YET ANOTHER CASE OF GBH . . .

Thyroid Patient Advocacy wishes to respond to an article published in The British Thyroid Foundation (BTF) Newsletter – Spring 2010 (No. 72) - on behalf of the tens of thousands of patients in the UK who are being left to suffer the symptoms of hypothyroidism so unnecessarily. We are responding because we do not feel the lady (CR) in the following “Case Study” has been given the care she deserves. Neither do we believe the British Thyroid Association’s (BTA) Medical Advisor was helpful with his response. By their acts of omission and commission, they have allowed this patient’s suffering to continue and, indeed, caused her further unnecessary suffering.

The British Thyroid Foundation writes:

“CR put her faith in a non-NHS “alternative” thyroid expert to treat her symptoms. She has decided to share her story to help other patients not to make the same mistake. She writes:

CASE STUDY: MY LIFE IS A NIGHTMARE

I have an underactive thyroid, diagnosed 12 years ago, and my main symptom has always been thigh and arm muscle pain and weakness, i.e. proximal myopathy.

Despite adequate (sic) treatment with levothyroxone, I never fully recovered my mobility and was restricted in how far I could walk and what I could do. (my italics).

I saw a consultant neurologist for a number of years who was sympathetic, but he explained that there was no further treatment available as no research has been done into continuing muscle symptoms in hypothyroidism, as it is a “rare” symptom.”

TPA responds: Thigh, arm and general muscle pain and weakness can be a consequence of low thyroid i.e. fibromyalgia. As the NHS consultant neurologist believes this to be a “rare” symptom of hypothyroidism, that no research has been carried out, and that there is no treatment available, he should be made aware of the many, many studies that have already been completed plus the research undertaken into finding the connection with this “rare” symptom and hypothyroidism. This would prevent other sufferers with those symptoms being denied the available treatment.

http://scottsevinsky.com/pt/reference/physiology/aim_rev_of_myofascial_pain_and_fibromyalgia.pdf.

We recommend that he read Dr John Lowe’s research paper, *T4 Replacement Therapy: An Obstacle to Recovery from Fibromyalgia*.
http://www.fibromyalgiaresearch.org/frfpositions/england2002/t4R.2002.full.htm

“Our 15-years of clinical experience and experimental research leads us to several conclusions: (1) Fibromyalgia is a set of symptoms and signs resulting from hypometabolism. (2) Most patients’ hypometabolism has multiple causes. (3) The most common and most potent cause of patients’ hypometabolism is too little thyroid hormone regulation, due either to hypothyroidism or partial peripheral cellular resistance to thyroid hormone. Common complicating causes of hypometabolism are a dysglycemic diet, multiple nutritional deficiencies, low physical fitness with subnormal skeletal muscle mass, sex hormone imbalances, and decreased adrenocortical reserve or frank cortisol deficiency. (4) Some 85% of our patients who go through our treatment program fully recover from their fibromyalgia. By "fully recover" we mean that they no longer meet the ACR criteria for fibromyalgia and that they are symptom free and fully functional. These patients recover only when properly guided through a program of metabolic rehabilitation that comprehensively corrects the multiple causes of their hypometabolism. Proper guidance, which implies both safety and effectiveness, requires that: (a) most hypothyroid patients use a thyroid hormone product

containing both T4 and T3 in a 4-to-1 ratio, and that thyroid hormone resistance patients use plain T3, typically in supraphysiologic dosages; and (b) clinicians adjust patients' dosages according to objective measures of their tissue responses to thyroid hormone without regard to thyroid function test results.

