



THYROID FLYER

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Newsletter of Thyroid Australia Ltd

Volume 2 No 1 January 2001

Feature - Childhood Thyroid Conditions

Editorial

By Megan Stevens

Well, here we are at the beginning of another year, one which some say is the true beginning of the new millennium! I trust you all had a wonderful Christmas and New Year.

As we begin this new year, we would like to thank all our members, all those who have contacted us for information and support, and all the medical practitioners who have assisted us over the past 18 months. We do appreciate all your help and support. Thanks too to all those who have helped at meetings and to the committee, without whom none of this would be possible.

We are working on the meeting program for 2001. Details of the meetings we have arranged so far can be found on the insert. We look forward to seeing you again this year.

Dr Tony Hall

Those of you who missed Dr Tony Hall's talk on thyroid eye disease on 18 November missed a most informative and interesting afternoon. We thank Dr Hall for his wonderful contribution to our knowledge on this complex topic. We hope to be able to ask him to speak to us again.

Thyroid Australia Ltd

Yes, since our last newsletter went out, we have been registered as a public company, limited by guarantee. We have also been approved as a Public Benevolent Institution (PBI) and a Deductible Gift Recipient (DGR) by the Australian Tax Office. This means that those of you who have so generously made donations of \$2 and over since 1 July 2000, can claim them as tax deductions. Receipts will be issued.

All members of the old association have been accepted as members of the new company.

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Thyroid Disease in Children

By Robyn Koumourou

Although thyroid disease occurs less frequently in children than in adults, the signs and symptoms can be similar. However, there are a few important differences that need to be brought to light.

The thyroid gland is located at the front of the neck, just below the Adam's apple. It is responsible for the rate of all metabolic and chemical processes in our body, and affects every cell, tissue, and organ. The thyroid gland is therefore essential for life, growth and development. Thyroid gland disorders consequently have a profound effect upon the human body.

When the thyroid gland produces too much thyroid hormone (overactive), the condition is called hyperthyroidism. When the thyroid gland produces too little thyroid hormone (underactive), the condition is called hypothyroidism.

Children with thyroid conditions are generally managed by a paediatric endocrinologist or a paediatrician in consultation with a paediatric endocrinologist.

Congenital Hypothyroidism

Congenital hypothyroidism is a disorder that affects infants at birth, and occurs in about 1 in 4,000 live-born babies. It is characterized by the loss of thyroid function, due to the thyroid gland failing to develop normally. In some cases, the gland is totally absent. About 10% of cases are caused by an enzyme defect leading to deficient hormone production, iodine deficiency and a brain pituitary gland abnormality. If the diagnosis is delayed, and immediate treatment is not given, congenital hypothyroidism can lead to growth and developmental defects, and severe mental retardation (cretinism).

Fortunately, routine testing for thyroid function in newborns has been mandatory since 1976. Within the first week of life, a heelprick blood sample is taken to assess an infant's thyroid hormone level. If any abnormality is found, a repeat blood sample is taken. If this confirms congenital hypothyroidism, the infant is immediately given thyroid hormone replacement therapy (T4 - thyroxine). Normal growth and development should then continue, with no adverse effects on the child's mental capacity.

Before newborn thyroid screening began, this condition was easily missed. Even within a few days, subtle symptoms would emerge, such as poor feeding, constipation, low body temperature, cool skin, slow pulse, prolonged jaundice, increased sleepiness, and decreased crying. After a few weeks, other physical signs would become more noticeable, such as poor growth and development, dry skin and hair, poor muscle tone, slow tendon reflexes, hoarse crying, enlarged tongue, umbilical hernia, and puffiness or swelling. By this time, there would already have been some devastating consequences. Treatment with thyroid hormone replacement would have resolved most of the physical symptoms, but the child would more than likely have had permanent brain damage.

Hyperthyroidism in Newborns

Hyperthyroidism, an overactive thyroid gland, is only seen occasionally in newborns. This condition is referred to as neonatal hyperthyroidism. If the mother has Graves' disease, the thyroid-stimulating antibodies in her blood can cross the placenta and stimulate the unborn child's thyroid gland, thus producing too much thyroid hormone. These stimulating antibodies can be measured and are helpful for predicting the risk of an affected infant. Some newborns may hardly be affected if the levels of antibodies are low. No treatment may be necessary as the mother's antibodies will soon clear from the baby's bloodstream, usually within two to three months. However, in rare circumstances, the levels of stimulating antibodies are enough to cause severe thyrotoxicosis. Immediate treatment with antithyroid medication will be given to

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correct the hormone imbalance. Newborns with advanced hyperthyroidism may display similar symptoms to those in adults, such as an extremely fast pulse, irritability, flushed moist skin, and a ravenous appetite with failure to thrive (i.e. the infant's body tends to be long and thin). Fortunately, treatment with antithyroid drugs is safe and effective, and will only be needed for a short period of time, until the stimulating antibodies pass from the baby's bloodstream. If the mother is on a high dose of antithyroid medication, the diagnosis can be delayed by about a week until the infant clears the antithyroid medication. Liaison with a paediatric endocrinologist is recommended prior to birth.

