THYROID FLYER

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Feature - The Impact on Families

Editorial

By **Christopher McDermott**

Welcome to the Spring and fourth edition of the *Thyroid Flyer* for 2002. The theme for this newsletter is thyroid and families. We have done this recognising the fact that our thyroid conditions have affected not only ourselves but our loved ones and those closest to us. Many of us are so grateful for the support of family and partners in helping us through our times of poor health - and also their patience with us waiting for us to improve - and be back to our "normal" selves which can take months or years.

We thought it would be good to hear some stories from the perspective of other family members.

Of course it is very important to have family members in mind given that it appears that thyroid conditions have strong genetic links.

On the committee of Thyroid Australia, we are having a busy time. We have only just recovered from organising our second annual one-day seminar at Monash. It was another very successful day with over 200 people turing up at the Monash Rotunda to hear our guest speakers: A/Prof Peter Colman, Mr Bill Johnson and Dr Alla Turlakow. Our thanks to those speakers who gave up most of their Sunday. Not only was each talks fascinating and informative but each speaker was surrounded at the end of their sessions with people with extra questions. It was an excellent opportunity for people to get answers to questions and extra information from the experts. We are planning to publish Bill Johnson's and Alla Turlakow's articles in future newsletters, so keep posted.

I would like to thank committee members and the extra volunteers who helped on the day. The large number of people arriving in the morning can be quite

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Congenital neonatal thyrotoxicosis and previous maternal radioiodine therapy

By **C M Smith, J Gavranich, A Cotterill, C P Rodda**

The risk of congenital thyrotoxicosis may well be apparent when a pregnant woman has florid thyrotoxic Graves' disease (figure). A maternal history of Graves' disease, however, may be overlooked, especially if the mother is taking thyroxine replacement after radioablation or surgery. Maternal thyroid stimulating antibodies may persist,[1] and consequently a woman's newborn infant is still at risk. Thyroid stimulating antibodies can be quantified by measuring the "thyroid stimulating hormone binding inhibiting immunoglobulin" (TBI) index.[2] This competitive radioreceptor assay measures binding to a porcine thyroid stimulating hormone receptor of the patient's immunoglobulin, compared with labelled thyroid stimulating hormone. A high maternal TBI index is a useful measure to indicate increased likelihood of disease developing in the infant. Although certain prediction of an infant being affected is not possible antenatally,[2-4] a maternal TBI index of more than 30 units predicts, and more than 70 units strongly predicts, that the infant will be more likely to be affected. Therefore all infants of mothers with a history of Graves' disease must be carefully monitored, both clinically and biochemically, for up to seven days postnatally.

Maternal radioiodine therapy does not protect against congenital thyrotoxicosis — a blood test helps to predict those at risk

Although Graves' disease complicates 0.1-0.2% of all pregnancies, congenital thyrotoxicosis is rare, occurring in 1 in 70 of these pregnancies, and its development may be irrespective of either maternal disease or antibody status alone. Congenital thyrotoxicosis is transient, lasting up to three months or more, and is due to the transplacental passage of the stimulating (infrequently inhibitory) maternal antibodies of the IgG class, which may cause substantial neonatal morbidity or death if untreated.[2] We present two cases, the first illustrating the antenatal use of the TBI index in the mother, and the second showing morbidity in a premature infant in whom maternal Graves' disease was initially unrecognised.

Case reports

Case 1

A male infant was born at 36 weeks by spontaneous vaginal delivery to a mother with Graves' disease. The mother had received radioiodine (iodine-131; 248 MBq) shortly after conception, at which time her pregnancy test had been negative and she had denied the possibility of pregnancy on specific questioning. She elected to continue with the pregnancy and experienced a recurrence of her hyperthyroidism in the first trimester; she had to restart taking propylthiouracil (50 mg every eight hours), and she continued this treatment throughout her pregnancy. Her thyroid function remained normal while taking propylthiouracil until delivery.

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Public Meeting 23 November 2002.
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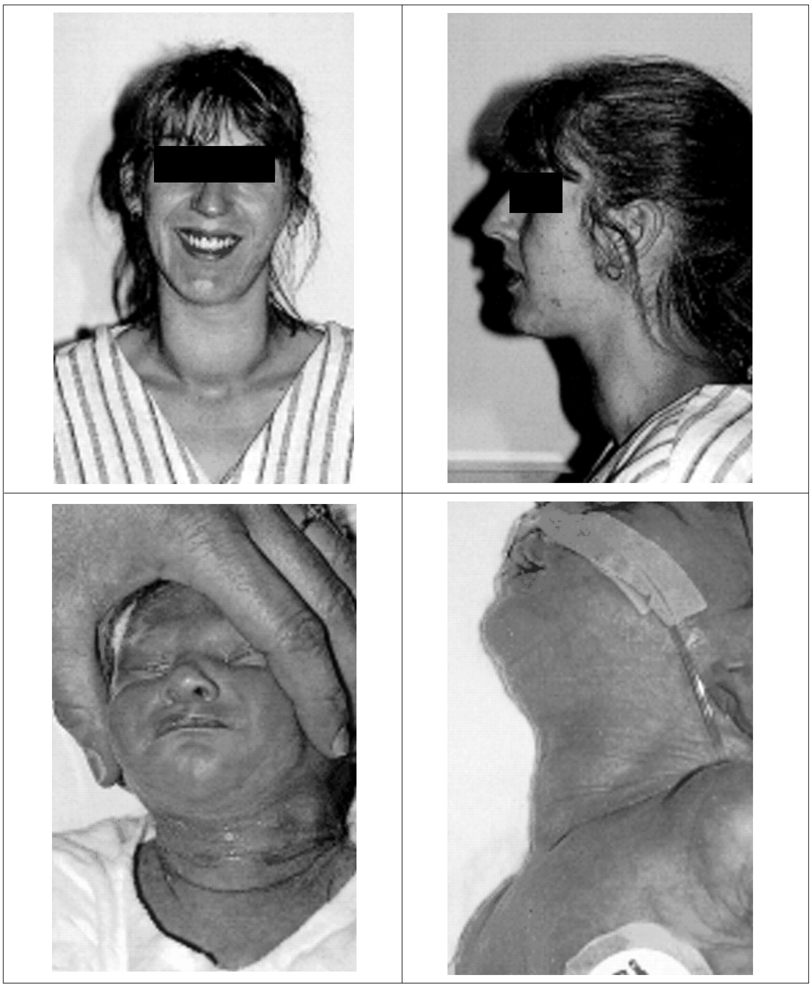
Thyroid Questions and Answers ***from Page 1***

