used to my new 'normal'; it was this strange feeling of being behind (my peers) because I had been catapulted ahead (into the future) and then shot back again".

We know that thyroid cancer is the most prevalent form of cancer in young women under 30, accounting for almost 25% of all cancers or more than 3,000 per year. In the 30-49 age group thyroid cancer claims 14% of all cases. This pattern differs from that of many common cancers, such as colorectal cancer, which tends to be more common in men and increases at ages over 50¹. And so, this begs the question: why is there not more support and information forthcoming from the medical system regarding thyroid cancer, given its increase in diagnosis?

Perhaps it has something to do with societal attitudes that thyroid cancer is a "good" cancer to get. While there is no such thing as a "good" cancer, the cure rate for thyroid cancer is as high as 96% or more with early detection and a wider range of treatment options. But being a young person and trying to convince one's doctor that there is indeed something wrong, is yet another reason thyroid patients feel adrift in the medical environment.

Grace argues that being 19 years old **does** make her an expert on her own body, and knew something wasn't right: "It shouldn't be up to the patient to prove to a doctor (that their illness) is "for real"...they may not have the energy to prove it; it took 8 doctors before someone believed that there was



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something going on that (should be taken) seriously”.

The amount of time it takes to schedule tests and biopsies is a concern to Shalima: “Sometimes it takes months before you know if you have cancer, and in that time your whole life is put on hold...I think if people found out sooner rather than later that they had cancer, it would eliminate a lot of stress, time wasted worrying and allow everyone to move on in their lives more quickly”.

Some of Katie’s frustration stemmed from the fact that all of the pamphlets the doctor gave her were geared for people over the age of 45. As a result, she sourced the internet: “I had a lot of trouble finding information or resources for issues that an 18-35 year age group would have, such as how to explain this to young children, working while sick, dealing with relationships. And there were no support groups for young people with thyroid cancer. I asked my doctor if she knew of another thyroid cancer patient under 30 that I could speak with. She had no information and wasn’t very supportive about my concerns”.

The struggles faced by young women diagnosed with thyroid cancer are myriad: lack of age-appropriate information about the illness; appointments with (sometimes) less-than-sympathetic doctors, and a medical establishment that all too often seems to view this type of cancer as less serious than others. This attitude often carries over with friends and family, too. During my research for this article, the one constant refrain that I heard from many people was the frustration they felt when they heard: “Oh, but that’s the cancer that won’t kill you, so it’s the good one to get”. That being said, patients of all ages continue to wonder what causes thyroid disease. And hopefully, they’re not alone: new data and studies are prompting researchers to investigate why thyroid cancer is increasing at a faster rate in young people than any other cancer.

1 <http://www.healthzone.ca/health/newsfeatures/cancer/article/965883--thyroid-cancer-a-growing-threat-for-women>

See Canadian Cancer Society Annual Statistics (2009, Special Report on Cancer in Adolescents) at www.cancer.ca

For more support specializing in resources for young people with cancer, visit YACC at www.youngadultcancer.ca





Pregnancy in Thyroid Cancer Survivors



An article review by Charna Gord, MEd, RD

Charna Gord is a Registered Dietitian working as an Education Coordinator in an Ontario public health unit. She underwent a total thyroidectomy for thyroid cancer in December 2007. This is the thirteenth in a series of thyroid cancer related journal article and other resource reviews that Charna has undertaken for Thry'vors News.

In this review, Charna summarizes the findings of the following journal article:

Hirsch D, Levy S, Tsvetov G, Weinstein R, Lifshitz A, Singer J, Shraga-Slutzky I, Grozinski-Glasberg S, Shimon I, Benbassat C. Impact of pregnancy on outcome and prognosis of survivors of papillary thyroid cancer. *Thyroid* 2010; 20(10): 1179-85.

Journal Article Main Message:

Pregnancy does not cause thyroid cancer recurrence in papillary thyroid cancer survivors who have no structural or biochemical evidence of disease persistence at the time of conception.

