# THYROID FLYER

**Inside** Page

FEATURE:

NEW:

Newsletter of Thyroid Australia Ltd Volume 2 No 2 April 2001

## *Feature - Thyroid Cancer*

## Editorial

By **Megan Stevens**

We are privileged to have Prof Robert Burton of the Anti-Cancer Council of Victoria writing our feature article on thyroid cancer. Associate Prof Duncan Topliss has also provided information about a new treatment available to patients undergoing scanning for residual thyroid cancer tissue. Thank you both. Our gratitude also goes to five members who have opened their hearts to us and given us a better understanding of how thyroid cancer has affected them.

### Helpers wanted

With our growing membership has come more work. We welcome any members who can give us a hand. Give Megan or Alun a ring on (03) 9561 2483, or Christopher on (03) 9417 1720, to discuss how you would like to help. We need help with the newsletter and assistance at our meetings. We need local meetings to be organised (we will help). Maybe you know someone who could help with funding. Maybe you have some ideas of your own. We would love to hear them. Organisations such as Thyroid Australia are only as strong as the volunteers willing to get involved. Why not give it a whirl?

### CIA forum

The Chronic Illness Alliance Children's and Young People's Working Party invites you to a free forum, entitled "Building A Better Consumer Focus With The Royal Children's Hospital" on Monday, 30 April, 10.00am–1.00pm, at the Epilepsy Foundation of Victoria, 818 Burke Rd, Camberwell (cnr Kintore St), Melway 45 J10. Members of the CIA Children's and Young People's Working Party, and the Association for Children with a Disability, will explain their work with the Royal Children's Hospital to improve services. They invite you to

***Continued Page 2***

## Thyroid Cancer in the Year 2001

By **Robert C Burton**

In 1997 there were 860 new cases (incidence) and 71 deaths for thyroid cancer in Australia, making it the 16th most common incident cancer. Survival after treatment for thyroid cancer was 95% at 5 years in New South Wales for the period 1980 to 1995. This makes it the most curable cancer in Australia, after non-melanoma skin cancer (250,000 new cases and 324 deaths in 1995). Like cancers at most sites, there is more than one type of thyroid cancer. Papillary and follicular thyroid cancer made up more than 90% of all new cases, with anaplastic and medullary (C-cell) thyroid cancers accounting for most of the rest. In this review I will concentrate on papillary and follicular thyroid cancers.

The thyroid gland is an endocrine gland, and makes two different hormones. Thyroxine is made by the cells which line the follicles of the thyroid gland. These cells are the source of papillary and follicular thyroid cancers. Thyroxine regulates the body's metabolic rate. If too much is produced, weight loss, palpitations, anxiety, sleeplessness, bulging eyes, tremulous hands and weakness result. If too little is produced then dry hair and skin, hair loss, lethargy, intolerance of cold and slow thinking results. Thyroxine hormone has iodine as part of its structure, and the thyroid gland takes up most of the iodine we absorb in our diet. Thyroxine production, and hence iodine uptake, by the thyroid gland is controlled by thyroid stimulating hormone (TSH), which is a hormone produced by the pituitary gland, a part of the brain. When TSH rises, more thyroxine is produced and this feeds back on the brain so TSH production falls. Most papillary and follicular thyroid cancers take up iodine under the influence of TSH, and some of them also produce thyroxine.

The second hormone is calcitonin, which is produced by C-cells or parafollicular cells which lie between the thyroid follicles. This hormone helps regulate the body's calcium. Cancers arising from these cells do occur but are rare. Anaplastic thyroid cancers are composed of cancer cells which are so abnormal it is not possible to know from which cells they arose. These cancers do not take up iodine and do not make hormones. These cancers generally have a 'bad' prognosis (outcome).

The diagnosis and treatment of thyroid cancer has become standardised in recent years, and most patients are now managed by specialised units, or multi-disciplinary teams involving surgeons, pathologists, endocrinologists and nuclear medicine specialists. In contrast to the past, where thyroid scans and ultrasounds and other diagnostic tests were done, diagnosis of most patients today can be made by a simple fine needle aspiration biopsy (FNAB) of a thyroid lump, which is how almost all thyroid cancers present. Blood tests for thyroid hormones, and a general medical assessment are all that are usually necessary before a thyroid cancer operation is undertaken. In this operation part or virtually all of the thyroid gland is removed, depending upon the pathologist's report on the FNAB and the operative findings. Post-operatively a dose of radioactive iodine may be given, again depending upon the pathologist's report on the cancer removed and the operation performed. Patients may then have to take thyroxine tablets for a period of time, or for life, depending upon the treatment used for the cancer.