The infant weighed 2400 g at birth (below 10th centile); birth length was 460 mm (10th centile) and head circumference 325 mm (10th centile). These measurements indicated mild intrauterine growth retardation. Apgar scores were 9 at one minute and 9 at five minutes. Clinical examination was normal. Initial jitteriness and hypoglycaemia (2.0 mmol/l) resolved over eight hours with frequent oral feeds. Thyroid function was tested on day 4 because of the maternal history. Free thyroxine (fT4) concentration was raised (50.7 pmol/l (reference range 15-40 pmol/l)), and thyroid stimulating hormone concentration was reduced (0.5 mU/l (reference range 1.0-25.0 mU/l). Maternal TBI index was raised (28 units (reference range 15 to [-]15 units; TRAK assay, Brahms Diagnostica GMBH, Berlin, Germany)). The infant was noted to be jittery, and he fed poorly. He was not tachycardiac and did not exhibit excessive weight loss postpartum. Lugol's solution (1 drop every eight hours) was started, together with propylthiouracil (10 mg/kg/day). These were continued for 12 days and 4 days respectively. The clinical and biochemical hyperthyroidism resolved, and follow up to age 2 years was normal.



An affected child (bottom) of a floridly thyrotoxic mother (top). Both have goitres. Published with mother's permission

Case 2

A 33 year old primiparous Vietnamese woman, who spoke little English, presented when the fetus was at 18 weeks' gestation. She had a history of long term hypothyroidism and was taking thyroxine 200 µg daily. At 33 weeks' gestation, spontaneous rupture of the mother's membranes occurred with the onset of premature labour. A male infant was delivered vaginally with uncomplicated meconium stained liquor, and Apgar scores of 7 at one minute and 9 at five minutes. His birth weight was 2005 g (50th centile), and clinical examination confirmed length of gestation. No other clinical abnormalities were present.

By day 8, he had progressed to sucking all feeds, had left incubator care, and had begun to gain weight. On day 10, a low grade fever was noted, and over the preceding two days he had lost 70 g in weight. Clinical examination was otherwise normal. On day 11 he had fever to 38°C and was increasingly lethargic, and he developed diarrhoea and an intermittent tachycardia up to 180 beats per minute. His mother was unwell concurrently with an upper respiratory tract infection. As the infant was normal on clinical examination and had a normal white cell count, a viral illness was diagnosed, although the possibility of septicaemia could not be excluded, and so blood, stool, and urine cultures were collected. Broad antibiotic treatment (amoxicillin and gentamicin) was started. As the cultures were negative the illness was still attributed to a virus. By the following day his temperature had settled to normal and his pulse rate fell to 140 beats per minute. Antibiotic treatment was stopped after 48 hours.

He was reviewed again on day 16 because his mother complained of his constant demands to feed. Clinical examination showed a tachycardia up to 200 beats per minute. His weight was 2050 g — a gain of only 45 g over the previous two weeks. Thyroid function tests showed a raised fT4 concentration of 60 pmol/l and a reduced thyroid stimulating hormone concentration of <0.02 mU/l. His mother was advised to stop breast feeding by junior staff who wrongly assumed that the raised fT4 concentration might have resulted from maternal thyroxine treatment crossing to the infant in the breast milk. The infant continued to be otherwise clinically well but was increasingly hungry. By day 20 he had also developed irritability. Thyroid function tests showed continuing suppression of the thyroid stimulating hormone (<0.02 mU/l) and an increasingly raised fT4 concentration (>77.3 pmol/l). Carbimazole (0.3 mg/kg/day) and propranolol (0.8 mg/kg/day) were started, resulting in prompt clinical and biochemical improvement, and were continued until day 56 and 62 respectively. Normalisation of fT4 concentration was achieved by day 28, although suppression of thyroid stimulating hormone continued until day 62.

The TBI index was not measured on maternal or infant serum in this case. Physical growth parameters to 11 months, when corrected for prematurity, followed the 50th centile for length and weight and the 75th centile for head circumference. Developmental milestones were achieved normally.

When the father, who was fluent in English, was told of the diagnosis of congenital thyrotoxicosis, he recalled his wife having had a large goitre and being very underweight when they first met. Subsequently, after radioiodine therapy for Graves' disease 11 years previously, she had become hypothyroid, requiring the thyroxine supplementation.

Discussion

In infants born to mothers with Graves' disease, overt symptoms and signs with biochemical evidence of thyrotoxicosis usually occur within the first week of life. Thyrotoxicity may last for up to three months or more, proportional to the clearance of the maternal immunoglobulin from the infant's circulation. Untreated, reported mortality is up to 16-25% in disease severe enough to be clinically diagnosed, and serious long term sequelae — such as craniosynostosis resulting in microcephaly and mental retardation — can develop in untreated survivors.[3] Affected newborns also experience significant acute morbidity. Tachycardia is common, although arrhythmia, congestive cardiac failure, and pulmonary oedema are less common, and exophthalmos and goitre are rare. There may be evidence of hypermetabolism with initial excessive weight loss and subsequent failure to regain birth weight in the neonatal period (as in case 2, in which the infant also developed diarrhoea, fever, sweating, flushing, and increased appetite). In case 1 the infant also had intrauterine growth retardation. In both cases, the infants were premature and exhibited restlessness and irritability before diagnosis, and often these non-specific symptoms, together with a tachycardia, provide the only clinical clues; the maternal history is therefore crucial.

