New statement on the management of primary hypothyroidism

The British Thyroid Association (BTA) has published a statement endorsed by the BTF and other professional bodies on current best practice for the management of primary hypothyroidism which updates the previous 2013 Royal College of Physicians (RCP) joint position statement and reviews recent hypothyroidism guidelines of the American Thyroid Association (ATA) and the European Thyroid Association (ETA).

This statement has been produced to help patients make informed decisions about their treatment. There is a wealth of sometimes conflicting and confusing advice published on the internet and hypothyroid patients have the right to know what evidence this information is based on and how reliable it is. The updated statement sets out the references to the research it is based on, and also a guide to the strength of the recommendations made and the quality of the evidence used.

The full statement along with questions and answers on the new statement will shortly be available on the British Thyroid Association website: www.british-thyroid-association.org

Mark Vanderpump, President of the British Thyroid Association explains the history and background to hypothyroidism treatment and the current dilemmas endocrinologists face:

ʻEvery day over one million people in the UK take the thyroid hormone levothyroxine sodium (L-T4), but few are aware of controversies that have surrounded the treatment of hypothyroidism for over a century. From the first injections of sheep thyroid in 1891 to the academic rivalry surrounding the identification of thyroxine (T4) and the ongoing debate over the advantages of combining L-T4 with liothyronine (L-T3), boosting a sluggish thyroid has never been straightforward. The goal of therapy is to restore patient well-being and normalise serum TSH levels. Most patients respond satisfactorily but a minority of treated individuals experience persistent symptoms despite adequate biochemical correction. The care of such individuals is challenging and remains the subject of considerable public interest.

ʻSynthetic forms of L-T4 have been available since the 1950s and were introduced without any consideration of the need for randomised controlled trials. The existing porcine thyroid extracts were far from physiological or natural as the pig thyroid produces T4 and triiodothyronine (T3) in a ratio of 4:1, compared with the ratio of 14:1 in human thyroid. Evidence appeared of potential harm from L-T4 over-replacement including atrial fibrillation and bone loss, particularly in postmenopausal women.

ʻMore accurate serum TSH measurement meant that patients tend to be prescribed lower doses of L-T4 than in earlier decades which are more closely matched to their serum TSH, T4 and T3 levels. The healthy thyroid produces mainly T4 and much smaller amounts of the physiologically more active T3 and approximately 80% is provided by conversion of T4 to T3, with the remaining 20% of the T3 coming directly from the thyroid. In contrast, people with hypothyroidism are treated with T4 alone, so all of their T3 is produced as a result of conversion from T4.

ʻIt has been suggested that one reason why some people are not happy with L-T4 treatment is that they are not getting their supply of T3 in

continued on page 2
continued from page 1

a physiological way, as if it is coming from the conversion from T4. In 2013 the European Thyroid Association (ETA) reviewed data on 1,365 patients in 13 randomised controlled trials of LT4 + L-T3 versus LT4 monotherapy and concluded that there was insufficient evidence to show that combination treatment is more effective than monotherapy. The ETA recommended that endocrinologists should rule out autoimmune disease associated with thyroid autoimmunity, reassure patients about their condition and support them in coming to terms with a chronic disease requiring life-long medication. If symptoms still persist for six months or more, endocrinologists may consider combination treatment on an experimental basis.

The GP Quality and Outcomes Framework thyroid targets in England encourage regular monitoring of patients with hypothyroidism and this may demonstrate greater fluctuations in thyroid levels than previously realised, accompanied by a tendency for micromanagement of L-T4 dosing in primary care, whether or not this is indicated by a patient’s presenting symptoms. L-T4 is considered the most perfect hormone replacement that has yet been devised for endocrine conditions, but there are undoubtedly people who fall outside the current treatment model. Animal-derived products that contain T4 and T3 are not physiological and patients may not answer in the longer term, but we do need to find ways to ensure that all our patients with hypothyroidism feel the full benefits of replacement therapy.