Many patients with papillary or follicular thyroid cancer will have total removal of the thyroid gland, followed by high doses of radioactive iodine (radio-iodine ablation), and then take thyroxine tablets for life. Using this approach the ten-year dis-

***Continued Page 2***

## Thyroid Cancer in the Year 2001 *from Page 1*

ease-free survival (cure rate) is in the range 90-100% for all patients under the age of 70 years, except for those with follicular cancer aged over 60 years. If the cancer is localised to the thyroid gland at the time of diagnosis the cure rate is almost 100%. Even if the cancer has spread to the local lymph nodes the cure rate is still at least 95%. For papillary and follicular thyroid cancer the cure rate for spread to other parts of the body is still about 80%, since most of these cancers take up radioactive iodine, which then destroys them.

Follow-up after the initial treatment includes adjusting thyroxine tablets so that the blood is ‘normal,’ and regular radioactive iodine total body scans to check that the cancer has not recurred. These are done at intervals decided by the specialist team. These diagnostic scans can detect thyroid cancer cells anywhere in the body. The scans are very taxing on individuals, who must stop their oral thyroxine for about six weeks before the scan, use a short-acting form of the hormone for about four weeks and then take no thyroxine for about two weeks before the scan. This is to ensure that the blood thyroxine is quite low as the time for the scan approaches. This will stimulate TSH production by the pituitary gland, so any thyroid cancer cells left in the body will take up the radiative iodine and be visible on the scan. If the thyroid cancer does recur more treatment with high-dose radioiodine may be given.

After the scan it can take many weeks of oral thyroxine before the blood level reaches normal. All in all, each of these scans takes about three months out of the patient’s life. In these three months individuals will have a low metabolic rate and feel lethargic, drowsy, depressed, have memory problems and cannot drive a car. Because survival is so good after treatment for papillary and follicular thyroid cancer, treatment modifications which avoid total thyroidectomy and radioiodine ablation in very good risk patients, such as younger females with small localised cancers, are being explored. Because follow-up radioactive iodine whole body scans are so stressful for patients and their families, new approaches involving reducing the frequency of scans and directly stimulating thyroid cancer cells to take up iodine are also being explored.

In summary many improvements in the diagnosis, treatment and follow up of patients with papillary and follicular thyroid cancer have occurred over the last half century. Today these are the most curable of the potentially serious (non-melanoma) cancers which humans suffer from.

*Professor Robert C. Burton is Director, Anti-Cancer Council of Victoria. His stepdaughter was treated for thyroid cancer in 1997.*

Further reading:

- Papillary and Follicular Thyroid Cancer, *New England Journal of Medicine*, Vol. 338, 297-306, 1998
- Prognostic Factors for Thyroid Carcinoma, *Cancer*, Vol. 79, 564-573, 1997

## Editorial *from Page 1*

assist and/or present your views on how this process can best serve you. Lunch is provided. RSVP by Thursday 26 April:

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### T4/T3 combination trial in Perth

Dr John Walsh of the Department of Endocrinology and Diabetes at Sir Charles Gairdner Hospital is looking for participants in a trial of T3/T4 combination therapy. The main eligibility criteria are hypothyroidism, a dose of thyroxine of 100mcg per day or more, a serum TSH of between 0.1 and 4.0, and good general health apart from hypothyroidism. Anyone living in Perth who is interested should ring Lynley Ward on 9346 2370 or Suzie Gegoff on 9346 2466.

### Thyroid awareness raising

We are thrilled that the thyroid message is getting out in the wider community. Three magazines have published articles in the last three months. Thanks to *She* and *New Woman* for including contact details for Thyroid Australia, thereby allowing us to provide support to those with thyroid conditions.

- “Feeling fat and tired?”, by Leta Keens, *She*, March 2001.
- “A gland affair”, by Sally Clark, *Australian Good Taste*, May 2001.
- “Gland trouble: Why didn’t I know I was so sick?”, by Lollie Barr, *New Woman*, May 2001.

### Stress and the thyroid

One of the most distressing symptoms I have suffered, before and after diagnosis with Hashimoto’s thyroiditis, has been severe muscle pain and/or weakness. This has been described by doctors as being due to either psychogenic shock or stress. I have not always had thyroid function tests when experiencing this symptom, but those I have had, have shown low normal free T4 and free T3 levels; levels which I believe to be too low for my own well-being.

Recently I have again had episodes of this symptom. It took a fresh, young, enquiring mind to make the connection. My daughter commented that I had been through stressful periods, adding, “Mum, you always crash two weeks after stress.”

So, on a bad day, while lying on my bed unable to move, I asked my husband to see what he could find about what stress does to thyroid hormone levels – and this is what he found:

> “Glucocorticoids in excess affect thyroid function. Although basal TSH levels are usually normal, TSH responsiveness to thyrotropin-releasing hormone (TRH) is frequently subnormal. Serum total thyroxine (T4) concentrations are usually low normal; however, thyroxine-binding globulin is decreased, and free T4 levels are normal. Total and free T3 (triiodothyronine) concentrations may be low, since glucocorticoid excess decreases the conversion of T4 to T3 and increases conversion to reverse T3. Despite these alterations, manifestations of hypothyroidism are not apparent.” [J. Blake Tyrrell, David C. Aron & Peter H Forsham, “Glucocorticoids & adrenal androgens”, in *Basic and clinical endocrinology*, Francis S. Greenspan (ed.), 3rd ed. (London, Prentice-Hall), 1991, p.334.]