Our clinical and research findings reveal an inimical impact of T4 replacement therapy on the population of fibromyalgia patients. Only rarely does a fibromyalgia patient improve with T4 replacement therapy. Most hypothyroid patients on T4 replacement therapy who consult us meet the ACR criteria for fibromyalgia; the symptoms of some are so severe that the patients are debilitated. Most of these patients fully recover when they abandon T4 replacement therapy and undergo comprehensive metabolic rehabilitation, including thyroid hormone therapy, as we have described it in this paper. The regularity of this finding forces us to conclude that T4 replacement therapy generally constitutes under-treatment of patients with thyroid hormone, and that specifically, this form of treatment is thus a major cause of the continued suffering of patients with a diagnosis of fibromyalgia."

"Last year, I consulted a self-styled 'thyroid expert' who had been recommended to me. He told me that I had clear signs of an adrenal problem and that this was adding to my hypothyroidism symptoms.The saliva tests he recommended apparently confirmed this diagnosis. He told me to take "adrenal glandular tablets" but I was to stop my levothyroxine for 6 days to "avoid an overdose situation", and then to take half my normal dose of levothyroxine with the adrenal tablet."

TPA responds: Because of the Royal College of Physicians (RCP), the BTA et al's. statement on the Diagnoses and Management of Primary Hypothyroidism, doctors, wrongly, believe that treating patients with the symptoms of hypothyroidism with levothyroxine (T4) only is the only therapy for all such sufferers, and that they will regain their normal health. Unfortunately, no account is taken of the fact that T4 is only one of the thyroid hormones, and it is a mainly INACTIVE hormone that MUST convert to the ACTIVE thyroid hormone triiodothyronine (T3). This conversion normally takes place mainly through the liver, kidneys, skin, brain and other numerous thyroid hormone receptors throughout the body. There are over 250,000 people in the UK alone who are either not being properly diagnosed in the first place (because their TSH is <10.0), or they are being treated with T4 only and for many and varied reasons, are unable to convert to T3. Without T3 – we die!

Sadly, it is becoming more and more apparent that hundreds of sufferers of the symptoms of hypothyroidism within the NHS feel the need to seek support elsewhere, and the reasons for this should be investigated and corrected. There are internet and local thyroid support groups in the UK where sufferers get the support they need. There are several doctors who work outside of the mainstream diagnosis and treatment guidance who are restoring these NHS failures to normal health. The "self-styled 'thyroid expert' is 100% correct. All sufferers of the symptoms of hypothyroidism should be tested to see if they are suffering from adrenal fatigue before even considering the use of any thyroid hormone replacement. This is best tested using the 24-hour salivary adrenal profile. The NHS ONLY test to see whether a patient is suffering from Addison's disease (very low or no cortisol secretion) or Cushing's syndrome (too high a level of cortisol secretion). They do NOT test for any shades between the two.

"I mentioned my worries about stopping my levothyroxine, but he brushed aside my concerns, saying "you'll just get better and better!".

TPA responds: Again, he is correct – there really is no need for such a concern. There should be no problem in stopping your levothyroxine for a week. While most patients take a daily dose, the long half-life of thyroxine lends itself to longer dosing intervals, such as alternate daily dosing. Once-weekly dosing is also possible, although a slightly larger dose than seven times the normal daily dose may be required. *(Grebe SK, Cooke RR, Ford HC,* *Fagerstrom JN, Cordwell DP, Lever NA, et al. Treatment of hypothyroidism with once weekly thyroxine. J Clin Endocrinol Metab 1997;82: 870-5)*

"I was assured that he would always be available to advise me by telephone".

TPA responds: Unfortunately, such good doctors are few and far between and he is probably in great demand, having to deal with those who are not regaining normal health within the NHS. It is best, in such circumstances, to leave a message giving your name and telephone number, asking a doctor to contact you when available.

"As soon as I took the adrenal tablets, my muscles went very painful and weak."

TPA responds: If there is a high level of T4 in the system, a significant proportion not being converted, then if adrenal support is provided, this will initiate conversion and may possibly be too much for her. This is why the thyroid has to be discontinued for a period to allow the surplus T4 to run down. But the painful and weak muscles are not really likely to be a symptom of this. We understand from her story that this had been the problem for over 12 years.