Hashimoto's Thyroiditis

The most common cause of hypothyroidism in children and adolescents is Hashimoto's thyroiditis, an autoimmune disease. Here, the body's own immune system attacks the thyroid gland and interferes with the production of thyroid hormones. The onset of this condition can occur at any age, and the diagnosis may be easily overlooked for years, as the symptoms of hypothyroidism develop very slowly. As the thyroid gland becomes increasingly underactive, physical and mental changes will become more obvious. Often the first sign is that the child's growth rate decreases unexpectedly and skeletal development is delayed. The child may also have an obvious swelling of the neck (goitre), as the thyroid gland becomes inflamed. Other symptoms may emerge, such as unusual tiredness or lethargy, dry itchy skin, increased sensitivity to cold, weight gain or generalized swelling, poor concentration, decreased energy, and constipation. If hypothyroidism is suspected, a simple blood test is taken, measuring the levels of thyroid hormone and thyroid stimulating hormone (TSH), in the blood. The presence of thyroid antibodies (anti-thyroperoxidase and anti-thyroglobulin) is also helpful in confirming the diagnosis.

Treatment

The treatment for Hashimoto's thyroiditis in children and adolescents is the same as in adults. Thyroid hormone replacement is taken daily for life. The dosage of thyroid hormone needs to be age-appropriate, as the body's demands for thyroid hormone vary with age. Regular thyroid function tests will need to be assessed by a doctor to ensure that normal hormone levels are maintained.

Side effects

For those children and adolescents being treated for hypothyroidism, the results are mainly positive. The majority of their symptoms will disappear, and the body's time for

'catch-up' growth will begin. An increase in bone development will also occur. However, in children who have had long-standing hypothyroidism, ultimate height potential may be partly lost. As the child regains normal thyroid function, behavioural problems may arise as their physical and mental processes speed up. An increase in energy and alertness may lead to a decreased attention span and a loss of concentration, especially in school. Teachers should be made aware of the child's condition, as well as treatment and possible changes in behaviour. Over time, any problems with behaviour, or at school, will resolve.

Graves' Disease

The most common cause of hyperthyroidism in children and adolescents is an autoimmune condition called Graves' disease. In Graves' disease the body produces antibodies that stimulate the thyroid gland uncontrollably, to make too much thyroid hormone. Children can have similar symptoms to adults, although they are less likely to complain about them. Initially the most prominent sign of this condition may be that the child displays increased energy. They may appear hyperactive and restless, be noisier in class, and easily distracted. This may lead to poor academic performance, and parent frustration. A child's hyperthyroidism may not be diagnosed until more pronounced signs and symptoms appear. These include an enlarged thyroid gland. Other symptoms include a fast pulse, nervousness, heat intolerance, weight loss, accelerated growth rate, shaky hands, muscle weakness, diarrhoea, and sleep and behavioural disturbances. Thyroid eye disease is very rare in young children.

Once a thyroid disorder is suspected, a simple blood test is performed to measure the levels of thyroid hormones and thyroid stimulating hormone (TSH) in the blood. The presence of thyroid-stimulating antibodies may also be helpful in confirming the diagnosis. If test results come back positive, then appropriate treatment is commenced immediately.

Treatment

Treatment of hyperthyroidism in children initially involves the use of antithyroid drugs, such as propylthiouracil (PTU) or carbimazole, and if well tolerated, these may be continued for months or even years. For some children, these drugs alone stabilize their condition, and no further treatment is needed. For some, a period of "block and replace therapy" (antithyroid drugs as well as thyroxine) is useful. For others, surgery or even radioactive iodine may be necessary, depending on the severity of their thyroid disorder, or their response to antithyroid drugs. Throughout a child's treatment, thyroid hormone levels will need to be moni-

tored regularly, along with their clinical symptoms.

Side effects

In children and adolescents with Graves' disease, the main difficulties usually occur before treatment is initiated. Once their condition is under control, their physical and mental capabilities return to normal. Antithyroid drugs can, however, occasionally stop the production of white blood cells or platelets. Sore throats, mouth ulcers, excessive bruising or skin rashes can indicate this. Patients should stop taking their medication and see their doctor immediately or attend the Casualty Department at their local hospital to test whether their blood cells or platelets are normal. Of course, these symptoms are common and it is most likely that they are not due to the antithyroid drugs. However, the only safe action is to stop the medication until after the result of the blood test.

Parent Involvement

Parent involvement is vital for children and adolescents receiving treatment for their thyroid disorder. They will need to supervise the taking of medication on a daily basis, and carefully monitor their child's progress. They will also need to be aware of the signs and symptoms of under- or over-medication, so they can work with their doctor to obtain the right level of medication.

As children grow, it is important for parents to keep close track of their child's thyroid hormone levels, as periodic changes in dosage will occur with changes in age. Doctors often recommend that a child have blood tests at least every three to six months. Some children may have a tendency to neglect their medication regimen, and this may lead to symptoms reappearing.

Thyroid disorders can run in families, so it is important to let your doctor know of your family background. If close family members have either hypothyroidism or hyperthyroidism, then it would be wise to keep a close eye on children in the family. Girls tend to be especially prone to developing thyroid problems, due to hormonal changes throughout their life.