*[Glugocorticoids include Cortisol, which is the primary stress hormone, and related compounds produced by the adrenal glands.]*

The authors indicated that there was no evidence of hypothyroidism, but this was undoubtedly for patients with properly functioning thyroids. The real question is what happens to patients who are dependent on a fixed dose of T4 and the conversion of this T4 as their only source of T3. Could stress in these circumstances not lead to hypothyroid symptoms of varying degrees?

I am interested to hear the views of our readers on this topic, both from those who are medically trained and those fellow thyroid sufferers who may or may not have had similar experiences to my own. Write to us and let us know what you have found.

# Thyroid Cancer & Thyrogen

By **Duncan Topliss**

Thyrogen® recombinant human TSH is manufactured by Genzyme Corporation (USA) which has an Australian subsidiary based in Sydney.

The drug is not registered in Australia, and until registration by the Therapeutic Goods Administration (TGA), cannot be considered for subsidisation by the Pharmaceutical Benefits Advisory Committee (PBAC). Registration in Australia is dependent upon the company submitting the required material on efficacy and safety for detailed evaluation by the TGA and the approval of the drug by the Australian Drug Evaluation Committee. Any eventual listing on the Pharmaceutical Benefits Scheme (PBS) is dependent upon assessment of cost-effectiveness, therapeutic benefit etc and satisfactory negotiations on pricing.

It is my understanding that the company intends to submit the drug for registration in Australia and presumably for PBS listing as well. If the drug achieves eventual PBS listing, it will be as a section 100 drug. This means it will have very specific conditions of dispensing regulated via a hospital pharmacy, which in practice will mean usage by specialists in the area in accordance with their prescribing privileges at that hospital and the hospital budget.

Thyrogen can be supplied in Australia under Special Access Scheme (SAS) regulations after specific application by the managing doctor to the TGA. Thyrogen is a category C drug which means it is not life saving but is of therapeutic value. A delegate of the TGA makes the decision on supply to the specific patient. This decision can be appealed.

In practice I would not anticipate, and have not experienced, any difficulty in gaining approval for indications as approved in the USA or indeed rational extensions of those indications, if application comes from a specialist in treatment of thyroid cancer.

The more difficult issue is the cost of Thyrogen which is $1,500 (AUD) for the standard two doses of 0.9mg required for scanning. The approval by the TGA under SAS does not mean any subsidisation of the cost which therefore must be met by the company (ie compassionate use), the patient, or the hospital if the patient is attending a public hospital. Obviously there is no obligation by the company or the hospital to meet this cost.

My small personal experience to date is consistent with the overseas experience. Clearly patients do not experience any period of hypothyroidism in preparation for scanning and the actual Thyrogen injection period is no problem.

The procedure is simple in that only daily attendance for 5 days without prior preparation is needed:

Day 1: Thyroid Function Test and Thyroglobulin blood sample, then Thyrogen injection intra-muscularly.
Day 2: Repeat Day 1.
Day 3: Blood sample and administration of scan dose
Day 4: Blood sample
Day 5: Blood sample and scan.

Thyroxine is taken throughout at the usual dose.

The quality of the scans as shown by the trials is very similar for Thyrogen vs T4-withdrawal. Some scans in the trials were rated better after T4-withdrawal and some better after Thyrogen, perhaps slightly favouring T4-withdrawal scanning.

Thyroglobulin response is another parameter that can be measured after Thyrogen and may come to be a sufficient longer term follow-up parameter without scanning.

Of course, if the scan indicates a dose of radio-iodine is required then T4-withdrawal has to be planned in accordance with current standard practice. Therapeutic use of Thyrogen to aid in the treatment of metastatic thyroid cancer instead of T4-withdrawal, is still being evaluated but is likely to become another indication for its use. It is already possible to apply under the SAS regulations to use Thyrogen in this way. As there is an absence of agreed demonstrated effective protocols this application would not be standard yet, and would, I think, only be considered in unusual or difficult circumstances.

*Associate Professor Duncan J. Topliss is Director, Department of Endocrinology & Diabetes, The Alfred, and is also a member of Thyroid Australia's Medical Advisory Committee.*

## Next issue of the *Thyroid Flyer*

The next issue of the *Thyroid Flyer* will be published in July 2001. Articles or letters for publication should be sent to The Editor by 15 June 2001.

## *Thyroid Flyer* by email

We would like to remind our readers that the *Thyroid Flyer* is also available in full colour as a PDF [portable document format] file as an e-mail attachment. Please let us know if you would prefer to receive the newsletter in this format instead of having it mailed out to you (or if you would prefer to receive it in this format as well as having it mailed to you).