"I tried to phone him for advice, but he was unavailable for days. His secretary urged me to continue as he had advised, saying "Be brave!", but my muscles got worse and worse."

TPA responds: The 'be brave', apparently from the doctor's secretary, sounds rather unlikely, and if it was said, no doubt has been taken out of context. There is no explanation for everything getting worse, whether she took the thyroxine and the adrenal support or not. And certainly no explanation for the subsequent events she recounted.

"After 5 days, I resumed my normal dose of levothyroxine and stopped the adrenal tablets, but I was missing 6 days' dosage of levothyroxine. In a misguided attempt to make up the missing levothyroxine, I took extra for a few days."

TPA responds: Please see my comments above regarding the long half –life of thyroxine. Nobody should increase their dose of levothyroxine to make up for days they had missed. It is advisable to follow the instructions on the Patient Information Leaflet tucked inside the box of levothyroxine. It states: "DO NOT TAKE DOUBLE THE AMOUNT OF TABLETS IF YOU MISS A DOSE". Always contact your doctor first.

"I seemed to be recovering, but then after two weeks, I suddenly got severe muscle pain and weakness again, plus terrible painful cramps in my calf muscles."

TPA responds: This could have been because of several reasons:

1. Your thyroxine dose was too low
2. Partial response to the single synthetic thyroxine replacement
3. Adrenal fatigue or exhaustion
4. Failure of the 5 dei-iodinase enzyme

5. Receptor resistance
6. Food allergies
7. Presence of systemic candidiasis
8. Hormone imbalances

When you have been quite unwell for a long time, all these problems have to be dealt with, and since each may affect the other, it all has to be done rather carefully.

If you find you are still suffering symptoms of hypothyroidism with taking levothyroxine, ask your GP to also check that none of the following blood tests are low in the reference range – ferritin (stored iron), vitamin B12, vitamin D3, magnesium, folate, copper and zinc. If any are low, they will stop your thyroxine from being utilised by the cells.

"I was unable to contact the "thyroid expert" for a week and when I reached him, he became aggressive, saying that I was "beyond his experience". He offered me a refund of his fee, and then abandoned me. He has since consistently refused to help me."

TPA responds: Should any patient refuse to follow a doctor's treatment protocol that had been specifically worked out for them, then his attitude would be understandable.

"My GP was unable to help me either, so I asked to be referred to a thyroid consultant. This however, took six weeks, during which time my muscle symptoms became even more severe. I was bed bound for weeks, with extreme pain and weakness in my thigh muscles, and constant painful cramps in my calf muscles. I was left to cope with all this on my own. It was a terrible, stressful ordeal. I also had no choice but to rely on paid carers and kind friends to look after me as I live alone."

TPA responds: It is extremely worrying that neither the neurologist, the endocrinologist, nor your GP were able to help you, even though you were clearly still suffering the same symptoms for over 12 years. The criticism aimed at the "self-styled thyroid expert" should also surely have been aimed at the above "accredited" experts.

Had your GP or endocrinologist ordered the appropriate blood tests to ascertain whether you were suffering any of the associated conditions that go along with hypothyroidism, you may well have been spared your continuing suffering (see above). You should have had your free T3 and rT3 levels checked and been treated according to those results.

Unfortunately, the recommended UK guideline thyroid function tests (TFTs) check ONLY for failure of the thyroid gland to produce sufficient amounts of thyroid hormones necessary to maintain "normal" blood levels of those hormones and "normal" blood levels of the TSH produced by the pituitary gland. TFTs do NOT check to see if there is peripheral resistance to thyroid hormones at the cellular level. Dr Mark Starr calls this "Type 2 hypothyroidism". This is not due to a lack of thyroid hormones. Therefore, blood tests do NOT detect peripheral hormone resistance. This problem is usually inherited. Environmental toxins may also cause or exacerbate the problem. The pervasiveness of Type 2 hypothyroidism has yet to be recognised by mainstream medicine, but already is in epidemic proportions. Type 2 hypothyroidism must be treated with a T3 containing product, either synthetic or natural thyroid extract.