In summary, the signs and symptoms of thyroid disease are similar in children, adolescents, and adults. However, there are a few key differences that relate to growth, development and behaviour. If children are treated early and appropriately, with regular monitoring, they will grow and develop normally, and enjoy life as a child.

Robyn Koumourou is a director of Thyroid Australia. She is writing a book about thyroid disorders and related illnesses in Australia.

Hypothyroid Musings

By Megan Stevens

Since Thyroid Australia was formed in June 1999, we have had dealings with close to a thousand thyroid patients, many of them suffering from hypothyroidism. The most common concerns we hear from these people are:

- “My doctor tells me that I am running the risk of developing osteoporosis in later life because my TSH is below normal.”
- “I have just had a thyroid function test, and my doctor tells me that my levels are normal, and yet I still feel rotten.”
- “Can you give me the name of a thyroid sympathetic doctor who will listen to how I’m feeling, instead of just looking at my thyroid function test results?”
- “My doctor tells me that I should lose weight. I try very hard to eat properly, and to exercise, and yet I cannot lose weight.”

“My doctor tells me that I am running the risk of developing osteoporosis in later life because my TSH is below normal.”

When I was diagnosed with hypothyroidism my TSH was not that high and, except for a blip when my thyroxine dose was cut, has consistently been below the reference range. Too often have I heard that my TSH was too low and that I was running the risk of developing osteoporosis, but fortunately my endocrinologist told me that this low TSH was okay.

Yes, it is well established that people who have ever suffered from the elevated levels of free T4 and free T3 found with hyperthyroidism have a greater risk of developing osteoporosis. But surely it is the abnormal levels of free T4 and free T3 (the active thyroid hormones) which trigger the leaching of minerals from the bones, and not the low TSH (a feedback hormone) which is simply being forced down by the elevated free T4 and free T3. Surely then if one’s free T4 and free T3 levels are still within the upper limit of the reference range then one does not have this risk of osteoporosis, even if one’s TSH is below normal. This is a question to which I would still like a proper answer.

In a recent study on 10,364 women, by Dr Martin Stenstrom of the University of Gothenburg in Sweden, presented to the World Congress on Osteoporosis in June 2000, the results suggested that there was no significant difference in bone mineral density between women who were and those who were not taking thyroxine. An-

other interesting finding was that the women on thyroxine were less likely to be thin than the women who were not on thyroxine.¹

Prof AP Weetman also summed up the situation in the *British Medical Journal* when answering the question as to whether there are any risks to taking thyroxine. He said:

“Providing thyroid stimulating hormone concentrations are restored to the reference range, the answer is no, and even if too much [thyroxine] is given, the risks of osteoporosis are more theoretical than real.”²

If anyone just looked at my TSH levels they would be telling me that I was hyperthyroid. It’s only when my free T4 levels are also examined that the true picture emerges - and my free T4 and free T3 levels have never tested above the reference range, even though my TSH is consistently below the reference range. This is a good argument for not just testing TSH levels without free T4 and free T3 tests being done at the same time.

It is, of course, well established that patients who have previously had thyroid cancer and are on thyroid hormone replacement therapy need to have their TSH levels suppressed to below the normal reference range so as not to stimulate any possible remaining thyroid cancer cells. These patients do apparently have a higher risk of developing osteoporosis.⁷

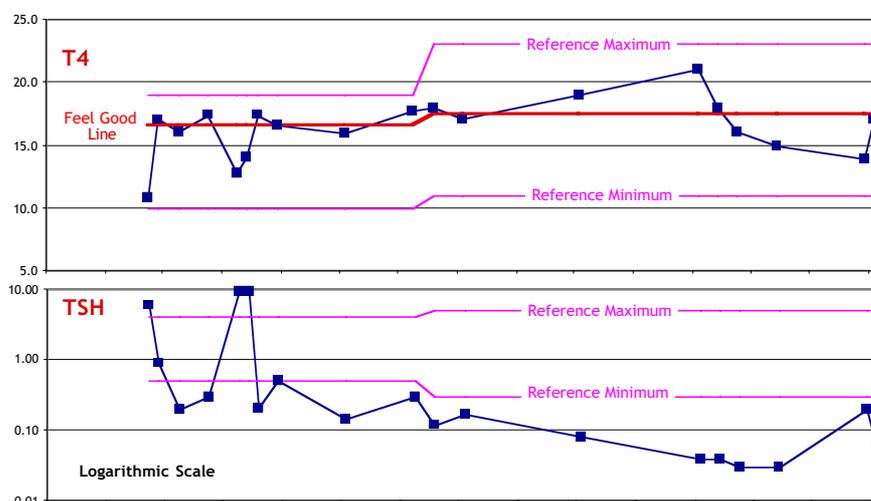
“I have just had a thyroid function test, and my doctor tells me that my levels are normal, and yet I still feel rotten.”

In the six years since I was diagnosed, I have also been told that my thyroid hormone levels were “normal”. I have, however, made a point of getting photocopies

of my thyroid function test results from the very beginning, as I wanted to understand what was going on with my own body, and to relate my test results to how I was feeling. (I am including with this article graphs showing my levels of free T4 and TSH since diagnosis.)