# Over To You

From time to time we would like to 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, T4 and T3) 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.*

## T4-Withdrawal Psychosis

My baby daughter was three months old when I first noticed a swelling at the base of my neck. The following day I visited my GP, who told me this was very common and not to worry about it. He ordered a full thyroid function test, which showed that my TSH levels were within the normal range. I was experiencing heart palpitations whenever I turned my head to the left. The swelling was only on the left side, so I felt that this was putting pressure on me internally, that somehow made my heart race. The next step was injecting radioactive iodine in preparation for scanning. The scan revealed that my thyroid was functioning normally. My GP still felt that I had nothing to worry about. He said that if I didn't like the swelling cosmetically it could be surgically removed. So I went home not knowing what else to do. As the weeks went by, I started to feel a growing uneasiness about it. Again I returned to my doctor requesting a referral to a surgeon. A visit to the surgeon resulted in me having a biopsy. Once again the results revealed nothing. My daughter was now one year old. By now I was starting to feel overwhelmed by dread and my instincts told me that something was very wrong. I revisited the surgeon and asked him to remove my thyroid.

Six months later I had my left thyroid removed. It contained follicular and papillary cancer. The surgeon was very surprised at the findings, as it was totally unexpected. Also there was no history of thyroid cancer in my family. I have to say that the cancer came as no surprise to me. I felt that all along the lump was suspect. I was then immediately booked into hospital the following week for a further operation, to have the remaining thyroid removed. The right side was clear. The cancer was fully contained in the left thyroid gland, so hopefully it was totally removed. After several months I had a dose of radioactive iodine to eliminate any remaining thyroid tissue, and started my hormone therapy, this being thyroxine, taken daily.

All was well for the next few months. My daughter was now two and a half years old. I was now under the care of an endocrinologist who stopped my intake of thyroxine in readiness for a further scan. For two weeks I took T3, then stopped all medication two weeks prior to the scan. Just days before the scan I visited the hospital for my radioactive iodine dose. Two days before the scan I awakened one morning with huge bags under my eyes. My endocrinologist informed me previously that I might feel flu like symptoms. I thought that maybe this is as bad as it gets. I felt incredibly tired and needed to sleep most of the time. The next night I woke in the middle of the night with a fright. My eyes felt as though they were rolling up into my head, my tongue felt like it was sliding down my throat suffocating me, my toes and fingers were also numb. I couldn't sleep. I telephoned my GP the next morning, fearing I was having a stroke. He was at a loss, and didn't know what to tell me, except that it wasn't a stroke. The day of my scan was here. Afterwards I was told that it was incomplete (this was on a Friday). I was told to come back Monday to have another scan.

Friday night was the worst night of my life. I was lying in bed beside my daughter, when I felt an icy cold shiver descend upon my head. I started shaking because I was incredibly cold. Looking around the bedroom, big black shadowy spiders were rotating around the walls. I got out of bed and peered out the front door at the night sky; all the stars and the moon seemed to have disappeared. Over in the distance, bright lights that looked like a spaceship descended from the heavens and looked to be landing about a kilometre away. Thoughts from "God" started entering my head. I grabbed some paper and started writing something like the Ten Commandments. I was convinced it was Armageddon and wanted to speak to a minister of the church. I woke my daughter fearing her safety from the black monsters in her bedroom. Luckily part of my brain still wanted to protect her, so that no harm came to her. But I did refuse to give her a bottle of milk, thinking that the devil had poisoned it. By the morning the house was full of people, family members, police and my minister.

I was admitted to the psychiatric hospital as an 'Involuntary Patient', being locked away with the worst of the patients. I refused medication, fearing that the doctors were trying to poison me. Part of me was very psychotic but there was also a part of me that was attempting to rationalise what was happening to me. It was like part of me was watching a graphic horror movie that couldn't be switched off. At one stage I thought I must be in some kind of game show. I also thought the other patients were clones of my family, even though they did not look like them, and became very frightened for my family's safety, as I had not been able to see them yet.

I was also very indecisive, even when entering a doorway I couldn't decide if I was to continue through the doorway or retreat backwards. Therefore the nursing staff were continually pulling me out of the doorways. At times some unnecessary force by the nursing staff was used upon me, which I considered unjust as I was very placid, tired, cold, frightened and confused. I could not decide the simplest thing.

At the very worst, that night, for psychotic reasons I ate soap and the tops of flowers that were in my room. I lay in bed in the darkness physically feeling myself 'unravelling' and 'shrinking' like a decaying corpse in a coffin. I was terror-stricken. I was sure I was going to die and waited for it to happen. All night

**Continued Page 5**

**Cancer Story 1 *from Page 4***

I felt my body decaying, my teeth getting loose, my eyes sinking into my head and my body shrivelling away into nothing. I was also hearing voices, talking about my diminishing body. By morning my body was shutting down. I could barely lift my head off the pillow.

My family wasn't allowed to see me for two days. I felt this was wrong, as it left me isolated with complete strangers and made me feel distrusting of everyone. My endocrinologist made a brief appearance on the second day. I did not get to see him again until several months later. I remember him looking at me blankly and barely speaking to me. I learnt later that he had told my husband that he did not know what was happening and had not heard of this happening before.