In case 1 the infant was relatively mildly affected, and congenital thyrotoxicosis was anticipated as the mother was still taking antithyroidal drugs, and a modestly raised TBI index had been detected antenatally. In case 2 an inadequate maternal history delayed the diagnosis and resulted in significant morbidity. Although maternal antibody levels were not measured, this case illustrates their persistence long after definitive maternal treatment. This case also highlights that a diagnosis of autoimmune hypothyroidism cannot just be assumed in a pregnant woman taking thyroxine replacement. Breast feeding should not be stopped in mothers treated with thyroxine for hypothyroidism even if the infant is hyperthyroid.

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Dr Christine Rodda spoke of this research at the Thyroid Australia Seminar in 2001. ❀

TSH:
A new "normal"?

New guidelines from the National Academy of Clinical Biochemistry (NACB)

By **Lawrence C Wood MD**

Dr. Carole Spencer from USC Medical Center recently reviewed new research indicating that the normal range for TSH is actually much lower than the range presently accepted in virtually all medical laboratories. A normal range is taken as the range that includes 95% of a randomly sampled population. But Dr. Spencer pointed out that many individuals are already in the process of developing hypothyroidism. In order to sort out those individuals who already show an increase of TSH due to thyroiditis, new studies excluded individuals with a personal or family history of thyroid disease, anyone with a visible or palpable goiter, individuals on medication (except estrogen), and anyone with a positive test for antibodies to thyroid peroxidase or thyroglobulin.

Based on these two new standards, the new normal TSH range was found to be between 0.5 µU/ml to 2.5 µU/ml. A lower TSH may indicate hyperthyroidism and a higher level hypothyroidism. In line with these standards, the TSH reading should be within this range if the patient is on thyroid treatment (lower if you have cancer and suppression of cancer is desired.)

It is too soon to know if higher doses of thyroid hormone will be safe for elderly individuals, especially those with heart conditions, but clearly this new research needs to be followed up with clinical studies. We urge all TFI members to discuss this new and important research with their physicians and medical laboratories in their area. We will keep our readers posted as results of research studies become available.

Lawrence C. Wood, MD is the President of Thyroid Federation International.

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Over To You

We publish letters and thyroid stories from our members. So if you would like to write to us or send us the story of how, when, where and why your thyroid condition was diagnosed, and how the condition and treatment has affected you, please do so. If you are able to include any lab test results (such as TSH, T_4 and T_3) at the time of diagnosis and during your treatment, all the better. The stories will be published anonymously unless you ask to be named.

The views expressed in this section are not necessarily those of Thyroid Australia. Check all treatment options with your doctor.

An Open Letter to the Husbands of Graves' Disease Patients

Dear Husband of Graves',

This letter is to all of us who are or were married to someone with Graves' Disease. It is a letter from my heart as I know of no other way to talk about it. If in some way it speaks to those of you who are now struggling or have struggled with the loneliness, the frustration at the lack of answers, the inability to help the ones you love, having to make major decisions without your partner, or going through the pain of divorce because of a disease very few understand and fewer still can relate to, then it will have been worth exhuming painful memories that time was mercifully putting to rest.

I've heard that the divorce rate skyrockets when someone has Graves' Disease. I am not surprised. This disease works to challenge every reason you had for being married and forces you insidiously to get to the bottom line - that a marriage exists only because you are willing to remain committed to your partner, regardless of anything else.

In a lot of ways my wife and I were fortunate; she was diagnosed with Graves' Disease after approximately nine months, at least that is the closest she and I can pin point when she began to first experience the symptoms we now associate with Graves'. During that time, however, while I always knew my wife loved me, frequently who I was married to was not my wife.

One aspect was the mood swings, the unexpected outbursts of anger and accusation, the unexplainable crying. This took the most work for me to deal with emotionally. I know I unintentionally do or say things that irritate her from time to time. But when compared with how we usually handled these issues, the anger of crying was out of proportion to the crime and it came with no warning. Unfortunately, I found myself putting up a wall between us for protection and I hated the estrangement. I became increasingly on guard when with her. I didn't want to be hurt. We've been married many years and she knew me well enough to know how to get in deep with her accusations. I detested the alienation but felt caught in a "Catch 22" - be on guard to mitigate the hurt and lose the closeness in the relationship. Remain open and get hurt. Fortunately the outbursts happened and then quickly dissipated but only recently has "being on guard" begun to melt.

Another was the feelings of impotence; being powerless to change the circumstance regardless of what you did. I've always thought my wife was beautiful and while she is attractive physically, her beauty to me has always had little to do with her looks. I enjoy the way she thinks and what she thinks about. When we talk, I learn something. I enjoy watching her meet people. I love hearing her laugh and am frequently in amazement at her ability to laugh regardless of the circumstances. Together we've been through some amazing challenges in life. Her indomitable spirit is what got us through them. While she was going through the worst of the disease, Graves' took all of that away. All I could do was stand by and watch. Nothing I did changed anything.

She had constant headaches from morning to night and over-the-counter medications didn't help. She hurt every time she blinked her eyes. Her feet were frequently so swollen they wouldn't fit in her shoes. The puffiness around her eyes and "bug-eyed" appearance was uncomfortable for others to see. My chest ached as I watched people who previously were attracted by her vivacious personality now avoid her altogether or talked with her in a stilted fashion. I watched her withdraw. I was watching the love of my life shrivel and die while being imprisoned in the role of bystander. All I could do was hold her and cry with her when the unrelenting discomfort got to be too much.

Three and one-half years have now gone by and the nightmare has finally come to a close. The disease went through its cycle and stabilized. My wife has now had corrective surgery to repair much of the physical damage of the disease. She still sleeps with a strip of plastic wrap over her eyes to keep them from drying out during the night and her feet are still swollen although less so. Mostly she has returned to living with that special brand of vitality which I so love. She is laughing again.