"My life has been a nightmare for the last year. Since April 2009, I have been virtually unable to walk. Although no longer bed-ridden, I still have severe muscle problems with pain and weakness, and dreadful stiffness, aches and inflammation in my thigh and arm muscles. I am still housebound, still struggling to get around the house, and cannot do housework or cook meals for myself. I rely on friends to take me out at all (sic), pushing me around in my

wheelchair.

So far, this has cost me a whole year of my life, not to mention the huge financial cost of paying for carers for months, plus the cost of useless and misleading saliva tests."

TPA responds: I am very sorry to hear that you are being left to cope on your own and suffering so unnecessarily.

"To my bitter regret, I trusted an over confident, self-styled "thyroid expert" who only knew enough to wreck my health and life, and then left me to my ghastly fate, admitting (too late) that he really knew and understood nothing about my case. It's a pity for me that he hadn't told me that earlier before I trusted him. He was uncontactable when things went wrong and I desperately needed proper advice, even though I had been assured that he would be available by phone."

TPA responds: Not only did you trust a self-styled 'thyroid expert', you also trusted your accredited neurologist, accredited endocrinologist and your GP, who also left you suffering with debilitating symptoms. They also left you to your "ghastly fate". You admitted that you gave this doctor's treatment regimen only five days, which, in anybody's prescribed routine, is far too short a period in which to detect any improvement in health or otherwise.

"I consulted this man to try and improve my muscle problems. He assured me that he would improve my life, but he has had the opposite effect of destroying it instead!"

TPA responds: The same critique should be levelled at your GP, and the NHS-based 'accredited' consultants who have, after 12 years, still not found the cause of your symptoms.

"My muscle symptoms are now many times worse than they were before. This has also had an adverse effect on my osteoporosis condition as I have been unable to exercise for the last year."

TPA responds: Your symptoms are probably due to fibromyalgia. Often this is a symptom of a lack of the active hormone triiodothyronine (T3). I would recommend that you read Dr John Lowe's information about this (see above link).

"My advice is NOT to trust anyone outside of the properly accredited medical profession. Don't make my terrible mistake and trust other people's recommendations of "alternative" doctors and nutritionists."

TPA responds: There are many excellent 'alternative' doctors and nutritionists - many who have helped thousands of sufferers with the symptoms of hypothyroidism. Thyroid Patient Advocacy (1633 members) has numerous instances of failures in diagnosis and treatment offered by 'accredited' endocrinologists where those failures have sought out, and been successfully treated, and brought back to optimal health by such doctors who you are currently criticising.

The BTF Medical Advisor writes:

“This lady has been taking levothyroxine for 12 years for hypothyroidism but still had muscle problems which a consultant neurologist could offer no help with.”

TPA responds: It does appear levothyroxine alone was unable to take away her pains she had suffered for all those years – if this lady had been tested to check her levels of free triiodothyronine (T3) and reverse T3 (rT3), they might have been seen to be low in the reference range. Giving her a trial of either synthetic T3 in combination with T4, T3 alone, or natural thyroid extract might have seen her pains and muscle weakness disappearing - and returned this lady back to normal health.

“She was then told by the self-styled 'thyroid expert' that she required adrenal replacement therapy on the basis of a saliva test. While a saliva test may have indicated the possibility of adrenal failure (which can indeed occur in the context of autoimmune hypothyroidism) further special testing should have been performed to confirm the diagnosis. After 12 years of levothyroxine therapy, I do not think there was any indication to stop it while adrenal therapy was started.”