I am, therefore, very interested in how my free T4 levels (and more lately my free T3 levels) are going. On examination of my past test results I have found that I don’t feel good when my free T4 falls below around 17, which is in the middle of the reference range. In fact, I will be a little stronger than that, and say that I feel lousy. I have also found that I feel positively great when my free T4 is at the upper end of the reference range, near or above 20 – the top quarter of the reference range.

Recently I was feeling below par, but thought that the normal stresses of living were taking their toll - things like running a support group for thyroid patients, like finally finishing a major personal project, like having my daughter doing her VCE, like my husband starting a new job, like dealing with teenagers, like recovering from a particularly nasty winter virus, like dealing with perimenopausal symptoms. But on reflection, and on examination of my thyroid hormone test results, I found that my free T4 levels have over the past year been slipping slowly and insidiously from 18 to 16 to 15, and now 14. No wonder I was feeling like I needed to sleep around 10 hours a night and feeling cranky when people around me stop me from achieving that. No wonder I was feeling tired, depressed, irritable, and my hair was falling out. A friend even told me that I seemed to have lost my spark. Fortunately



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for me my doctor was happy to increase my dose, with another check in 3-4 weeks' time. (Thanks Doc!) [This test showed that my levels were now closer to my "Feel Good Line".]

Since I was diagnosed I have made it my business to read everything I could find about thyroid function and problems - trying to find out what I should be doing to make myself feel better - to control my condition instead of having it controlling me. For instance, in 1995 the British Thyroid Foundation published a series of articles, entitled *How thyroid patients see us*, by the eminent endocrinologist, Sir Richard Bayliss. These articles were based on a talk Sir Richard gave to a Thyroid Club meeting at the Medical Society of London. I love this article, and we have sent out many copies to those hypothyroid patients who have contacted us, desperately looking for some hope. In these articles, which I feel should be required reading for all doctors, Sir Richard made one particular statement which struck a chord. He said:

*"The amount of thyroxine replacement prescribed seems to be a hit-and-miss business, the dosage being based neither on careful clinical assessment nor on laboratory tests. ... Certainly it is my experience that patients feel at their best when the free thyroxine level is towards the upper end of the reference range or marginally above it and the TSH towards the lower limit of the normal range."*³

This corroborated what I had found myself. Then I read another article, entitled *Hypothyroidism and its treatment*, written by Dr A D Toft, also for the British Thyroid Foundation. He confirmed what Sir Richard Bayliss had had to say, writing that:

"The correct dose is that which restores good health; in most patients this will be associated with a level of T4 in the blood towards the upper part of the normal range or even slightly high and a TSH level in the blood which is in the lower part of the normal range", adding that, *"In a small number of patients well-being will only be achieved if TSH is low but in this circumstance the concentration of T3 in the blood will be unequivocally normal."*⁴

I had also often wondered, when listening to many of those who have been treated for hyperthyroidism and are now hypothyroid, and who say that they really struggle with the symptoms of hypothyroidism, whether they could be suffering a form of "withdrawal" after their bodies had been more accustomed to a surfeit of free T4 and free T3 for so long. This time the TED Association came to the rescue. Dr M G Prentice, writing an article entitled *Thyroid*

eye disease and its symptoms - an endocrinologist's view, said:

*"Very similar symptoms to non-specific but quite severe symptoms sometimes suffered during an acute thyroiditis or acute thyroid eye disease are those suffered by patients who have been thyrotoxic for some time and are then, through treatment, rendered euthyroid with normal thyroid function. It is well recognised by some groups in Scandinavia that these patients may suffer a form of thyroid withdrawal. This can be very uncomfortable for the patient, feeling as though the plug has been pulled, as some of them describe it. They lose all of their energy, everything becomes an enormous effort and they suffer from aches and pains, hot and cold feelings and feel generally unwell and often depressed also. In this group of patients, if I suspect some of their symptoms may be due to this effect, I may raise their thyroxine replacement temporarily to give them free thyroid hormone levels near the upper range of normal and gradually wean them down over a period of a year or two."*⁵

I wonder, however, whether these former hyperthyroid patients might also not feel better if their free T4 levels were maintained near the upper range of normal as Sir Richard Bayliss and Dr Toft have suggested.

"Can you give me the name of a thyroid sympathetic doctor who will listen to how I'm feeling, instead of just looking at my thyroid function test results?"

At Thyroid Australia, we do not recommend particular doctors. This is because one of the major reasons why people like a particular doctor is because they personally get on with that doctor. We have found some of our clients praising a particular doctor, while others have a strong antipathy towards that same doctor. We do however suggest to people that if they are not happy with a particular doctor they should look for another. We suggest to people who are unhappy with their GP that they should try to get a referral to see an endocrinologist, or go to another GP. Then again we also get clients who say that they have approached their GP for a referral to an endocrinologist, only to be refused. In my case, I found I needed to see an endocrinologist to get my thyroxine dose to the required level it, as the GP I was then seeing kept it too low for my own well-being.

- Too often we find that hypothyroid patients are being told that their thyroid hormone levels are fine when their free T4 and free T3 are just within the lower end of the reference range, with their TSH between the middle and upper limit of its reference range. Not one person we have spoken to whose free T4 and free T3 levels were in the bottom half of the reference ranges said

that they were feeling well. This all supports Sir Richard Bayliss' observation regarding T4 levels.