‘L-T4 therapy offers a safe, rational, and simplified approach to the correction of hypothyroidism, and for the vast majority of patients, treatment results in improved physical and psychological well-being. However the management of patients with a sub-optimal clinical response remains challenging. Benefits of combination therapy with LT4 and L-T3 are still unproven and the potential for harm exists with unregulated use of unapproved therapies. Strategies to improve medication adherence, optimise drug delivery, and standardise thyroid hormone formulations will ultimately improve patient outcomes. It is recognised that thyroid specialists are committed to delivering individualised patient-centred care and shared decision making in all patients with primary hypothyroidism. The BTA hopes that this position statement will assist clinicians in implementing evidence based strategies for the management of hypothyroidism.’

Reference:

News from BTF

Welcome to our new trustees

Mark Lansdown who is a Consultant Surgeon in Leeds specialising in Endocrine and Thyroid Surgery. Originally from the West Country he trained in medicine in Cardiff then worked on the south coast before moving to Yorkshire as a Lecturer in Surgery at Leeds University in 1986. He was appointed Consultant Surgeon in Leeds in 1994 where he continues to work. Soon after this appointment he helped BTF as a medical advisor, helping to answer patients’ questions. He has previously been a Trustee of AMEND, a sister charity to BTF for patients with multiple endocrine neoplastic disorders. This column he takes up his role for two years as President of the British Association of Endocrine and Thyroid Surgeons. When not at work or with his family he can usually be found on a bike in the Yorkshire Dales.

Dr Petros Perros who is a Consultant Endocrinologist at the Royal Victoria Infirmary, Newcastle and an Honorary Senior Lecturer, Institute of Genetic Medicine, Newcastle University. He was until recently President of the European Group on Graves’ Orbitopathy, Chairman of the British Thyroid Association Thyroid Cancer Guidelines Group and member of the Executive Committee of the BTA, and member of TEAMoD (Thyroid Eye Disease Amsterdam Declaration Implementation Group). Dr Perros has supported the BTF for a number of years, having previously been a BTF Trustee from 2004 to 2010. He is also a medical advisor for the BTF and the medical editor of BTF News.

Patient journeys films on website

All of the films produced by Coast highlighting patients’ experiences of diagnosis and treatment of thyroid disorders are now on the BTF website. These include films of physicians treating patients and personal stories from patients with hyperthyroidism and thyroid cancer patients. My Story on page 11 is written by Alison, who shared her story in the hypothyroidism suite of films.

Join our members panel

We are always on the lookout for new members for our Members’ Panel. If you would like to provide feedback on projects and research applications you may wish to join this group: email your details (name, address, type of thyroid disorder, treatment etc with a current medical exemption certificate) to info@btf-thyroid.org with the subject header ‘Members Panel’. Please note all members of the panel must have an email address.

BTF News 89 • PAGE 3
Thyroid eye disease case study

BTF Founder and Director Janis Hickey was featured as a case study on thyroid eye disease for researcher Dan Ezra’s project on 3D facial imaging in the April/May 2015 edition of Eye News. Go to http://bit.ly/1vx58R2 to see the full article.

Iodine and Salt

The Times published a letter on 5 May written by the UK Iodine group (of which the BTF is a member) responding to an article on salt consumption - see page 5.

Thyroid Eye Disease

After three years of work by TEAMed (Thyroid Eye Disease Amsterdam Implementation Group), definitive guidelines for thyroid eye disease (TED) have recently been published. Dr Petros Perros, a founding member of the group explains the reasons for the need for new guidelines: ‘It is estimated that there are about 2,600 new cases of TED every year in the UK. The figures probably have been fictitious for the past 10-20 years for reasons that are unclear. Nonetheless far too often TED is undiagnosed for several months, or misdiagnosed as allergy or conjunctivitis, adding to the frustration of patients and denying them treatments that can make a difference. Simple, safe and low cost interventions commenced early on offer great hope. Selenium supplements, lubricant eyedrops, prisms, meticulous attention to controlling the thyroid, avoidance of radioactive iodine and smoking cessation can prevent deterioration of the eye disease and improve quality of life. In 2009 the European Group On Graves Ophthalmopathy (EUGOGO) spearheaded an international drive to improve the care of patients with TED. The Amsterdam Declaration for people with TED was signed by 84 national and international professional and patient-led organisations including the BTF, pledging to improve patient care. In the UK TEAMed was given priority. The EUGOGO index.glp/campaigns-teamd which aimed to implement these objectives in the UK. In particular diagnosing TED early and getting patients to be seen in specialist centres was a high priority. One way of achieving this is through clinical guidelines.