Research Background:

Papillary thyroid cancer occurrence is more frequent in women than men, and commonly occurs in women of child-bearing age. It is well accepted that pregnancy in healthy women can stimulate the thyroid gland and its hormones, and the growth of thyroid nodules. Previous studies on pregnant women who were diagnosed with thyroid cancer during a pregnancy have showed mixed outcomes with some research indicating that pregnancy hormones can trigger papillary thyroid cancer. As there was little research on pregnancy in thyroid-cancer survivors, and as thyroid cancer may recur or persist after treatment, the authors of this study decided to find out what happened to a group of women who got pregnant after surviving thyroid cancer; did their thyroid cancer recur or worsen?

What was the research objective?

The purpose of the research was to determine whether papillary thyroid cancer survivors were at risk of progression or recurrence of thyroid cancer due to pregnancy.

How was the research conducted?

The research was a retrospective case-series design. It followed 63 survivors of thyroid cancer who gave birth to 90 babies after initial thyroid cancer treatment. These women were followed for about 4 years after delivery and they were all treated by endocrinologists at one medical centre in Tel Aviv, Israel from 1991 to 2009. They were all under the age of 45 and were given the same clinical, biochemical and imaging tests, and demographic questionnaire. Thyroglobulin (Tg) levels and neck ultrasound findings were compared before and after pregnancy. Persistent disease was defined by the authors of this study as having either a detectable Tg level on L-thyroxine treatment (hormone replacement pills), a neck mass found on ultrasound or radioactive uptake outside the thyroid bed, and increasing anti-Tg antibodies.

Thirteen (about 20%) of the women had persistent papillary thyroid cancer before getting pregnant. Of those 13 women, six patients had thyroid progression during their first pregnancy, 3 gave birth for their second pregnancy with mixed results for disease progression, and there was no disease progression in the 4 women on their third pregnancy. At their last follow up appointment, 11 of these same 13 patients still had signs of papillary thyroid cancer. Two of the women bore no evidence of the disease.

**What were the research findings?**

In women who show evidence of persistent papillary thyroid cancer before getting pregnant, the risk of disease progression during pregnancy is significant. In this study, the researchers state that the women with persistent disease likely had a more aggressive cancer as shown by their need for repeated

Pregnancy does not have an impact on disease recurrence in survivors of papillary thyroid cancer unless there is evidence of disease persistence before conception.



radioactive iodine treatments. There was no relationship found between the group of women with persistent papillary thyroid cancer and their age, duration since they were last pregnant and any other lab indicators.

Pregnancy is not a risk factor for thyroid cancer recurrence in women with a negative pre-pregnancy ultrasound scan and undetectable Tg/Tg antibody levels on L-thyroxine treatment. None of the women who had normal pre-pregnancy neck ultrasounds had new abnormal findings after delivery.

What were the final recommendations?

Pregnancy does not have an impact on disease recurrence in survivors of papillary thyroid cancer unless there is evidence of disease persistence before conception.

What's New at TCC

As part of our Annual General Meeting day this year, we enjoyed several combined activities on May 28, 2011.

In the lovely location of the Burlington Arts Centre, the morning was filled with a well-attended Patients' Forum including presentations by Dr. Meera Luthra (Endocrinologist at St. Joseph's Healthcare in Hamilton, ON) and Shalimar Manuel BScHE, MA, patient-member of TCC from Halifax, NS.

Dr. Luthra's presentation included an overview of thyroid cancer; its development, treatment and follow-up. Her presentation was very well-received by the 60+ attendees including patients, family and friends who attended especially appreciated her straightforward descriptions and clear explanations.

Shali's presentation was equally well-received as she described her own thyroid cancer journey, as well as detailing the outcomes of her Masters research study: *A Bend in the Road is Not the End of the Road*. This study (described in detail in the Fall 2010 issue of Thry'vors News) included nine young women between 17 and 29 years old who talked about their thoughts and feelings regarding a thyroid cancer diagnosis such as: loss of trust and feeling of 'normalcy', increased sense of

appreciation, etc. To view her lecture, watch the Youtube videos in the Audio-Video library of our website. Following the presentations, we held our annual meeting, attended by 21 members – most of whom were volunteers with the organization, or were wanting to learn more about becoming helpers. At this time, TCC has 50 active volunteers from across the country who work within 9 committees.