- Too often people tell us that their doctors are only testing their TSH levels, and telling them that they are fine. This is not good enough. As far as I am aware, the medical practice guidelines in Australia stipulate that when a person who is being treated for a thyroid condition has a thyroid function test, tests for all three thyroid hormones (Free T4, Free T3, and TSH) should be included. T4 and T3 are the ACTIVE thyroid hormones, whereas TSH is only a feedback hormone. The levels of the active hormones must be tested.
- Too often people are told that maybe they should try some anti-depressants to get rid of their depressive symptoms, instead of having their thyroxine dosages raised so that their free T4 and free T3 levels are within the upper limit of the reference ranges to see if that will help.
- Too often we hear of people with classic hypothyroid symptoms (especially lethargy, feeling cold and brain fog) whose TSH is at the upper end of the reference range who are told that there is nothing wrong with their thyroid. This even occurs when further tests have revealed free T4 at the lower end of the reference range and the presence of anti-thyroid antibodies. It is heartening to note that in America the problem appears to be better understood. The American Association of Clinical Endocrinologists notes in its January 2001 thyroid awareness promotion that:

*"Even though a TSH level between 3.0 and 5.0µU/ml is in the normal range, it should be considered suspect since it may signal a case of evolving thyroid underactivity."*⁶

Prof Weetman when discussing the incidence of thyroid disease in people with elevated TSH states:

*"The simplest explanation is that thyroid disease is so common that many people predisposed to thyroid failure are included in a laboratory's reference population, which raises the question whether thyroxine replacement is adequate in patients with thyroid stimulating hormone levels above 2 mU/L."*²

In Australia TSH levels in these ranges would generally be regarded as categoric evidence of normal thyroid function.

The people who contact us tell us of the debilitating symptoms they still have - fatigue, dry skin, thinning hair, depression, susceptibility to cold, weight gain, etc. -

all common hypothyroid symptoms. The worst thing I think about having low free T4 and free T3 levels is that your self-esteem and assertiveness also fly out the window, making it very difficult for you to feel confident about rationally and calmly asking your doctor for an increase in dosage - to see if you will feel better when your free T4 and free T3 levels are higher, but still within the upper limit of the reference range.

So, I beg of doctors, please LISTEN and take note of all your patients' symptoms, and don't just rely on the test results being somewhere in the reference range. The patients also need to be symptom free. And I beg of thyroid patients, do TELL your doctors about your symptoms - doctors cannot listen if they are not told what's going on.

"My doctor tells me that I should lose weight. I try very hard to eat properly, and to exercise, and yet I cannot lose weight."

And then we come to the issue about weight. Something I can relate to quite well. I have a couple of theories as to why hypothyroid patients struggle to lose weight, some of which relate to the length of time it took to be diagnosed. I know in my case it was nearly a decade before I was diagnosed, and in that time I often turned to high energy foods to get that extra energy which I lacked. I also struggled to get motivated to exercise properly. My muscles ached so much that it really was not comfortable. I don't know what it's like for other hypothyroid patients, but I suspect that this might be a common problem - and these bad habits are difficult to break, especially when your thyroid hormone levels are not in the right range for your own body. I also know that I managed to lose weight quite easily when my free T4 levels were in the upper part of the range. It was then that I managed to control my desire for sweet and fatty foods (high energy foods) and when I managed to set up and stick to a decent exercise programme. I therefore think that any hypothyroid patient will have a continual battle if they try to lose weight when their free T4 and free T3 levels are towards the lower end of the range - metabolising food properly and having enough energy to lose weight just doesn't happen when you still have hypothyroid symptoms. I am hoping that now that my thyroxine dose has been increased I will again find it easier to lose weight.

And while on this topic, at the Thyroid Information Seminar held by the Australian Thyroid Foundation which I attended in Sydney on 25 October 1997, Prof Cres

Eastman (a member of our Medical Advisory Committee, and Patron of the Australian Thyroid Foundation) said that generally, for FULL thyroid hormone replacement, hypothyroid patients need around two micrograms of thyroxine per kilogram of body weight per day. Therefore the hypothyroid patient weighing 75kg probably needs around 150mcg of thyroxine per day. (Men, pregnant or lactating women and babies generally require more, and elderly people generally require less.) Subsequently, at the talk he gave to our members in September 2000, A/Prof Duncan Topliss (another member of our Medical Advisory Committee) said that it was the LEAN body mass that needed to be taken into consideration. This is yet another matter which needs further clarification.

So, my message to hypothyroid patients, and to the doctors who treat hypothyroid patients, is that thyroid hormone levels not only need to be within the reference ranges, but they need to be right for the individual patient - at a level where the hypothyroid symptoms go away and where the patient is not hyperthyroid. The hormone levels need to be more in the ranges which Sir Richard Bayliss and Dr Toft suggest - a high normal free T4 and free T3 and a low TSH. I would like to suggest that if hypothyroid patients don't have a high T4 and T3, together with a low TSH, they will not feel well, they will still be suffering hypothyroid symptoms, and they will struggle to lose weight.