Here I was, from the onset, with my heavy black coat on, freezing cold, and refusing to take it off day or night. I also complained of numbness in my fingers and toes. I was later to find out that these were classic symptoms of hypothyroidism.

All the doctors kept talking about me having some sort of breakdown and having to deal with the past. It was at this stage a psychiatrist was recommended. Only my mother, for two days, kept arguing with them that this was uncharacteristic of me and it must be my thyroxine withdrawal. She convinced them of the importance of having the scan on Monday. So they injected a large dose of Valium into me and wheeled me down to have my scan. The doctors were still considering schizophrenia, but concluded that I was too old for this to be appearing now.

On about the third or fourth day I remember a calmness descending upon me. I was so tired I barely moved and I had not eaten or drunk for days. My mouth and tongue felt very sluggish. A nurse took my blood pressure and found it was dangerously low. She could not find my pulse, apparently it was very faint. They tried to take blood, but my veins had all collapsed. It wasn't until they let me see all of my family that my eldest daughter's concern convinced me to swallow my medication. The next day there was a marked improvement and the first thing I did was drink about twenty-five cups of water. I was severely dehydrated. I was now taking thyroxine and Respiredal (anti-psychotic drug) daily.

In the next two weeks the improvement in my psychosis was rapid, which led to my discharge from hospital. I was sent to see a psychiatrist on a weekly basis, to sort out 'past traumas'. On my first visit, my psychiatrist suspected hypothyroidism straight away and wrote his report stating this. I was relieved to now have a better understanding of what had happened to me. I contacted Thyroid Australia and read up on everything I could get my hands on about my condition. It all made sense now and confirmed a severe case of hypothyroidism.

It was still not over; the worst was yet to come. Over the next few months my bowels had shut down completely. The bathroom was now a place of mental anguish every eight days. I was so cold I had to take very hot baths before going to bed to allow me to sleep. My brain was in some kind of fog. I could not read or write and it took all my concentration to even talk. I lost custody of my baby girl, as I was unable to look after her. My left toes were cramped under all the time. I had muscle spasms all over my body and numbness in my hands. My hair was turning grey and failing out. The skin around my fingernails became thickened and coarse. I couldn't lift my arms above my head for any amount of time and I was constantly exhausted. All my emotions were dulled. I couldn't cry even when I wanted to. I felt and looked like a walking zombie. After three months, my TSH levels were back to normal. But the trauma of the last few months now plunged me into a dark hole of depression. I could not function at home by myself, cooking, cleaning etc. I had to live with family members to support me psychologically. I had frequent anxiety attacks and had to take Valium to combat this. I became almost suicidal and I was especially fearful of my 'brain fog' as I thought I was heading for insanity. My psychiatrist put me on to anti-depressants, within four weeks I started to improve.

In the meantime I visited my endocrinologist, this being five months since my supposed breakdown. He still seemed at a loss with what had happened and even mentioned menopause. I couldn't believe it. During the last few months I had collected a lot of information from Thyroid Australia. My psychiatrist even photocopied it and we worked together to get me well again. Incredibly, when I tried to show this same information to my endocrinologist, he was not even interested in looking at it. He then informed me that the scan taken five months ago, still showed some residual thyroid tissue. He felt that maybe in a year or so, when I had sufficiently recovered, we could go through the same procedure again, this being 'hormone withdrawal'. I was dumbfounded and horrified. I burst out crying in panic. I could not breathe properly and I was shaking all over. At this moment I couldn't care less about the cancer returning. I feared hypothyroidism much more and knew for certain that I would never cease my medication of thyroxine ever again whatever the cost.

I never saw my endocrinologist again. It was obvious to me that he knew very little of my condition. I made an appointment with a specialist on the Thyroid Australia Medical Advisory Committee. What a difference that made. He understood what I had been through and stated that what I experienced was rare but very well documented. He strongly advised against hormone withdrawal treatment. He has now organised compassionate use of the drug Thyrogen. I am currently awaiting this treatment with a mixture of anticipation and great nervousness. I am still taking a low dose of anti-depressant to get me through the next month; it helps suppress the fear that is always lurking beneath the surface.

### *Post Script*

Leading up to my Thyrogen treatment was particularly hard. Logically, I knew that all would probably be fine. But I still didn't trust myself psychologically. I was acutely aware that my mental frailness may present itself physically in some form of reaction.

I occupied my mind with 'good thoughts' as I had the first Thyrogen injection. The next day I had a second injection. All was going well so far. On the third day, I had my radioactive iodine dose in readiness for a scan on the fifth day. After the scan was completed, I was told that it went very well, and showed what my endocrinologist expected. No further treatment or scanning was needed to be done for another 12 months. I felt ecstatic. The whole week went by without incident. I now feel like I've been given my life back, and more importantly, I have my beloved three and a half year old daughter back in my full-time care.