Where do you turn when your whole world is turned upside down? How do you cope with a situation of changing emotions, many questions, few answers and no idea when it will all end, if ever? While I survived Graves' disease, I don't think I took particularly good care of myself emotionally during this time. I mostly did my "guy thing"; I didn't talk about it to anyone. It didn't seem appropriate to talk to my wife, my usual confidante. She already had a full plate

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A Sister’s Viewpoint

By **Connie Terry**

I am writing this article to give, from my viewpoint, my experience of how my sister’s thyroid eye disease has affected me and our family. This [is] a frank and honest article which describes the difficulties faced by my sister and myself in seeking help and advice from health care professionals. Although this is written from a personal view, the telling point in the process is that I am a health care professional. So if I find my experience stressful and worrying, what can it be like for someone without my background knowledge?

This was how I felt as a professional trying to seek advice and guidance, with my sister recently diagnosed as having thyroid eye disease. Where do I go? Who do I see? It was a bit like a mystery tour by bus – lots of little stops but not knowing the final destination. A merry-go-round of pieces of advice and help here and there, but no final solution or something to help ease our load.

Although through my work I have seen patients with thyroid eye disease, I had tended like most people to group them by the all too obvious signs of their disease. Oh yes, I dealt with them efficiently and professionally, and to my mind I had therefore nursed them correctly. (The latter was a most poignant attitude with what the future held.)

My sister was diagnosed two years ago and I held a very junior post at the time. My grandmother had under-active thyroid disease. All this meant to my sister and myself was seeing a big bag of tablets that appeared during certain points in the day, usually mealtimes. We therefore thought that all grandmothers did this. My own mum just knew that granny took the treatment prescribed by the doctor, it still being the era of ‘doctor knows best’.

It was only when my sister was diagnosed that we began to realise the serious nature of the illness and the effect that thyroid eye disease would have on all our lives. Of course, being the only health professional in the family everyone looked to me to be the expert. “I’m only an ophthalmic nurse” didn’t quite ring true as an argument! To the family I projected a professional manner, but inside I was as frightened as they all were. I had only a vague idea that this disease was inherent so I felt like using a normal coping mechanism – ignoring it, as it will go away. But as we are a close-knit family I could hardly ignore the people I love.

Although I am a nurse working in an ophthalmic department I did not know a great deal about thyroid eye disease as, being a small unit, we did not see that many cases. My first step was therefore to increase my own knowledge of the disease, and of course to ask the doctors with whom I work. Most made polite noises. All except one avoided answering direct questions such as: “Will my sister get better?” or “What is the best treatment, and who is the best person to go to?”

The local physician was very helpful, although at the time it is fair to say that he just frightened me. He laid the bare facts on the line and honestly said, “Look, your sister will not get better and there is no cure”. He also made me face up to the fact that this disease runs in families and that it could well affect me. So we began the merry-go-round of visits to the hospital, the general practitioner, this specialist might be able to help, and each recommending different treatment or strategies. My mother and myself accompanied my sister on all of these visits.

As the disease manifested itself my sister stayed in the house more and more, and one event that really hit home was how much her appearance was changing. My ten year old niece was looking at pictures of the family and did not recognise her own mum. It also became obvious that my sister couldn’t bring herself to ask such important questions as “What will happen to me?” “Can it affect my children?” Gradually, over time she slowly began to cope with her disease. I purposely do not use the word accepted, for to this day she has not accepted her condition.

To cut a long process short, after many years we finally found a specialist we felt happy with and the decision was taken to opt for surgery. The consultant then moved to Dundee! Luckily he agreed to continue treating my sister, so the time had come for surgery and we all faced this with trepidation and fear. Then my sister became pregnant with her third child. Talk about bad timing!!

Now my sister has just given birth to her third child and we will soon have to think about going back to the specialist to see what courses are open to my sister. Once again, the whole family will pull together to help in whatever way is necessary.

So what is my point in telling you this story, that must be very familiar to the readers of the TED newsletter? Well, as a professional with some knowledge of how the health care system works, if I found our experience difficult what must it be like for the majority of people? This to me highlights the fact that nurses’ education is sadly lacking and an awareness of the needs of patients with thyroid eye disease needs to be promoted. As a member of the RCN Ophthalmic Forum I would suggest to you that you should invite nurses from your local eye clinic to your meetings so that they may increase the awareness of thyroid eye disease. Only by working together can we raise the profile and therefore the quality of care that patients deserve.

I met Connie at an Ophthalmic Nurses Conference in Bristol last November. The TED Association is very grateful to her for this sincere and honest article and for her support and care of all thyroid eye disease patients. - Sally Mitchell (Editor), TED Newsletter.

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Setting Up A Support Group in Your Local Area

Could those members who are really keen to set up some sort of support group in their local area, please contact me and I can provide you with the information you need and provide assistance to do so. You may want to start with a coffee morning or more formal meetings.

Please contact me if you are interested in getting something going in your area.

Scientific Review

By **Alun Stevens MSc FIAA**

In this edition we are once again focusing on the articles reviewed in *Clinical Thyroidology* over the last year. This journal is published by the American Thyroid Association and is edited by Robert D Utiger, a well respected American endocrinologist. Those wanting to read the full reports should visit http://www.thyroid.org/publications/clinthy/index.html

March 2002

Lithium therapy can cause silent thyroiditis and hyperthyroidism

Lithium carbonate is commonly prescribed for patients with bipolar disorder. It is well known to have antithyroid actions and hypothyroidism and goitre are common side effects of lithium therapy. Lithium has also been associated with hyperthyroidism caused by subacute lymphocytic thyroiditis and Graves' disease. The study considered 100 consecutive patients with subacute thyroiditis and 300 consecutive patients with Graves' disease. Hospital records were then checked for serum lithium levels. The number of patients at the hospital receiving lithium therapy was estimated to allow the calculation of the percentage with both conditions. The results showed that amongst lithium treated patients, subacute thyroiditis was more a more common cause of hyperthyroidism than Graves' disease was. Both were more common than in the general population.