TEAMed embarked on this project three years ago and was able to secure support by the Royal College of Physicians as part of the College’s ‘Concise Guidance Series’. After extensive deliberations between experts in endocrinology and ophthalmology and expert patients the guidelines were published in April 2015. They focus on four key areas: (a) criteria for early diagnosis of TED by GPs and endocrinologists (b) initiating simple, effective treatments as soon as the diagnosis is made (c) guidance on which patients should be referred to specialist centres and (d) empowering patients with Graves’ disease to recognise the early symptoms of TED, by use of a TED early warning card www.bit- thyroid.org/images/stories/secוול.pdf. It is hoped that the guidelines will facilitate an earlier diagnosis and better treatment of patients with this disfiguring disease.
March. This is a renowned course for specialist endocrine nurses and supply BTF t-shirts or running vests, but in Birmingham organised by the Society for Endocrinology on 16-17 March. Wilma Beckett Endocrine Nurse Update Meeting can send you sponsorship forms, posters and other publicity materials. We can also supply BTF t-shirts or running vests, but please allow enough time for us to get the right size for you.

If you are employed, please check with your employer to find out whether it operates a match-funding scheme (matching all or part of the support please get in touch so that we can help with the BTG by taking part in the Morrisons 10k Run on May 7. Lee Briggs is taking part in a women only event and is keen to raise awareness of thyroid disorders.

Future Fundraisers
Catherine, who was diagnosed with an over-active thyroid three years ago, raised an incredible £1,145 and said: ‘The whole day was absolutely amazing, probably the best experience of my life. We went through the finish line in four hours 28 minutes which I was very proud of. I ran with my friend Kate who I completed the Cardiff Half Marathon with back in October’.

Greg Bolt, whose mum has an overactive thyroid, took part in the Southampton Half Marathon in April and raised nearly £300. After the race he said: ‘It was a very tough couple of hours (one hour 44 minutes to be exact). For the entire race I focused on my rationale for completing the race, all the supportive friends and family who sponsored me and of course thyroid disorder sufferers themselves. I feel very proud to have helped the British Thyroid Foundation!’

Flora raised nearly £900 and said after the race: ‘I was very happy to support the BTF and I will continue to do so as thyroid disorders are my area of interest and I would like to support the highly commendable work BTF does in whatever way I can’.

Gregory Bolt

Flora Cook

Michael Smout who has raised funds for the BTF by climbing some of the Munros, completed the Edinburgh Half Marathon on 31 May and raised £126.

Michael Smout

May Loh, a yoga teacher who has an overactive thyroid, raised funds for the BTF through a gentle Zen Yoga outdoor picnic in Greenwich Park in May.

Heather Lacey held an ‘Easter Bake Off’ cake sale at her workplace and raised £40.

Laura Umbenhon (2nd from left) ran the Bournemouth Half Marathon in April and raised £66 for the BTF. She said: ‘The race was a personal challenge and I managed it in two hours and four minutes - not too bad for my first ever half marathon!’

Laura Umbenhon (2nd from left)

Lillian Squires and her boyfriend Rowan Williams raised nearly £200 for the BTF by completing the Reading Half Marathon in March. They managed a great time of two hours 24 minutes.

Mike Gibbs raised £87 by holding a collection for the BTF at his 60th birthday party.

Vinay Eligar completed the St David’s Day 10k run on March 1 and raised a fantastic £215. Vinay decided to take part in the run as he is currently working on a thyroid research project looking into the genetics of thyroid hormone replacement.