Thyrogen has given me back my 'self-trust'. Future treatment and scans can now be looked forward to with a new confidence, without fear.

# Thyroid Cancer at 62

In March 1992, when I was sixty-two years of age, my thyroid gland was totally removed. While the operation was in progress a frozen section was taken which gave the surgeon the correct diagnosis. Unfortunately, I cannot remember the variety of cancer I had, nor have I kept any notes on my blood levels etc. Perhaps it was and is selective amnesia? Both the surgeon and my G.P. have always kept me fully informed about all of my tests. Due to my complete confidence in these two men I do not give the results a second thought after they have told me. On two occasions the replacement thyroxine has been adjusted downwards, now I take only one tablet each morning. I feel well, apart from fatigue caused from both age and being my husband's sole carer. I am mentally alert, still drive, run the household and continue with my main hobby which is painting.

It was in early October 1991 when I had the first indication of a problem with my throat. I felt a sharp short pain as I applied cream onto the front of my neck. Two weeks later it still hurt, but only when I touched it. My GP sent me for an ultra sound which showed an enlarged thyroid gland, said to be non-malignant. He also sent me to a specialist surgeon for a second opinion.

By December I was feeling unwell and becoming very lethargic. I was placed on the surgery list for March, at my request because I am a hayfever sufferer from approximately August to March each year. The thought of sneezing post-op did not appeal. The week prior to my admission to hospital I found swallowing more difficult and by the end of that same week any exertion made me short of breath. As an ex operating theatre sister, I knew what was happening, so I put my self to bed, fully expecting an early admission. Luck was with me, as it has remained.

Previously, my surgeon had asked me if I had had any aches in my head - a carefully worded sentence I later discovered. I had been a migraine sufferer but it wasn't until the lower part of my face and my front upper teeth began to ache that I realised what he had meant. My teeth had been checked by my dentist who couldn't find anything amiss.

Apart from my parathyroids 'resting', everything went very well post-op, my throat didn't hurt except when I swallowed. I was talking normally and breathing very well! To restore my parathyroids to health I was given intravenous calcium and consequently didn't suffer any complications. My wound healed remarkably well and today the scar cannot be seen unless it is in a 'good light' and my head is tilted backwards, even then it is barely visible. I attribute that to my surgeon's method of closing the wound and to the naturopathic creams I used after it had healed and during the radiotherapy process. My skin, the pale Irish type, never 'burned' and all sign of redness had completely gone two weeks after the last treatment, even today it is still soft and supple and not discoloured.

On the evening of the operation my surgeon told me that my thyroid was 'not benign'. This didn't upset me at all because I had already sensed that it would probably be malignant. In an odd way I was relieved because I knew I hadn't been making it all up. It explained why I had experienced this inexplicable tiredness for such a long time, and later a sudden loss of energy; why my moods swung so much, why my skin was becoming very dry and why my fingernails were brittle. [I have since discovered the main common complaint that cancer suffers have is an unexplained tiredness - my parents who suffered different cancers had it, 'not sick, but not well'.]

On the day of my discharge from hospital I was given a tasteless dose of radio-active iodine and told to keep away from all young people for a specified number of days while I was radioactive. I thought I was free from any further treatment, other than regular health checks for the remainder of my life, but, on one of my regular visits to the surgeon he told me that I should have radio-therapy as a 'belt-and-braces' to ensure nothing was missed. It was from that moment that I became 'undone' - I ruined a box of his paper tissues, I cried all the way to see the radiologist and sobbed as I was being measured for future cobalt therapy - five sessions per week for six weeks. For most of those weeks my shaking chin had to be strapped to keep it still during each session. I dreaded every minute in that room.

Somewhere in this nightmare I experienced a test where I was injected with a dye(?) and told to drink litres of water before being screened. I think it was something to do with radium and malignant cells wandering around in my bones. [*Editor: The injection was probably radioactive iodine in preparation for a scan.*]

Another time in the nuclear medicine department I was expected to lie under something that looked like the lid on an Aga stove, only this one was much, much bigger. I remember screaming as they lowered it over my head, so they did the procedure another way where they sat me up against this enormous black disc. I was totally unnerved and I remained that way until the six weeks were over. The milder more acceptable, if noisy, examinations were the detailed chest xrays where a machine clunked its way along as it took each film.

There were pluses in all this - although I had lost a lot of weight I had returned to my pre-marriage size and my ankles and legs regained their slenderness. Best of all my allergies had gone and I could eat all foods without a reaction. When I regained my energy life was very good, very good indeed. My two children, who were in their early twenties suddenly realised that Mum was not invincible, and since then ask how I am and really want to know. A lovely feeling. My husband was a great support and has continued to be until he developed Alzheimer's disease.

Nine years later, my ankles and legs have again thickened as has my waist, my food and other allergies have returned and my two front upper teeth ache whenever I am upset or tense, also read - angry! My voice is still strong although it weakens when I am tired, as my surgeon said it could. All my chest x-rays have been clear, and I pass my annual physical examinations with ease. I have only praise for the medical and nursing staff who have looked after me. I was, and am, a very lucky person.