Miller KK, Daniels GH. Association between lithium use and thyrotoxicosis caused by silent thyroiditis. *Clinical Endocrinology* 2001;55:501-8

Thyroid hormone stimulates bone growth

Thyroid hormone is essential for normal skeletal growth in children and it stimulates skeletal turnover in adults. The production of growth hormone is suppressed in children and adults with hypothyroidism which in turn suppresses the production of Insulin like Growth Factor I (IGF-I) which has an affect on bone growth. Bone cells contain thyroid hormone receptors and thyroid hormone is therefore likely to have a direct effect on bone which could include the production or regulation of IGF-I. This study evaluated the effect of T_3 on human bone cells in the laboratory. The bone cells were grown from bone obtained during hip and knee replacement surgery on 6 women and 5 men aged 40 to 70. T_3 was shown to have no effect on the level of IGF-I, but T_3 did have an effect on the level of IGF-I receptors in the bone cells. T3 therefore controls the sensitivity of bone cells to stimulation by IGF-I rather than by directly stimulating bone growth.

Robert Utiger comments that the most important reason for growth failure in children with hypothyroidism is probably the reduction in the production of growth hormone, but these findings suggest that this problem will be made worse because the sensitivity of the bone cells to the growth hormone will also be reduced. These findings also explain why children with Growth Hormone deficiency and hypothyroidism respond poorly if treated with either hormone alone, but require both hormones.

Pepene CE and others. Effects of triiodothyronine on the insulin-like growth factor system in primary human osteoblastic cells in vitro. *Bone* 2001;29:540-6.

July 2002

Many people in the US have unrecognised thyroid dysfunction

Thyroid disease, especially subclinical thyroid disease, is common amongst patients seeking medical care. This sub study of the 1988 to 1994 National Health and Nutrition Examination Survey was done to asses thyroid function in a large number of people in the US. The study subjects were 17.353 noninstitutionalised pople over the age of 12. In order to categorise people, TSH levels above 4.5 mU/L were considered high whilst levels below 0.1 mU/L were considered low. Total T_4 levels above 170 nmol/L were considered high and below 4.5 nmol/L were considered low. The results were statistically applied to the overall population. They showed that 4.6% of the population had hypothyroidism, with 4.3% of this being subclinical. 1.3% of the population had hyperthyroidism with 0.7% of this being subclinical. An interesting statistic was that 5.1% of the white population had hypothyroidism while only 1.7% of the African American population had hypothyroidism. Thyroid 11.3% of the population had raised Thyroid Peroxidase antibodies and 10.4% had raised Thyroglobulin antibodies. The prevalence amongst African Americans was 50% lower than amongst whites.

High TSH values increased with age, rising from 2% in the 30 to 39 age group to 12% in the 70 to 79 age group. The prevalence of low TSH did not change with age.

Hollowell JG and others. Serum TSH, T4 and thyroid antibodies in the United States population (1988 to 1994): National Health and Nutrition Examination Survey (NHANESIII). *J Clin Endocrinol Metab* 2002;87:489-99

Serum TSH and thyroid hormone concentrations vary from month to month

The reference ranges for TSH, T_4 and T_3 are broad, which helps to explain the high incidence of subclinical thyroid disease. The variations are due to analytical reasons as well as natural variations which include daily and seasonal changes. This study examines the extent of changes over a one year period within and between subjects without thyroid disease based on 15 men in Denmark. The men were aged 24 to 52 and did not have signs of thyroid disease. Blood samples were taken between 9.00 am and noon each month for 12 months and were analysed for TSH, T_4 and T_3. There were substantial variations within subjects and even bigger variations between subjects for all measurements. The statistical measure of variation for the individuals was about half that for the group. This means that an individual could experience a large, and potentially clinically significant change, in levels and still remain within the group reference range.

Robert Utiger comments that the results are important for two reasons. Firstly, they highlight the extent to which hormone levels need to change before one can be confident that it is not just a normal fluctuation. Secondly, they help explain why some people have symptoms, sometimes pronounced whereas others do not even at the same hormone levels. It all depends on where they started, meaning their Set Point for TSH secretion.

Andersen S and others. Narrow individual variations in serum T4 and T3 in normal subjects: a clue to the understanding of subclinical thyroid disease. *J Clin Endocinol Metab* 2002;87:1068-72.

Thyroxine therapy is not associated with an increase in hip fracture in women

Spontaneous hyperthyroidism is a risk factor for osteoporosis and hip fracture. Whether thyroid hormone replacement is similarly a risk factor for these conditions is not clear. This study evaluated the frequency of hip fracture in patients treated with thyroid hormone and in a matched control group. The subjects were 23,183 patients treated with thyroid hormone for at least one year and 92,732 control patients in the UK. Patients aged less than 16 or those with any history of hyperthyroidism were excluded. The average T_4 dose was 107 mcg daily and the average duration of treatment was 3.1 years. 88% of the patients were women and 66% were aged over 60. 1.6% of the treated group had suffered a hip fracture and 1.4% of the control group. Amongst patients aged over 60, 2.3% of the treated group suffered a hip fracture and 2.1% of the control group. The fracture rate was also similar in treated and control women – 1.7% versus 1.5% - but treated men had a 1.2% fracture rate whereas control men only had a 0.7% fracture rate. The patients in both groups who suffered fractures were more likely to have other medical conditions or be taking drugs which are known to affect bone. The conclusion is that hip fracture in women is not associated with thyroxine therapy, but it might be in men.

Robert Utiger comments these findings are reassuring and they confirm other studies. The differences for the men are unexplained, but might lie in unexamined conditions which might affect the fracture rate.

Sheppard MC and others. Levothyroxine treatment and occurance of fracture of the hip. *Arch Intern Med* 2002;162:338-43.