Vinay said after the run: ‘I was very happy to support the BTF and I will continue to do so as thyroid disorders are my area of interest and I would like to support the highly commendable work BTF does in whatever way I can’.

Steve Robb, a veteran fundraiser for the BTF, has taken part in some tough challenges this year. Fortar Multi Terrain Half Marathon, Greater Manchester Marathon and the HKRA Highiland Fling Ultra Marathon (53 mile trail run) so far. His daughter was born with congenital hypothyroidism and Steve is determined to raise as much as he can.

British 10k

We have a fantastic 12 runners taking part in The British 10k London Run on 12 July. They are Debbie Webb, Freddie Cooke, Ian Cooke, Sarah Cooke, Lorraine Scott, Amy Goldsmith, Graham Walters, Jennifer Walters, Jill Walters, Bruce Crowley, Caroline Crowley and James Crowley.

Donations
Many thanks for your generous donations. We are grateful for them all, including those donated online, often in response to advice and support from our telephone contacts, local coordinators and BTF head office and also for donations by members at the time of joining BTF or at renewal time.

Mrs Yates donated £2000.

The Gunter Charitable Trust donated £1005.

The Kier Foundation donated £200 as support funding.

Bar staff at the Longniddry Branch of The Royal British Legion Scotland donated £100.

Donation of £114.25 in memory of Robert Alitchison Whitefield.

Donation of £845 in memory of Robert Bacon.

Donation of £481.75 in memory of Johan Venters.

Three runners took part in the Virgin London Marathon on 26 April 2015. They were Tina Jackson, Catherine Preedy and Flora Cook.

Tina was running for the BTF as her sister was diagnosed with thyroid cancer. Despite a fall at ten miles she managed to carry on and finish the race in seven hours and 24 minutes and raised £125.

Flora raised nearly £900 and said after the race: ‘I was very pleased with my performance in January, participating this year was definitely worth the wait! The support from the crowds was absolutely amazing.’

Oliver Brodski raised nearly £700 for the BTF by taking part in the Morrisons Great Manchester 10k Run.

Rowan Williams

Lillian Squires

Future Fundraisers
Craig Taylor is cycling from John o’Groats in the north-east to Galle Craig Coffee Shop in the Mull of Galloway, the most southerly point of Scotland (460 miles) in five days in September. Some of the journey includes an incline of just over 1500ft! Craig has had an under-active thyroid gland since he was five years old and is keen to get involved in raising awareness and funds.

www.justgiving.com/craigasdaylor5k/

Anastasia Pinches is taking part in the Tough Mudder Yorkshire event in August. She was diagnosed with an under-active thyroid at the age of 14.

www.justgiving.com/anastasia-pinches

Lee and Jayden Briggsinshaw are competing in a 5k run on 12 September. Jayden was born without a thyroid and is keen to raise awareness of thyroid disorders.

www.justgiving.com/lee-brigginshaw

Jacqui Hoyle is taking part in a women only swim on 12 July.

www.justgiving.com/jacqui-Hoyle2

Goldsmith, Graham Walters, Jennifer Walters, Jill Walters, Bruce Crowley, Caroline Crowley and James Crowley.

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We are now a listed charity on BT My Donate – an alternative way to make a donation.

The advantage of setting up a page with BT My Donate is that all the money raised comes directly to the BTF with no commission deducted by BT and no monthly fees for the BTF (JustGiving charge £15 a month and charge 5% commission fee.) To sign up with BT My Donate go to www.btplc.com/mydonate.
Somehow this made it seem much more homely. The Geiger counter moved back and forth across Louise's neck. There was no reaction. Nothing. It wasn't that she had a sluggish thyroid. What the Geiger counter revealed was that there was nothing there to be sluggish. As another doctor explained later, 'Her thyroid is just not functioning. There's nothing but the husk'.