Everybody is entitled to as good a quality of life as they can get - even hypothyroid patients. For hypothyroid patients to achieve a decent quality of life, their thyroxine doses need to be individualised and optimised to suit their own bodies and they need to be free of symptoms. Maybe when this happens Thyroid Australia will stop getting so many calls about the questions I listed above. Maybe when this happens Thyroid Australia will stop getting so many complaints about how unhappy some thyroid sufferers are with their doctors. Maybe when this happens we will be able to say that all doctors are sympathetic to thyroid patients.

My suggestion therefore to those who feel their thyroid hormone levels are too low, is that they go to their doctors with the following very reasonable proposal:

"I know that my free T4 and free T3 thyroid hormone levels are within the reference range, but they are at the lower end and I am still not feeling well. I feel I therefore have some room to move within the reference range and would like to try a

slightly higher dose under your supervision to see if this helps. I would like to increase my dose of thyroxine by 25mcg (or 50mcg) for about 4-6 weeks and then have another blood test to see how I'm going. Can you please help me feel better?"

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3. Sir Richard Bayliss, "How thyroid patients see us", British Thyroid Foundation, *BTF News*, Nos. 13-15, Summer 1995 - Winter 1995.
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5. M G Prentice, "Thyroid eye disease and its symptoms - an endocrinologist's view", TED Association, *TED Newsletter*, No. 22, August 1994.
6. American Association of Clinical Endocrinologists, *Thyroid Awareness Month:2001*, January 2001 <http://ahorn.aace.com/pub/spec/tam2001/presstam2001.html>, Accessed January 2001.
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Megan Stevens is President of Thyroid Australia and suffers from Hashimoto's Thyroiditis

Next issue of the *Thyroid Flyer*

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

Diagnosed with Graves' at Fourteen

Roughly two years ago - only a few days before my fourteenth birthday - I found myself sitting in the office of my local GP with a racing pulse, bulging neck, bug eyes, and shaky hands. It wasn't that I'd swallowed a tennis ball and it had got stuck half way down my throat, I actually had Graves' Disease, only I didn't know it, yet. The doctor explained kindly and patiently that after careful consideration of the blood test and ultrasound it was by now apparent that I had a problem with my thyroid. She explained the symptoms, and to each I nodded in agreement - high pulse, nervousness, shaky hands, headaches, depression, sore eyes, swollen neck, the list went on. She smiled and told me things would look up and she was going to refer me to a specialist at the Children's Hospital.

After this a lot of things were suddenly drawn into sharp perspective. I had been very sick for a very long time. In hindsight it can be drawn right the way back to when we went on a trip to India in January 1998, when I became so exhausted that I couldn't enjoy myself. I thought it was jetlag or something and that going back to school would be a relief. I was wrong, things only became harder and I lived my life struggling through each day like my head was wrapped in cotton wool and I couldn't access various bits of it at the vital times.

I never thought anything was wrong with me, I only thought that it was adolescence and that everyone was going through the same thing, so why should I complain? I couldn't play sport, but going to a school that demanded hundred percent participation from everyone in Saturday morning sport, I had to. I twisted my ankle. And then three weeks later I blacked out while riding a horse and fell off and got concussion. That was what started it all - the trips to the doctors - one doctor wrongly diagnosed me and

gave me Valium to stop my pulse from beating so rapidly.

But finally I found a doctor who immediately saw what was wrong and sent me along my way to the Children's Hospital. It was a week after my fourteenth birthday when my endocrinologist first laid eyes on me, then a pathetic little girl whose body was so toxic with this disease that it was necessary to work quickly. My blood tests had shown that I was extremely sick with the disease. She started me out on nine tablets a day for two weeks and then I went back to see her and she kept up the dosage for a further two weeks, then I was to go down to six tablets and then four and then I would see her again after a month. Supposedly this was to make me much, much better. It did help, but not enough.

We battled on for months, struggling to find the right dosage. My doctor was becoming increasingly pessimistic that we would ever find the right amount of medication to bring me down to normal. I went back every month and had a blood test that tested my T3, T4 and TSH. By December some improvement had been made, but not enough, so my doctor put me on a dose of one thyroxine tablet a day and four tablets of propylthiouracil. It didn't work, so she upped the dosage of my tablets.

In February that year I went on school camp for a week, by then I was taking six tablets of propylthiouracil a day and one tablet of thyroxine. Things were tough at school, because people looked at me and were afraid of me. They saw someone who had a chronic illness and they figured that if it could happen to me then why couldn't it happen to them? My friends stuck by my side, but they didn't really want to hear about it either, it made them uncomfortable, so I kept my trap shut and bore it. On other occasions, though, they were proud of my big neck and bulgy eyes and shaky hands. One of

them used to think it was funny how she could feel my neck beating if she put her fingertips on my thyroid gland. Another used to monitor the way my hands shook to see if I was getting better.

But then in March 1999 my doctor became fed up with fiddling around with doses of medication. By about that time I was taking twelve tablets of various stuff a day, and a one point it went up to fifteen. My blood tests were showing fickle results. My T4 was relatively normal, being around eighteen or nineteen, while my T3 was so extraordinarily high - at around thirty - that it wasn't funny. So, my doctor said, there were two options - battle on, or going in for the chop and have surgery. She didn't really put it that way, she basically said it was time to have surgery, but in the end those were the options.