Radioiodine scans have little value for cancer patients who have undetectable thyroglobulin levels after initial therapy

Most thyroid cancer patients are treated with a thyroidectomy and iodine-131 (I^{131}) to destroy any remaining thyroid tissue. Most patients had a diagnostic whole-body I^{131} scan some 6 to 12 months later which was preceded by several weeks of withdrawal from thyroxine therapy. This retrospective study sought to determine whether this process provided any useful information in patients who had undetectable thyroglobulin levels after the withdrawal of T_4. The study group was 261 women and 54 men, 86% had had papillary cancer and 14% follicular cancer. All had been treated with near total thyroidectomy and the administration of 30 to 100 mCi of I^{131}. This has shown uptake in the thyroid bed in all cases, with 33 patients also having uptake in lymph nodes and 4 having distant metastases. On their initial whole-body I^{131} scan (between 6 a 12 months after the initial treatment), 225 patients (71%) had no uptake. 90 (29%) had uptake in the thyroid bed and none had any metastases. During subsequent follow up which ranged from 9 to 19 years, 281 (89%) had persistently undetectable thyroglobulin and negative whole-body scans. 29 (9%) had persistently undetectable thyroglobulin, but had I^{131} uptake in the thyroid bed. 2 patients (1%) had recurrent thyroid cancer in the lymph nodes. 3 (1%) died of other causes. The conclusion is that patients who have undetectable thyroglobulin concentrations after withdrawal of T_4 therapy rarely have abnormal I^{131} scans and few later have recurrent cancer.

Robert Utiger comments these results confirm an earlier study and demonstrate that patients with undetectable thyroglobulin are unlikely to have any I^{131} uptake (except in the thyroid bed in some patients). He adds that it seems clear that diagnostic whole-body scans have little value and the prognosis is excellent for patients who have undetectable thyroglobulin concentrations when their TSH is high – whether this is due to withdrawal of T_4 therapy or to the administration of TSH.

Pacini F and others. Diagnostic 131-iodine whole-body scan may be avoided in thyroid cancer patients who have undetectable stimulated serum Tg levels after initial treatment. *J Clin Endocrinol Metab* 2002;87:1499-5010

Fertility is not impaired after radioiodine therapy in women with thyroid cancer

Some women treated with high doses of I^{131} for thyroid cancer have transient impairment of ovarian function, but it is unclear whether fertility is impaired. This study assessed the frequency of menstrual disturbances and pregnancies in a group of women who had been treated with I^{131}. The study group comprised 496 women aged below 40 years at diagnosis who were treated at a single centre between 1949 and 1997 and survived for at least 2 years. Ages ranged from 8 to 40 and 77% had papillary cancer and 23% follicular cancer. After initial surgery, 65% received a single dose of I^{131} (30mCi to 80mCi) and the remainder received multiple doses so that they received total doses of between 230mCi and 1600mCi. The extra doses were required because of persistent or recurrent tumours. 80% of the women had normal menstrual cycles. Those with irregularities had received higher doses of I^{131}. No women had permanent loss of menstruation. Amongst the 67% of women who reported that they wanted children, 275 women had 427 children.

Robert Utiger comments that the results are reassuring, but there is no commentary about the outcome of the pregnancies. These results complement a larger study that focused on the outcome of the pregnancies. This showed that the rate of spontaneous abortion was slightly higher amongst the cancer patients whether or not they had been treated with I^{131}, but that is was much higher in the 12 months after I^{131} treatment. The incidence of stillbirth, premature delivery and congenital abnormalities was similar in the pregnancies that preceded or followed the I^{131} treatment. Fertility may occiasionally be impaired, but the outcome of any pregnancy is not different from that in the normal population unless the pregnancy occurs soon after I^{131} treatment.

Vini L and others. Prognosis for fertility and ovarian function after treatment with radioiodine for thyroid cancer. *Postgrad Med J* 2002;78:92-3.

Schlumberger M and others. Exosure to radioactive iodine-131 for scintigraphy and therapy does not preclude pregnancy in thyroid cancer patients. *J Nucl Med* 1996;37:606-12.

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Emotional impact of thyroid cancer

There's no such thing as a "good cancer"

By **Dianne Dodd**

Thyroid cancer affects women three times as often as men and frequently during their childbearing years. Its impact is felt on the whole family. Although thyroid cancer is treatable, thyroid cancer (thyca) patients undergo a draining and often lengthy treatment. As with any major illness, patients may face anxiety, anger, depression, reduced self-esteem and even marital and/or family strain. In addition thyca patients cope with hormonal changes. I wrote this article to share my experiences; to let others know what to expect through the treatment process, to help thyroid cancer patients and their families be better prepared and to reassure patients and caregivers they are not alone – there are resources in the community to help families shoulder the burden of a major illness.

Diagnosis and the waiting game

Many patients experience long waiting periods leading up to a cancer diagnosis. This can be a real roller coaster ride, with one physician reassuring the patient while the next makes some passing comment that sends her crashing into despair. Some patients research their illness on the Internet or through books. However, until a diagnosis is made this may only serve to worry rather than empower. It is difficult to make day-to-day decisions not knowing what the future will bring. Many patients choose to wait until a diagnosis is confirmed before telling family, friends and colleagues, thus facing their anxiety alone. Receiving a diagnosis, whether good or bad, is often a tremendous relief.

Absorbing the reality of a cancer diagnosis initially throws most people into a state of shock, fear and sometimes denial. Each person must set her own timetable for sharing the diagnosis with others. But remember, ***now is not the time to cut yourself off from loved ones***. Communicating the news openly with friends and family allows them the chance to share their feelings and to offer help and support. Some parents try to protect their children from the truth. But when a family is turned upside down by cancer, children sense their parents' distress. Not knowing the cause they will imagine things to be much worse than they really are, or worse still, blame themselves for the mysterious upheaval. Explain that Mommy (or Daddy) will be sick, maybe tired or even sad for a while, but will get better in time. Children have wonderful capacities to help, to understand, and to be warm and nurturing toward a sick parent.

Everyone will need time to absorb the information. Some will want to talk about it, others avoid the topic for a while. Sometimes timetables and approaches differ within a family. For example, caregivers try to protect themselves or their loved ones by engaging in false cheeriness. This denies the person with cancer the opportunity to discuss real fears and anxieties. Each suffers alone, the patient feeling emotionally deserted while the caregiver feels unappreciated in carrying the extra burden of housekeeping, child care, and nurturing. Such resentments are difficult to express, however, because cancer is no one's fault.