We concluded our busy day with interactive presentations from Candice McPherson of TZone Vibration Studio and from the Burlington Branch of the Taoist Tai Chi Society of Canada (each donating their valuable time to us). It was a very interesting and entertaining way to thank our volunteers. TCC also thanks Genzyme Canada who was the sponsor of the Patients Forum and provided delicious refreshments for the meetings.

TCC is always on the lookout for new volunteers. If you'd like more information about how you might contribute your time and talent, please contact the Volunteers' Support Committee Chair at volunteer@thyroidcancercanada.org



LID Recipe Box

Rubs

Mediterranean Herb Rub

Use on meat (pork, chicken, lamb) or on roast veggies.

1 tbs dried basil
1 tbs dried mint
1 tbs dried oregano
1 tsp dried parsley
1 tbs dried rosemary

Procedure:

Combine all ingredients well.

Marinades

California Marinade

2 cloves garlic, minced
1/4 cup olive oil or canola
1 tsp rosemary leaves, crushed
1/2 tsp dry mustard
1/4 cup wine vinegar
1/4 cup sherry or apple juice

Procedure:

Carefully warm oil in sauce pan and add garlic. Sautee briefly but don't let brown. Remove from heat and add rosemary, mustard, wine and sherry or apple juice. Let cool in fridge before using as marinade on meats. Ok to use right away if marinating vegetables for grilling.

Citrus Marinade

2 large garlic cloves, sliced
1/3 cup olive oil
3 tbs sugar
2 tbs balsamic vinegar
1/2 tsp dry mustard
1/4 cup fresh lemon juice
1/4 cup fresh orange or lime juice
1 1/2 tsp freshly grated lemon zest
fresh ground pepper

Procedure:

Cook garlic with oil just until it just begins to turn golden. Remove pan from heat and with a slotted spoon discard garlic. Stir in remaining ingredients and cool. Makes about 1 cup.



Poem by Janice Veri

What value tranquility
Or inner peace-
Someone far greater than I
Created these feelings for
a mere few

The entry price
Not money or power
But understanding
Of the delicate balance in life

Having this privilege
We are humbled
With the knowledge
We are but a small part of
a master plan

Our duties, not onerous
Are simple
And sweet
We must give thanks for the
life we have

Children and creatures
So vulnerable
A flower's beauty
Even but one day to view these
with new eyes



The following event is offered by CancerDogs. Please contact the organizer directly for more information.

CancerDogs is an organization based in Ottawa, which is developing an accurate low cost, non-invasive general cancer screening method that detects cancer in the earliest stages when there are few or no symptoms and the cancer is still localized.

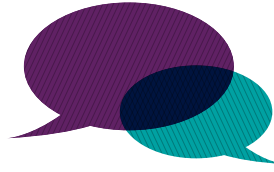
The idea is that cancer cells emit different metabolic waste products than normal cells. Their presence in cancer patients' exhaled breath, blood or urine is so great that they can be detected by a dog's keen sense of smell, even in the early stages of disease. CancerDogs is training dogs to detect the bio-chemical traces of cancer the same way other dogs are trained to detect traces of explosives or drugs.

CancerDogs is conducting a study whereby they are collecting breath samples from people. All that is required is a breath sample into a surgical mask or similar, so that patients' samples can be compared to non-patient samples in testing the accuracy of the dogs and/or training them. The trained dogs will not be present at the time of sampling. To qualify to help with this project you must have been recently diagnosed with thyroid cancer (eg. via Fine Needle Aspiration cytology) but not yet treated for cancer with surgery or treatment.

For more information about how to participate, visit the CancerDogs website www.cancerdogs.ca or contact Glenn at info@cancerdogs.ca



Ask Thry'vors



by Melanie Thomson

The members of TCC's Medical Advisory Panel are available to answer your general questions about every aspect of thyroid cancer. A list of our Medical Advisory Panel members appears on our website at: www.thyroidcancer canada.org/medical-advisory-panel.php

In This Issue:

We ask our MAP surgeons about routine central neck dissections with thyroidectomies.