So we went off to see a surgeon on the third floor of the Children's Hospital. He explained the procedure to us, and we went away to think about it. After a while we agreed on a date - the thirteenth of April. And then all that was left was to wait. A couple of days before surgery I was put on iodine to help prevent bleeding afterwards.

And then on the day I walked into the day center and sat down in a little room where about five different doctors came to tell me what would be happening - the surgical registrar, the endocrine registrar, my own doctor, the anaesthetist, and a nurse. I was nervous, but I was brave, I didn't let it overcome me. Then at around three in the afternoon they took me down to the place where I got into a surgical gown and the next thing I knew I was wheeled into a little room where there were two stony faced men looking down at me and telling me that they would see me in an hour. The last thing I remember thinking was 'this stuff will never put me to sleep'.

Two hours later I woke up and the pain was unbearable, I couldn't help but shake my head around to try and get rid of it. There were kind people telling me to relax and when I opened my eyes I could see a fuzzy looking pair sitting on a seat near me - my parents. They wheeled me along a lot of corridors and into a room where I must have fallen asleep because the next thing I knew my brother was there with my parents. I asked him what time it was and he told me it was eight. I remember thinking that I couldn't believe he'd missed Drew Carey to come and see me (he later told me he recorded it).

For the next day I was fairly sick. The following night a family friend came around to see me and I was too sick to really talk to her. My mum was worried because I had a fever and my face had become extremely puffy. That was just extra bleeding inside that would go down. I had a massive scar on my neck, I couldn't talk, and everything just seemed too hard. I couldn't eat but I had a drip pumping fluids, morphine, and some extra calcium into me. By Thursday they took me off everything but the morphine and started to try and eat. I threw up a

few times and then the kind endocrine registrar came around to see me and asked me if I could feel any tingling. It was a funny thing, but I hadn't noticed it until he told me that and then suddenly I realised that that's what the problem was.

Days went by, people dropped in but I couldn't really talk to them and I just wished they'd go away. There were some problems. My voice wasn't getting better and I had a calcium deficiency and my blood tests showed my thyroid was slightly underactive. My surgeon told me I could go home on Friday, the endocrinologist thought different. They took me off the drip calcium on Saturday and by Sunday morning my calcium was so low that I could barely feel anything when I touched it and my bones were beginning to feel very bendy.

So for the next few days they took lots of blood tests. I thought I would kick the walls down I wanted to get out of there so much. On Tuesday they moved me down to the adolescents' ward where I stayed a night and thought I would be in there for a lot longer when finally the endocrine registrar came down and told me I could go home that day. I could have hugged him, but I didn't, I just smiled and

said thank you. When I got home I burst into tears.

For the next two weeks I stayed at home. And then gradually I went back to school for small amounts of time. I didn't go back to school properly until July, after the school holidays. I became very depressed, I was convinced I was still sick, and I still believe I was. But my doctor wouldn't do anything about it. She said I was tired because I was depressed, and sent me to another doctor she knew who was supposed to talk to me about things. He didn't help in the slightest only told me I needed to go on anti-depressants, so I smiled at him, nodded, told him I would be in touch, turned my back and never looked back.

I learnt to deal with it myself. For a long time it was very hard, but I managed. Today I still have the scar on my neck, nearly a year and a half later, and I'm still tired all the time, and I still get very depressed about things. But I'm managing, and although I think that surgery wasn't necessarily the right step to take, I'm glad I had it purely because it meant something was actually getting done about how sick I was.

Letters

Dear Megan

Thanks again to you and your husband for an illuminating afternoon of learning. I hope the swell of people will boost members.

I'm nervous about my appointment with [the endocrinologist] on 7th September (a week before I turn 75). I've made such a mess with my relationship with doctors especially specialists. After 40 years of nursing I know how your reputation spreads. My family have had to deal with the neglects of myself and my obsessive independence. There is a strong feeling with doctors that I need a psychiatrist (by the way I'm treated). It's a long complicated story but one I wouldn't mind being printed if you think it would be of interest.

I was very lucky to have a happy childhood, till my mother died of TB and Cardiac Asthma at 37 yrs. She and my father had known one another all their lives as their parents had migrated from Ireland and settled in a working class suburb of Sydney. My father was a baker and pastry cook and retained his supervising job through the Depression. Afterwards - it was similar to now - people being sacked for no reason -

my father went to the Manager to complain about one of the good workers being sacked and told "You can go too". I remember his white face when he arrived home. My mother said "Now we can go into business". She left a very supportive family to go to a country town where it snowed in winter and the population was very poor. The children at school had no shoes so the few lucky ones had snow fights and sat in front of a huge fire to hear stories. My mother died after 4 years there and I had to leave school to look after two younger sisters and the shop at 13 years old. My brother joined the Army. My father's drinking became a problem! I loved my father very much and always went to the bakehouse early each morning to help him before my mother died. He said I would be the next Eileen Joyce - ha ha encouraging my piano playing.