Subsequent consultations, however, gave us somewhat better news. Louise's condition could be controlled with thyroxine. This, we learned, was a substance derived from the thyroid gland of a sheep, and Lulu would have to take it for the rest of her life. Further hope that we also clung on to was that the relatively early diagnosis meant that Louise should be able to lead a normal life. She might not become a genius, but then, how many people do?

So – diagnosis: hypothyroidism; treatment: thyroxine tablets; prognosis: good. Keep taking the tablets. Lulu!

In time, however, we were to discover that it was nowhere near as simple as that. Louise's rate of development was impaired and she attended nursery groups and later a special school. Nonetheless, she was always slow and ungainly and she couldn't swim, although she loved the water. My parents and I worried regularly and my mother tracked down a special swimming costume for Louise when my sister was an adult so she could float in the water - I think Mum found it in Harrods. She remained on thyroxine throughout her life. She was heavy as an adult - but that may have been the effects of living in an institution. Despite the extra weight she had a beautiful body and she still had fair hair at 48 when she died. She certainly did not look like a cretin as the Victorians cruelly described those with brain damage.

I am now the remaining member of our immediate family. My father died in 2012 and my mother died last year. But now I have a new task - thanks to Louise - which is telling her story.

Don't Bring Lulu - a Family Tale of Trial and Triumph by Ron Onions and Sarah Onions is currently for sale on Amazon and eBay.


Sarah Onions

For just £1 per week you will be allocated a six digit Unity lottery number. You can purchase more than one entry if you wish. Every Saturday, the lucky winners are selected at random and the prize cheques issued and posted directly to you, so there is no need for you to claim. You must be 16 or over to enter. Winners have to match 3, 4, 5 or all 6 digits of the winning number in the correct place in the sequence.

Unity is a lottery with a difference. We receive profits directly from the number of lottery players we recruit, so we need your support. For every £1 entry, 50p comes directly to the BTF as profit.

How it works

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My Story

Alison was diagnosed with hypothyroidism nearly four years ago. A diagnosis of an under-active thyroid came as a huge unexpected shock to her.

After my diagnosis I felt very angry and bitter about having a life long condition and wanting to have tablets for the rest of my life. Just to feel 'normal'. I realise now that I was grieving for the person I used to be and coming to terms with the fact that I would have to ask for help just to feel better. Despite having the most supportive and understanding family, no-one knew what I really felt like. I had never felt so alone.

I didn't tell anyone outside my family how I was feeling. It is difficult when the first thing you think of on waking in the morning is 'I can't wait to go back to bed'. I pushed myself to keep looking and behaving normally. I had a family to feed and look after and I was involved in lots of activities. Some days my energy would suddenly sag to a massive low and I'd have to just stop what I was doing - too exhausted to even finish cooking a dinner.

I was miserable, had no interest in my lovely garden or even cleaning the house, let alone anything that I used to enjoy. I went about my day, going through the motions but not really being there. I didn't care and I wasn't bothered. What I did care about was the fact that my children were becoming too tight and despite a good diet I kept on piling on the weight until I was 8kg more than I had always been.

I had 'brain fog', I couldn't concentrate for very long and my memory was dreadful. Sometimes I would stop speaking in the middle of a sentence because I'd forgotten what I was saying or couldn't remember an everyday word. I was always cold - my husband and I went to parkour and we still use the same bed. He also carried out further tests for other common problems suffered by hypothyroid people such as low iron, low ferritin levels, low B12 and vitamin D, all of which I was deficient in. I was treated for these deficiencies, which helped me feel much better.

Getting my iron levels back up slowed my hair loss. I'm delighted to say that my hair is much better condition, doesn't fall out so readily and new thick dark hair is growing back. Result!

During my research I discovered ways in which to work with my GP to enable him to treat me and my symptoms, not just a blood test result. We tailored my treatment to be optimal for me. It has taken time, with gradual increases in my levothyroxine, regularly checking my FT3 and FT4 as well as the TSH levels to find the optimum levels for me to feel well. He also carried out further tests for other common problems suffered by hypothyroid people such as low iron, low ferritin levels, low B12 and vitamin D, all of which I had been deficient in. I was free of these deficiencies, which helped me feel much better.