Families can avoid such an impasse. While ***it is the patients' right to set the agenda***, patients can help by sending clear signals to family or friends that they are ready to talk, or not. Caregivers and friends should be receptive to these clues. Patients can also help by telling friends, family and colleagues what kind of help and/or support they need. Most people are happy to help if they know what to do. Similar communication approaches will also work with physicians, many of whom believe that cancer patients cannot, or do not want to, absorb all the information at once. They, too, wait for clues from the patient.

- When I'm hypo, don't ask if you should walk the dog, do the laundry or bring dinner over, just do it.
- Invite my family over. Sometimes I need time alone. Even if they're being good, my children can keep me from resting.
- Drive me to appointments until I can drive.
- Handle phone calls, faxes, emails from family, friends and well-wishers. Sometimes its just too much.
- Patients are often anxious and distressed when visiting their physician. Take a tape recorder, or better yet, a calm friend or relative to help ask questions, and remember what the doctor said.

Surgery

Thyroid surgery, whether a partial or total thyroidectomy invokes fear and anxiety. Many patients report that the thyroid surgery is relatively painless and that surgery was the easiest part of their treatment. Following surgery most patients prepare for radioactive iodine treatments. It is especially important at this time for patients to preserve their physical and mental health by getting lots of rest, eating healthy foods, and avoiding stress-causing situations. Caregivers and patients may need to relax housekeeping standards for a while, or get help with childcare and housework. Patients who accept offers of help will not only keep themselves well rested but will provide friends and family with an opportunity to express their concern.

Going hypothyroid

To prepare for radioactive iodine treatment, patients must be off thyroid medication, usually for six weeks, inducing a state of hypothyroidism. Being hypothyroid can be debilitating and is a process that is often repeated for follow-up diagnostic scans. It helps to know what to expect.

Every patient is different. A few lucky thyca patients breeze through what survivors have affectionately dubbed 'hypo-hell'. However, most experience considerable discomfort and emotional upset. Hypothyroidism causes a general slowing of metabolism which may result in indigestion, constipation, nausea, headaches, weight gain, fatigue, muscle aches, slow reflexes, memory loss and cognitive problems, intolerance to cold and puffy eyes.

Thyca patients are especially vulnerable to depression due to the hormonal imbalances caused by rapid hypothyroidism. Rapidly changing, contradictory feelings are not uncommon. Patients may become angry and irritated and exhibit unexplained hatred toward partners, spouses, relatives and friends. Patients may also get confused and forgetful – a phenomenon sometimes called 'brain fog'. Hypothyroid patients may also become extremely withdrawn and appear not to care about family, friends … even their own children. Patients may also become emotionally dependent.

Remember that however bizarre the thyca's behaviour may be, it is a normal reaction to withdrawal of needed hormones. Remind yourself of this and remind your partner. All of this will pass. Indeed caregivers play an important role during hypothyroid periods by being supportive, by avoiding negative reactions, and by assessing whether the patient and/or family may need professional help. While it can be very draining to be around a depressed person, it is important to relate to him or her frequently. Even if the patient is withdrawn, try sitting nearby, reading a book or the newspaper if they don't want to talk. Just letting them know you are there helps. Caregivers may find the thyca patient's expressions of anger, fear and inner confusion frightening, especially those who avoid confrontation in their relationships. However, lashing out in anger at the patient only serves to reinforce the sick person's feeling of worthlessness. Patients need to express negative feelings – indeed it is part of recovery. Remember, they are not angry with you. They are angry with fate, or God, or who or whatever they blame for bringing cancer into their lives. Also try to avoid distancing yourself from a patient, another common reaction, as this will leave the patient feeling abandoned. Guard against excluding the thyca patient from family activities, conversations and decision-making. Patients are ill, they are not mentally incompetent!! They will recover more quickly if you make them feel included, loved and needed.

Thyca patients themselves can also help, even when in the depths of hypo-hell. Fatigue is a significant contributor to depression and mental distress so try to not overdo it. Accept offers of help and don't be afraid to tell people what you want or need. If you begin to feel emotionally neglected by your spouse, children, friends or family, ask yourself whether they are ignoring you or whether you have withdrawn from them.

Sexual relations can also be fragile at this time. Although fatigue, depression, illness, loss of self-esteem and changes in both body image and relationships may cause a loss of interest in physical intimacy, illness alone is rarely the cause of infidelity or marital breakdown. Remind the patient that it is not her physical attributes which make her attractive to you, but intangible qualities, like sense of humour, caring and intellect, none of which are lost during illness. Keep talking and don't be afraid to show affection. Hugs work wonders!

- Illness causes as much stress to a spouse as to the patient. A worried spouse, burdened with extra work could use a 'day off', assistance with chauffeuring kids, or maybe some help at mealtimes.
- Listen while she sounds off. There's a lot happening to her and she needs to verbalize without hurting someone's feelings.
- Act normal, and don't try to cheer her up when she is depressed. It's normal to be depressed when things are going badly.
- Children are amazingly resourceful. Coming to understand that when 'mommy is hypo, she's going to be sad', and that she still loves her child, can help the child mature and eventually deal with adult relationships. Be understanding and patient with a patient who is not acting her old self.

Radioactive iodine (RAI)

Once the patient is sufficiently hypothyroid, she undergoes radioactive iodine treatment. Perhaps the worst aspect of this phase of treatment is its necessary isolation. Hospital personnel often refuse to come into a patient's room and everything is covered in plastic and cellophane to prevent contamination and for ease of clean-up. Upon discharge, and especially if treatment was administered on an outpatient basis, patients are asked to follow a number of precautions to avoid contaminating other people. Being instructed not to touch their own young children for a week nor to be near pregnant women leaves many patients feeling like lepers. Already sick and tired, patients find it incomprehensible that everyone is so fearful of this irradiated iodine, when they had to drink it!! Still, once the treatment is administered patients may begin taking thyroid medication and will feel better within several weeks.