# A Potted Cancer History

**Do you have a family history of thyroid cancer?**

My mother had a small goitre removed when she was 58. My sister had to have nodules removed in April 2000. She is 55.

**When were you diagnosed?**

When my thyroid was removed in 1992, a section was sent to pathology and cancer was detected.

I was devastated and wondered if I should have had my thyroid removed earlier, in spite of the fact that my doctor said there was no need to remove it until it bothered me.

**What form of cancer did you have?**

Hurthle Cell Carcinoma.

**What symptoms did you experience?**

I noticed I was starting to become puffed and out of breath when doing some climbing as the nodules were pressing against the tube.

**What treatment did you have?**

After a total thyroidectomy I had radioactive iodine treatment. I was given a radiation capsule and had to remain in isolation until the geiger counter gave me the all clear. Ridding the body of radioactivity depends upon the amount of liquid you drink and the amount you void. I set my target at drinking one glass of water every half an hour.

**How did the treatment affect you?**

I had to stop taking thyroxine before having radioactive iodine treatment and go on an iodine free diet, usually 3-5 weeks before. I noticed some symptoms - increasing tiredness, lack of muscle tone, mainly using fine motor skill movements, e.g. cleaning my teeth, forgetfulness. I planned my social life around the times I knew I was to have radioactive iodine treatment, i.e. every six months.

**What was your recovery like?**

After the radioactive iodine treatment I slowly increased my dose of thyroxine to 150 mcg over three weeks, having been warned that it is dangerous to increase my thyroxine dose too quickly because of my metabolism.

My recovery was gradual, mainly taking 4-6 weeks to feel normal. Some side-effects have been noticed - slight loss of hair, swollen & dry salivary glands, sore, swollen lips, watery eyes with a tendency towards conjunctivitis.

**Have you had follow up scans and what are your experiences?**

I have had numerous scans, MRI's etc., indicating that the cancer had spread. I had my lymph glands removed and another operation to remove nodules from my lung. Currently I have numerous spots on the lungs and hope that the radioactive iodine treatment will keep them under control.

**How are you feeling now?**

My feelings sometimes seem like a yoyo. I'm still working and find that for me, this is the best therapy as I feel I would become very depressed if I stayed home. My future prognosis is unsure so I tend to want to live life to the fullest, sometimes exhausting me and my husband.

*September 1985:* Large, multi nodular goitre appeared, almost certainly benign.
*April 1986:* Thyroid a little larger.
*November 1986:* Small dose suppressive thyroxine - 100 mcg.
*December 1987:* Gland unchanged.
*April 1989:* Gland increased in size.
*April 1990:* No immediate reason to interfere with gland.
*December 1991:* Marked increase in goitre size. Appointment with surgeon.
*April 1992:* Total thyroidectomy. Pathology examination found tumour - classified as minimally invasive Hurthle cell carcinoma.
*July 1992:* Treated with radioactive iodine. Increased dose of thyroxine 200mcg.
*December 1995:* Reduce thyroxine to 175 mcg. TSH at lower limit of normal. Serum thyroglobulin 8pmol/L.
*February 1997:* TSH 16.59 (0.40-4.70). Raised TSH consistent with inadequate thyroid replacement therapy. Free T4 is indicative of active thyroid cells. CT scans reveal nothing.
*December 1998:* Rising thyroglobulin level indicates recurrent Hurthle cell carcinoma in lymph nodes and lesion in left lung.
*January 1999:* Removal of lymph nodes.
*May 1999:* Thoracotomy - removal of lung nodules.
*August 1999:* Elevated thyroglobulin level.
*February 2000:* Increase in lung nodules, rising serum thyroglobulin level.

I have had two radioactive iodine treatments and each time the thyroglobulin has gone down compared to pre-treatment levels.

*June 2000:* Thyroglobulin 10,000 to 3,300 approx.
*January 2000:* Thyroglobulin 8,000 to 2,200 approx.

# Letter

Dear Robyn,

I did not have a family history of thyroid cancer nor did I give such a disease any thought. My reason for going to the doctor in the first place was a persistent cough and a feeling of pressure in the throat. I had numerous tests, including a nuclear x-ray and a biopsy, that all proved negative but it was decided to operated to remove some nodules from my throat.

Whilst removing the nodules the surgeon believed that the sight was malignant and a biopsy was done after the operation which initially returned a negative result however the surgeon insisted on another test and this time it was found to be positive.

So, one week after having part of my thyroid and some nodules removed, I again went into the operating theatre to have the remainder of the thyroid and some surrounding tissue removed. Following the operation I had a dose of nuclear medicine to eradicate any remaining cancer cells. This consisted of swallowing a tablet and sitting in complete isolation for four days. There were no adverse side effects of this treatment apart from being isolated.