I decided to focus my energies away from feeling sorry for myself and into getting well again. I wanted my life back. I started researching thyroid conditions and was amazed to find that others with an under-active thyroid had the same symptoms. By chance I came across the BTF website and saw that there was a Milton Keynes support group, the nearest to me, living in Northampton. I telephoned the group organiser Wilma who listened to me. I was overwhelmed with relief and burst into tears. Going along to the support group was a real boost. Firstly, I was delighted to see that none of the ladies at this meeting were bald! There was hope! Co-incidentally the speaker at that meeting was a trichologist and was there to talk and answer questions about hair loss related to thyroid conditions. Secondly, I was able to speak to people who had been or were going through the same experiences as me and who were happy to share their stories and successes.

The other thing I wanted to find out more about was diet. I decided to see a nutritionist. She gave me information on how to eat well and healthily incorporating all food types. Gradually, my energy and enthusiasm for life has returned, my weight has gone back to normal. I go to the gym at least twice a week for tough and fun classes. It was almost a eureka moment when I broke a sweat at the gym for the first time ever. I took part in a 12 kilometre, 50 obstacle Iron Run in March with my colleagues. The training was hard and the run was harder but I felt so pleased that I'd risen to the challenge and for me it was 'one in the eye for hypothyroidism'. It wasn't going to stop me living my life.

I've also helped out at public events for the Milton Keynes branch of the BTF. I love speaking to individuals to raise awareness of thyroid conditions and giving sufferers hope that with the right treatment, they can feel better too.

Since the start of my treatment with levothyroxine it has been a roller coaster. It was only after my fourth increase of levothyroxine that I found my optimum level that allows me to feel normal. I make sure I exercise regularly. I make sure I eat well and I take my medication correctly. I stay positive. This is what works for me.

I know that it isn't a 'given' that I will always feel good, and that my hypothyroidism symptoms will come and go. I know that I will always have to keep on my toes and be able to recognise when things are not quite right and to deal with them or adjust my treatment if necessary, but now they are all just little things and I can cope.

More than anything I'm warm, I have hair, I have enthusiasm for life. I love life! I'm in control, I'm happy – I'm back!

As well as identifying two new common thyroid function discoveries between low-frequency and high-frequency variants, the study in question also involved assessing the impact of rare and very rare genetic variants, which are known to be important for the treatment of thyroid disorders.

The trial, conducted at the University of Birmingham, aims to identify new insights into thyroid physiology and may lead to the development of new treatment options for individuals with thyroid disorders.

Dr Peter Taylor, winner of the BTF Research Award 2015, commented: ‘Thyroid hormone levels are very important for childhood development and adult health. It is now becoming increasingly recognised that even modest variations in thyroid hormone levels can have a substantial impact on health. Interestingly, twin studies have already indicated that in healthy individuals’ thyroid hormones are largely genetically determined, but the genetic make-up of thyroid function remains largely unknown.’

To date only common genetic variants have been studied in detail in large populations. However, this has only explained a fraction of the genetic variation in thyroid function. The UK10K project (http://www.uk10k.org) was set up using enhanced gene sequencing to enable researchers to understand the link between low-frequency and rare genetic changes, which can result in key changes to the proteins that control cell processes. Data were collected from 4000 people in the UK and leading epidemiological cohorts in Europe and Australia.

As well as identifying two new common variants in two genes associated with thyroid function, we identified an uncommon variant, which actually was near a known rare variant associated with familial dysalbuminemic hyperthyroxinaemia (a rare condition) amongst other metabolic abnormalities leads to higher thyroid hormone levels. We also discovered rare variants associated with thyroid function in people with the genome in NRG1 whose protein is essential for the development of the brain and the heart.

Further analysis identified that common genetic variants only explain about 20% of the total variation in thyroid function. Therefore further study of these rare variants will yield new insights into thyroid physiology.