All this may be irrelevant to my disease but those happy secure years helped me through many tragedies and difficulties till my sixties. In my 40's (mine and his) my husband developed thyroid cancer and had a 5 hour op - a hemi-thyroidectomy. A Mr Eddy saw him after the lump had been removed by another Specialist who rang me and said "At the week-end I've been read-

ing in the Medical Journal about this man who specialises in work of the neck. I've made an appointment." When Mr Eddy saw him on examination said "The prognosis is good. I believe you haven't much money. If you go to the Melbourne I'll do it for nothing," which he did. He said he'd give him 25 years - he lived 35 years (age 73 years). In his sixties he married a woman young enough to be his granddaughter.

There are so many stories - like most people I could write a book. The greatest tragedy was my son's suicide at age 20 - his third attempt successful. This broke my heart but I coped for the sake of the other children. I can't remember ever being depressed.

My 50's were my best years. I did all the travelling I'd started in my 20's, and the 60's started out well. I retired and went on a Peace Bike Ride from Adelaide to Darwin then to South America with my son, his girlfriend (now his wife) and her mother.

Then a divorce (mutual agreement), hysterectomy - came out with bad infection, sold the house we'd own built, went on a trip around Australia and Kangaroo Island waiting for my present house to be vacate. Then my

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Over to You: Letter from Page 7

youngest child joined Mother Theresa's Missionaries of Charity giving up a contract with the Education Department as Occupational Therapist - assimilating disabled children into State Schools. She went on holiday to India at 29 years (worked in the refuge with Mother Theresa), came back and joined, giving up \$40 an hour 10 years ago. That is when my disease reared it's ugly head. She had been brought up an artist. She's a convert.

A local woman doctor heard a murmur and sent me to a heart specialist who couldn't hear it, took my BP [blood pressure], and said "Come back in a year's time". This went on for 3 years. In the end I was ringing his office frequently. When he saw me he said "Every time the phone rings it's Mrs. M..." I replied "Well, I feel rotten". He then ordered a blood test. I was crying I felt so sick. He then rang my son and when I took the prescription to the Chemist he said it was three times more than in his book and rang to check there was no mistake. When it settled down I had radioactive iodine treatment and for a while seemed OK. I had atrial fibrillation and eventually an enlarged heart. I resisted the op for three years saying there are too many old people but agreed when warned I could have a stroke or heart attack. Last year I had the aorta valve replaced and the mitral repaired. Unfortunately the wound has healed but is keloid which is a genetic problem. The area is raised so it rubs on everything and is painful. It is getting much better after a year so I should be feeling good. I do a lot of the time and control my diabetes (old age) with diet and lots of long walks. My problem is I get infections often. Before the heart operation I was hospitalised with pneumonia, when I went to Manila to visit my daughter (she had been back here to have a breast removed and had secondaries in her lung and throat), I developed bronchitis and UTI [urinary tract infection] there and since coming back another UTI, mumps and flu. I'm hoping for my rude health pre 60's so here's hoping. Sorry Megan to go on and on but I find the thyroid support group a ray of hope.

Editorial from Page 1

Committee

With these changes in our organisation, the committee of the old association have been appointed as Directors of the new company. Contact details for the Board members, and their areas of responsibility, can be found in the insert to this newsletter. These directors will hold office until we hold our first Annual General Meeting, which will be after 30 June 2001. Apart from the position of President, which will be filled by the current Vice President, members will have the opportunity to elect the directors at the AGM.

We would like to welcome our new Treasurer, Gail Pascoe, who has agreed to serve on the Board. She brings with her a wealth of experience which will be invaluable to the company. Gail works in the publishing industry as a Creative Director and has significant experience of financial matters as a senior manager. She joined Thyroid Australia in July 2000 after being diagnosed with Hashimoto's thyroiditis. Gail has agreed to act as a director of Thyroid Australia.

We also thank Colleen Dean who performed a sterling job as Treasurer of the old association.

Constitution

Thyroid Australia Ltd now operates under a formal constitution. Members are entitled to a copy at any time. If you would like a copy, please contact us. We will ask for a small charge to cover copying and postage.

Better Health Channel

In January 2001 Thyroid Australia has had the privilege of acting as guests on the website of the Better Health Channel, an initiative of the Victorian Department of Human Services. The Better Health Channel can be found at <http://www.betterhealth.vic.gov.au>. (Look under "Advice > Previous Topics > Thyroid" on the top menu bar.) We thank all at the Better Health Channel for this opportunity. It was an interesting and worthwhile experience. We trust we were able to help those who requested information.

Thyroid Australia website

Please take the time to visit our website again at <http://www.chronicillness.org.au/thyroid/index.htm>. It has had a major revamp and has a great deal more available information.

The site now contains a number of articles on various thyroid topics and a Frequently Asked Questions section. The links section has also been up-dated.

Thyroid eye disease meeting in Adelaide

The Australian Thyroid Foundation has organised for Dr G Davis to speak on thyroid eye disease at 7.30pm on 27 February at the Pilgrim Centre, 12 Flinders Street, Adelaide.



Disclaimer

All materials provided by Thyroid Australia Ltd are for information purposes only and do not constitute medical advice.

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