The specialist involved with me was very good in explaining the operations, the treatment and the follow-up procedures and was very helpful. Although my recovery was very slow, things progressed quite well. The difficult part was getting the required levels of calcium and thyroid hormone correct and balanced and this took many months and even now, 8 years later, needs monitoring.

Today my main problems include tired and aching bones, and the fact that I feel the cold terribly and have difficulty getting warm even when others around me are comfortably warm. During the operation part of my vocal cords were damaged and consequently my voice is not as strong as it used to be which is a minor problem.

I had follow up scans every three months for the first 3 years and now have a yearly scan and a bone density scan every 2 years, my dose of Oroxine (thyroxine) is 200mcg one day and 175mcg the next. At the time of the operations I was really too sick to think much about the future, but am grateful now for the work and dedication of all the staff involved then and since.

# Neck X-Rays Cause Cancer

**Do you have a family history of thyroid cancer?**

No, however my sister has also had thyroid problems and has had part of hers removed. We are led to believe that the intensive X-ray "treatment" for acne we both had when we were in our late teens caused my cancer and her "abnormalities". The X-ray treatment was done by a well-known dermatologist and was common practice then. He did say to us that we might have "problems" due to this treatment in about 30 years' time. His prediction was very accurate, almost to the year, for both of us.

**When were you diagnosed?**

I noticed a large lump growing in my neck in the mid-1990s. I went to a GP about it in mid-1996. Unfortunately, I was sent by this suburban GP to see a general surgeon who turned out to be verging on incompetent. By his own admission, he told me that he had been successfully sued in the past. On another visit, he waved a male patient's cancer test results at me and said, "I have no idea where to start". He also told me he'd recently taken a young man's thyroid out unnecessarily. All of this should have sent me running to get another opinion. Instead, I allowed him to do an FNAB (fine needle aspiration biopsy) puncture into my neck, with no anaesthetic. When the results came back he said he couldn't decide what to do, as they were 'inconclusive'. Again, I should have sought another opinion. He told me to come back in 12 months' time.

By mid-1997, 13 months later, the lump in my neck was significantly larger. Again this surgeon did an FNAB on the lump without anaesthetic. Again he told me that the results were 'inconclusive', but he said perhaps he should operate and 'investigate' anyway. He basically left the decision to me. I decided to go ahead, as I was becoming rather worried.

At the hospital after the operation, the aftermath of which was extremely painful, the surgeon came in and without any apology or sympathy said: "You have cancer". I was stunned. Then I became very angry – about his misdiagnosis, the delay in treatment, his lack of care and caring. I did not return to him but was referred by a recommended oncologist to my current specialist, Dr X.

**What form of cancer did you have?**

I am not certain; it could have been papillary. Well-defined but fairly large and indications were that it had spread to nearby lymph nodes.

**What symptoms did you have?**

The symptoms were a significantly swollen neck. I also became very overweight within a fairly short time (2-3 years), for no apparent reason. I was also extremely fatigued and suffered a lot of migraine headaches.

**What tests were done to confirm the diagnosis?**

Two FNAB's were done, 13 months apart.

**Did this condition affect your thyroid hormone levels?**

I can't answer this, as no thyroid hormone level tests were done prior to the operation, to my knowledge.

**What treatment did you have?**

I was operated on for a total thyroidectomy. However, a significant amount of thyroid tissue was left and I was given radioactive iodine a few weeks later. This was extremely painful and I had to be hospitalised for pain control for over a week.

**Did your specialist explain your condition and treatment thoroughly?**

The general surgeon who did the original operation most certainly did not. However, once I contacted the oncologist and was referred to Dr X, I was given a lot of explanations and support.

**How did the treatment affect you physically and emotionally?**

The initial operation and radioactive iodine treatment were very painful. I was left significantly depressed and anxious.

**What was your recovery like?**

Once I felt that I was being competently treated, my recovery improved. However, I experienced a lot of anxiety each time the annual scan came around. I did not find the doctors and technicians at the Alfred Hospital's Nuclear Medicine Department very supportive. They explained very little.

**Was thyroid hormone replacement needed after treatment?**

Yes, I was put onto thyroid hormone replacement immediately after the initial operation. Over the ensuing five years my dosage has increased. I am now on 250mcg a day. This is, I believe, at the high end of the range, however I feel very fatigued if the dosage is decreased.

**Have you had a follow-up scan and what were your experiences?**

Every 12 months after the operation I have had radioactive iodine and a subsequent scan. In late 1998, I had another large dose of radioactive iodine (100 millicurie, I think), as there was still some thyroid tissue present. Although I was hospitalised, this time the treatment was not painful.

I had an annual scan in February 2001 and was told that it was clear. This is the second clear scan for two years running. I have been told that I will now just be monitored by regular blood tests.

**How are you feeling now?**

I am cautiously relieved but not altogether convinced that the disease won't return. I am still overweight and cannot shed the kilos, no matter how I try. I believe that this is common amongst thyroid disease patients. I tire very easily. However, my migraines have disappeared.

Thyroid Australia Ltd
ACN 094 832 023 ABN 71 094 832 023