The results of the study Whole genome sequence based analysis of thyroid function were published in the leading international scientific journal Nature Communications in March.

Dr Peter Taylor, winner of the BTF Research Award 2014 was joint author of the study. He comments: ‘Thyroid hormone levels are very important for childhood development and adult health. It is now becoming increasingly recognised that even modest variations in thyroid hormone levels can have a substantial impact on health. Interestingly, twin studies have already indicated that in healthy individuals’ thyroid hormones are largely genetically determined, but the genetic make-up of thyroid function remains largely unknown.’

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Further analysis identified that common genetic variants only explain about 20% of the total variation in thyroid function. Therefore further study of these rare variants will yield new insights into thyroid physiology.
Let us know your personal story alongside the TSH level you achieved, and we’ll publish it in future issues. Please use the form above to submit your story.

BTF News Issue 89

We often receive letters relating to what level of TSH is ‘right’. Here are two medical queries as an answer to that we thought would be of interest.

What should TSH levels be in the elderly?

JH asks: I was interested to read in BTF News Issue 88 (page 12) that research has suggested that there is a ‘slightly high’ TSH level in the elderly (over 80 years of age). I am 80 with an under-active thyroid may need to increase my dosage of levothyroxine. Since that reduction in my level has steadily increased to 1.9. That is in the upper half of the normal range. Although my general health, which is affected by long and short-term problems, has deteriorated my doctor seems reluctant to increase my dosage. I would therefore be interested to know whether Dr R’s recommendation of achieving a level closer to 0.15mU/L is still appropriate.

Why do MY TSH readings fluctuate?

HA asks: I am a 30 year old woman and have been diagnosed with hypothyroidism (TSH was 15.6). As I have suffered with this condition for such a long time I am unable to immediately identify when I am going more hyper. When this happens I require a blood test from the GP and it has always shown that my TSH level has gone up to about 3. I feel at my best when my TSH is around 1.5.

I have been on a dose of 100mcg of levothyroxine for the past 6-7 years. I have found that I am very sensitive to changes in dosage. I would like to understand why my body responds differently to different brands, and what I can do to maintain the same dose of levothyroxine?

Secondly, I experience hypo symptoms every two to three weeks and I think for a blood test and my doctor increases my dose by 25mcg so I am taking a total of 125mcg and after a month or so I am hypo. I have had two tests done, the most recent seven months ago. The only time I have taken more than 100mcg and my dose has been fine is when I was pregnant. Every GP I see has a different opinion on how to control thyroid levels and what is a ‘normal’ range for me, although I know that for me anything over a TSH reading of 2 leads to symptoms of hypo.

Our medical advisor replies: There are several possible reasons for fluctuating thyroid hormone levels in patients taking levothyroxine. There is a small variability in the content of active levothyroxine between manufacturers and from batch to batch of the same manufacturer. The regulations are very strict though and this is minimal and unlikely to be the culprit (see MHRA report http://webarchive.nationalarchives.gov.uk/20150423004851/http://www.mhra.gov.uk/home/groups/psd/documents/policy documents/safetyadviseswiss/c025569.pdf). If levothyroxine is taken with food then its absorption can vary from day to day. This is why it is generally recommended that it is taken on an empty stomach, away from other medicines, and away from iron tablets, calcium and antacids that can interfere with levothyroxine absorption and should be taken separately. The common cause for fluctuating thyroid hormones is the patient is forgetting to take the tablets. This is not a criticism directed at you, just a statement of fact. From my own personal experience, whether I have to take the levothyroxine at 7am or before bed I take it consistently and I am aware of how often I think I have taken them, but am wrong. It is interesting that in previous mail shots you have found your TSH to be more stable. This is well documented for chronic conditions that require close adherence to medication, like diabetes and hypertension, and it is usually down to women taking much more care about taking their medication this important part of their life. If you are bound to question (because I like many doctors and scientists, am sceptical by nature) whether you are truly able to tell when your TSH is ever so slightly above its normal range. Is it not possible that there are other times when it is elevated and you are not aware of it and because you don’t ask for a blood test, you never know? As mentioned in the above reference about the SORTED study, a comprehensive study into TSH levels found that patients did not feel any different whether their TSH level was normal, low range, or high normal.

http://press.endocrine.org/pdfs/pdf/12104/ c2006-0099 So, I think either it is a coincidence that on some days you feel unwell when your TSH was a bit up, or you are a rare exception and you can indeed tell when your TSH is slightly up. If you worry my patient I would be tempted to check your thyroid blood tests every few weeks and get you to record what you think your TSH is and see how closely the match.