TPA responds: It is good to know that the BTA Medical Adviser recognises the 24-hour salivary adrenal profile may show adrenal failure – yet NHS doctors and accredited endocrinologists will not accept the results if they lie anywhere between primary adrenal insufficiency and Cushing’s syndrome. Had “further specialist testing been performed to confirm the diagnosis” within the NHS, she would have been told, yet again, that her test results were “normal” if Addison’s and Cushing’s were not indicated.

It is extremely worrying yet again, that the BTA Medical Adviser appears to be totally unaware of the adrenal/thyroid connection. He should know that in the Patient Information Leaflet (PIL) which is to be found inside every box of levothyroxine, there is a section that states "Before taking levothyroxine, make sure you have told your doctor if you: *are suffering from a condition caused by an underactive adrenal gland"* - and in another PIL it states "*Tell your doctor if you are suffering from a disease causing decreased function of the adrenal glands."* Any doctor who is not checking for adrenal fatigue is practising dangerous medicine and putting their patients life at risk.

“The cause of her current symptoms is not clear although they do seem to be related to stopping her levothyroxine."

TPA responds: CR has already told us she has been suffering from these symptoms for 12 years – her 24-hour salivary adrenal profile showed she was suffering from low adrenal reserve, which has been left untreated. It is clear she needs her adrenal function boosting, and she should be given a trial of T3. Why is this not being done?

“Currently, she still has symptoms even while taking an appropriate dose of levothyroxine and I would have expected these to have improved over time.”

TPA responds: As the symptoms have not improved, we ask the question “what has her accredited endocrinologist and/or GP done to try to find the reason WHY she was not getting better with her "appropriate dose of levothyroxine”? She has symptoms when she doesn't take levothyroxine and symptoms when she does. Perhaps if this lady had taken her adrenal glandulars for more than five days and followed the "self-styled 'thyroid expert’s" advice she might have regained optimal health.

“Unfortunately, recent consultant referrals at this stage do not seem to have helped her. Meanwhile, the lesson from this very unfortunate experience is to consult doctors who are accredited appropriately in endocrinology.”

TPA responds: This ‘Case Study’ is a reflection of the parlous state of the NHS endocrinology specialty in relation to the diagnosis and management of hypothyroidism. In adhering to erroneous guidelines, promulgated by the RCP, BTA et al. arrived at in the face of conflicting scientific evidence. Patients are being failed appallingly. TPA is approached by such cases on a daily basis (27 in the last 7 days). If these patients were being given the best treatment available, **THIS WOULD NOT HAPPEN.** The majority of TPA members have previously consulted doctors who are "accredited appropriately in endocrinology" and been left in the sort of morass in which this poor lady finds herself. This is the reason thousands of such patients are desperate to seek help from thyroid groups/internet thyroid support forums, and doctors who work outside of the mainstream diagnosing and treatment protocol. TPA has abundant evidence that these patients have, in the course of time, regained optimal health, returning to a normal standard of life.

The “lesson from this very unfortunate experience” is that many doctors who are accredited appropriately in endocrinology can fail miserably, have failed abominably, and will continue to fail wretchedly, whilst following the guidance (diktat) authored by the RCP, the BTA et al. who have chosen to deliberately ignore the scientific evidence that has been available for over 40 years.

Attn: The BTA's Medical Adviser's response to M/s CR's 'Case Study' in the BTF Spring 2010 Newsletter

How many torsade de pointes events do the BTF/BTA consider acceptable during an episode of thyrotoxicosis before they will revise their flawed protocol for treating the symptoms of hypothyroidism where there is involvement with failing adrenals?

Would cardiac arrhythmia every twelve hours, culminating in a life–threatening series of torsade de pointes not be sufficiently dangerous that they ought to mention this possibility ~ from using the ‘only use thyroxine’ approach to treating hypothyroidism?

Are fourteen episodes of torsade de pointes sufficiently dangerous for them to reconsider whether or not their entire protocol for treating hypothyroidism is flawed?

We would appreciate the BTA's Medical Advisors responses please.

Anon