Follow-up

Following treatment, many physicians recommend diagnostic scans which require the patient to become hypothyroid once again, each time for six weeks. Following each treatment or scan the thyroxine dose must be adjusted, a process which takes time and patience. Thyca patients need to maintain a suppressed TSH in order to reduce the risk of recurrence. This means living with slight hyperthyroidism which can cause agitation, anxiety, mood swings, insomnia, tremors, weight loss, diarrhea, heart palpitations, and intolerance to heat. In the initial phase, many patients experience confusing swings between hypo and hyperthyroid symptoms.

In the period immediately following active treatment, both patients and family members expect everything to go back to the way it was before. They may become angry, resentful and/or depressed when this doesn't happen, or it doesn't happen as quickly as they'd like. But many people take a year or even longer after treatment before they feel normal again, and many patients, like other cancer patients, must find a different definition of 'normal'.

After a lengthy absence from work, most find that returning to employment helps them to feel more normal. However, they aren't always sure what or how much to tell co-workers. Again, it is up to the patient to send the right signals. Most people are genuinely concerned and they will respect your right to privacy or your need to talk. Just as no healthy marriage falters as a result of illness, most employers accommodate illness. If you find, however, that ungrounded fears of absenteeism, death, or contagion caused by your cancer, result in dismissal or unfair treatment at work, there are human rights provisions in place to protect you. Become familiar with them and stand up for your rights.

Don't be afraid to ask for help

While most people can cope admirably well with a temporary emergency, thyroid cancer treatment which can extend into months even years of disruption, adds strain to families. A few may find they need professional help. For example, if a patient has a predisposition to depression and/or anxiety disorder, hypothyroidism can trigger the onset of these conditions. Depression coincident with cancer treatment is not unusual, nor is it just something one has to suffer through. In fact, suffer-

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Thyroid cancer ***from Page 9***

ing through can actually inhibit recovery. During treatment patients CAN be treated for depression, a very treatable condition, usually with a combination of anti-depressants and/or counselling. Because depression causes great lethargy and there is a stigma attached to being treated for depression, patients often feel they don't deserve treatment. Caregivers can play an important role in encouraging the patient to seek help.

Although it may not fit with our image of families as loving and nurturing groups, the reality is that families, like individuals, are not perfect. They respond to the crisis of illness in ways that reflect their distinctive coping strategies. Some remain open and calm, others react with fear and anger. Thyca treatment may exacerbate existing unresolved psychological, personal, marital or relationship problems within a family. Gender differences in communication and in coping strategies can add further strain. When the patient is a woman and her caregiver a man – often the case with thyroid cancer – our social conventions are challenged. Unaccustomed to performing the social, emotional management work that most women perform in families, a husband may suddenly find himself called upon to sooth children's disputes, keep dinnertime conversations on an even keel and just listen.

If you need to ask for help, do so. It does not mean your family is falling apart. On the contrary, asking for help is the first step in strengthening a family or relationship. There are support groups, where spouses and close relatives or their partners, who have to live with thyroid cancer, can talk to each other. Many find this beneficial. As well, many cancer clinics offer psychological counselling and other professional counsellors for individuals and families.

No one forgets: the years after

Having cancer is something that no one ever forgets. Cancer forces us to face our own mortality, to lose our sense of control and security and to accept a compromised state of health. Aptly compared to grieving the death of a loved one, this loss may be initially greeted with denial, then anger, depression, and eventually acceptance. Most patients find that they must acknowledge all these tumultuous feelings, before they can recover fully. All of this takes time. Well meaning relatives and doctors should not dismiss the suffering of thyca patients by telling them they have the 'good cancer', leaving patients feeling guilty that their illness is not very serious.

The long term emotional impact of cancer is not all negative. Most people discover hidden strengths and compassion in people they least expected it from, and many relationships are strengthened. Many spouses do learn to nurture, and children may also learn to be more considerate of an ill parent. Sadly, however, some cancer patients have reported the loss of one or more friends. Many people are unsure of how to treat an ill person. They may avoid calling, or even looking at you. If this happens, ask yourself whether you may have withdrawn from them in a period of anger or depression. Then, once you are feeling well enough, try contacting them and letting them know what they can do for you. If this doesn't work however, it is not your fault. Perhaps your illness reminds them of their own mortality, forces them to relive some particularly painful episode in their past, or they have their own unresolved fears of desertion or rejection. Although it is inescapably sad, many patients have to accept the fact that some people will slip away.

Many patients also report that, having faced cancer – that much feared disease – everything else seems insignificant by comparison. This can have a calming effect. Many find they worry less over small things, and have the vision to see each day as a precious gift. Maybe this means enjoying enhanced relationships or starting a new hobby or interest. For some patients, volunteer work is good therapy which allows them to put their new-found knowledge and empathy to good use. There are lots of support agencies who would be glad to hear from you.

Dianne Dodd, who has had thyroid cancer, is a member of Ottawa Area Chapter of the Thyroid Foundation of Canada, and is the Chair of the newly formed ***Canadian Thyroid Cancer Support Group****.*

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Graves' Husband ***from Page 4***

without my "stuff". What about talking to other men? Mostly I didn't. Occasionally I would talk about the topic when I was desperate and someone asked. But mostly, while I found some willing listeners among my friends, those times were never particularly satisfying. They would sympathize but had little or no experience with which to relate. This whole issue of "where does the husband of Graves' go for help" is one area I now know I would do differently. I would take the time to find other men in the same predicament and I would talk to them. If nothing else, I would know I was not alone.

Sincerely
David Bos
Jeffersonville, Indiana

Editor's Note:

David is the husband of Bonnie Bos, Indiana and Kentucky State Director.

This letter was originally published in the National Graves' Disease Foundation Bulletin #38 in 1995. Reproduced with permission. ❀

Next issue of the *Thyroid Flyer*

The next issue of the *Thyroid Flyer* will be published in February 2003. Articles or letters for publication should be sent to The Editor by 1 January 2003.

As of 2003, the *Thyroid Flyer* will be published in February, May, August, and November; instead of in January, April, July and October. The deadline for each issue is the 1st day of the month before the publication date.

This change is to allow the Editorial team time off over the Christmas/New Year break.

Thyroid Flyer by email

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