I am not your doctor and the information that I have is mostly from a patient perspective. However when the serum TSH is slightly elevated, I often do not advise increasing the dose. Instead I would have the TSH repeated one month later. This would allow me to see if there is a definite trend in the serum TSH. If the TSH has risen further, or not responded, then it would be reasonable to make a small adjustment. If it has settled then no need to change. I often find that it drops to the middle of the range without a need to change the dose.

The best thing for you to do is discuss your concerns with your doctor. If your GP feels they are unable to address your concerns you may refer me to a specialist. I would be interested to hear what happens, so do let us know.
BTF LOCAL COORDINATORS

Our voluntary local coordinators organise meetings but will also be happy to take calls on thyroid disorders that they have experienced. Please see the key below

BTF TELEPHONE SUPPORT CONTACTS

Our telephone contact volunteers are happy to take calls on thyroid disorders that they have experienced. Please see the key below

CAROLINE BRITISH THYROID FOUNDATION

Ch  Thyroid disorders in children
C   Cancer of the thyroid
FC  Follicular cancer of the thyroid
PC  Papillary cancer of the thyroid
HCN Hürthle Cell Neoplasm
CS  Thyroid cancer surgery
RAI Radioactive iodine (I-131) ablation
Gole
TS  Thyroid Surgery (non-cancer)
U   Under-active thyroid
ITSH Isolated TSH deficiency
O   Over-active thyroid
GR  Graves' disease
RI  Radioactive iodine treatment for an over-active thyroid
TED Thyroid eye disease
PH  Post-operative hypoparathyroidism

OUR PARTNER ORGANISATIONS

AMEND The Association for Multiple Endocrine Neoplasia Disorders
Tel: 01892 516076 www.amend.org.uk

Hypopara UK Helpline: 01342 316315 www.hypopara.org.uk

Thyroid Cancer Support Group Wales Tel: 08450 929737
www.thyroidcancersupportwales.co.uk

Thyroid Cancer Support Group Ireland www.thyroidcancersupport.ie
email info@thyroidcancersupport.ie

Cancer52 www.cancer52.org.uk

Butterfly Thyroid Cancer Trust Tel: 01207 545469 www.butterfly.org.uk

Thyroid Cancer Support Group Wales Tel: 08450 929737
www.thyroidcancersupportwales.co.uk

British Thyroid Association www.britisht-association.org

British Association of Endocrine and Thyroid Surgeons www.baets.org.uk

The British Thyroid Foundation, 2nd floor, 3 Devonshire Place, Harrogate, North Yorkshire HG1 4AA
Tel: 01423 709707 or 01423 709448 website: www.btf-thyroid.org Office enquiry line open: Mon to Thurs, 9am – 4pm.

MEMBERSHIP RATES

CURRENT MEMBERSHIP RATES

Members living in the UK

By cheque By standing order Lifetime membership
Full: £20 per year
Concession: £10 per year
Full: £17 per year
Concession: £8.50 per year
£20 by cheque

Members living overseas

£25 Europe
£35 Outside Europe

By cheque from a UK bank account By standing order through a UK Bank By sterling bank draft drawn on a UK Bank

Concession: unwaged and children under 18. Please help us by ensuring that you pay the correct subscription.

The Buy a teddy Bear and support the BTF! Buy one of our adorable teddies for just £6.99 + postage and all the profits will go towards the BTF to help fund research into thyroid diseases for more info:

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PAGE 16 • BTF News 89