Q1: Some centres report that it has become customary for associated surgeons to routinely perform central compartment neck dissections with all thyroidectomies (where there is predetermined thyroid cancer). They argue that since such a high percentage of recurrences occur in lymph nodes in this area, that prophylactic dissections are preventative. Do you agree with this reasoning? Why or why not?

A1: by Dr. Irving Rosen

Recently the concept of a central neck dissection (CND) has been articulated as an entity and earned discussion as a “new

procedure”. In actuality I and other experienced surgeons included this maneuver as part of a thyroidectomy for thyroid cancer and looked upon the procedure as standard. I obviously agree with this procedure since it may remove additional malignant material and alert one for enhanced surveillance. I even did further nodal sampling. It is difficult to ascribe a survival benefit for this procedure but that has been an issue with nodal involvement on a historical basis. Some have described increased parathyroid and vocal morbidity with CND but I did not experience this and it is avoidable with appropriate care.

A2: by Dr. Raymond Ng

I agree with prophylactic neck dissection. I also routinely request a detailed preoperative ultrasound of the neck to assess the lymph node status in the central neck compartment. For head and neck surgeons with experience in thyroid surgery and neck dissection, the complication rate is very low. Removal of metastatic lymph nodes allows better control of disease with other treatment modalities such as post surgery radioactive iodine therapy.

With thanks to members of TCC's Medical Advisory Panel:

Raymond H.W. Ng MD., Ph.D., FRCSC,
Division Chief, Otolaryngology – Head and Neck Surgery,
Rouge Valley Health System

and

Irving B. Rosen MD., FRCS (C) FACS,
Professor of Surgery, University of Toronto Faculty of Medicine, Department of Surgery, Mount Sinai Hospital

Meet Drs. Ng and Rosen in person at our Neck Check event in Toronto. See below for more info.

Con-neck-tion Meetings, New Brunswick

Jodie says “Join us for supper at a restaurant in Moncton once a month. We are a very relaxed group and generally just share our stories. They are the last Tuesday of every month at 5:00 pm at:

Mike's Restaurant on Mountain Rd.

For more info, contact Jodie at: jomcnama@rogers.com or 506 382-2499



Events

TCC Events

Thyroid Cancer Awareness Neck Check Event – Toronto

Date:
Saturday, September 10, 2011

Time:
9:30am–6:00pm

Location:
Sherway Gardens Shopping
Mall, Hwy 427 and QEW,
Toronto.

Visit Thyroid Cancer Canada's booth in the Sears Court. Meet representatives of TCC, get information about thyroid cancer, and have your neck checked for thyroid nodules by specialist surgeons (members of TCC's Medical Advisory Panel) Drs. Irving Rosen and Raymond Ng. The doctors will be available to answer your questions about neck nodules.

Community Events

The following event is offered for your information. Please contact the organizers directly for more information.

Neck Check Run/Walk for Thyroid Cancer Awareness

Date:
Saturday, September 24, 2011

Time:
9:00am–12:00pm

Location:
Starting in Eua Claire, Calgary

The 'Neck Check Run/Walk for Thyroid Cancer Awareness' is a benefit for Thyroid Cancer Canada. To participate, or sponsor a runner check out the Running Room online event information.

You can:

1. Volunteer to help out;
2. Run/walk in the event (in Calgary, Sept 24);
3. Support an existing runner;
4. Make a general donation in support of the cause.

All of the above is being organized by a volunteer patient member of our group and all proceeds generously go to TCC (our volunteer-led patient support group). Thanks Donna and her team!

Visit <http://www.events.runningroom.com/site/?raceId=7099>



Thyroid Cancer Canada thanks Brightworks Interactive Marketing for newsletter-design services. Brightworks is a digital communications agency with a strong focus on healthcare, who are proud to support TCC in this way. For more information on their services, see www.brightworks.ca.

**Like you, we have been touched by thyroid cancer.
We are a non-profit organization and we are all volunteers.
If you would like to donate or to become a volunteer
please visit www.thyroidcancer.ca.**

Donation cheques may be made payable to:
Thyroid Cancer Canada
Mail to: Thyroid Cancer Canada
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Toronto, ON M5N 3A8

