

Press Release

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Hypothyroidism Debate - What's the Story?

The Thyroid Trust, a London-based support organisation for people affected by thyroid disorders, has published a position statement ahead of the adjournment debate in the House of Commons on 21st May about hypothyroidism. This debate has been called by Sir Vince Cable, leader of the Liberal Democrats. The House of Lords is also due to debate issues faced by hypothyroid patients, specifically about access to the drug liothyronine (also called T3), on a date to be established.ⁱ

This release shares perspectives from a leading physician and two patients with contrasting experiences, while putting the debate into a wider context.

- Levothyroxine, the standard treatment for hypothyroidism, is one of the top three most dispensed drugs in the NHS in England, costing over £96millionⁱⁱ in 2016.
- Most cases of hypothyroidism are easily treated with Levothyroxine but a significant and often overlooked minority (<20%)ⁱⁱⁱ, can have a very hard time with this illness - and these debates highlight the plights of these people.
- Media reports last year revealed liothyronine has increased in price by 6000% and the manufacturer, Concordia, have been accused by the Competitions and Markets Authority of overcharging by £100m, with price per pack rising from £4.46 to £258 in 10 years^{iv}. This cost should be managed by more robust procurement processes in the NHS, tax payers money is being needlessly wasted. EU prices are around 2p to 26p per tablet whereas the NHS pays over £9 per tablet.
- A separate NHS consultation^v considered withdrawing Liothyronine from use but received strong submissions from both patients and doctors^{vi}, including a petition signed by over 31,000^{vii} patients, concluding that it should continue to be made available to those patients who find it helps them and do not do well on the standard treatment, since there is no alternative.
- Liothyronine is now being withheld from some patients who require it since some individual practices or CCGs are refusing to prescribe it due to cost - contrary to the latest guidance^{viii}.
- At the same time, care of these patients more generally also requires a greater focus.
- T3 is not a wonder solution for everyone though it is sometimes touted as such - which is likely to be fuelling artificial levels of demand.

Hypothyroidism can affect all of our physical and mental processes.

- The thyroid is a gland in our neck and controls our metabolism - which is not just about our waistlines and energy levels but all of our physical and mental processes.
- If our metabolism is slowed or speeded up, we can experience debilitating apathy,

brain fog, anxiety or even, in extreme cases, serious mental disorders^{ix} as well as a range of physical symptoms.

- Hypothyroidism is a very finely tuned disorder and a significant minority of thyroid patients are not being treated as they should be, not only because of the issues around access to T3.
- The goal of treating an underactive thyroid is to get blood test results within a 'normal' range AND to restore wellbeing^x.
- Perhaps because most hypothyroid patients are "easy to treat", doctors do not always remember that many patients may benefit from their healthcare practitioner fine tuning their dose of Levothyroxine and should be tested for other possible causes of symptoms and referred to a specialist promptly^{xi} if wellbeing can't be restored in primary care.
- It can sometimes take several months or more to get the balance right.
- We know from talking to patients that in many cases these treatment guidelines are not being applied, hence we believe that patient demand for Liothyronine is likely being artificially stimulated.

Dr Anthony Toft, MD FRCP, Consultant Physician, previously president of the British Thyroid Association and Physician to Her Majesty the Queen in Scotland, has written about the importance of treating thyroid patients as individuals^{xii} and says of Liothyronine:

"If the hormone cost what it should there would be no argument about prescribing Liothyronine. Government should put an end to what is effectively racketeering by a single UK supplier and look to other suppliers overseas. Some patients undoubtedly benefit from taking Liothyronine in addition to Levothyroxine, despite the failure of underpowered studies to demonstrate an advantage.... It is quite wrong to take the easy route of placing Liothyronine on a prescription blacklist, and disadvantaging a small but significant group of patients with what is a very common disorder."

One patient, Maureen Elliott from Kent was told last year her doctor could no longer prescribe Liothyronine due to the cost. This led to her firstly becoming extremely unwell and subsequently having to purchase the drug online from abroad, which raised lots of concerns and cost varied wildly from over £600 to £60 for a two month supply, when she is entitled to free prescriptions on the NHS.

Maureen is keen to share her story in order to shine a light on the issue she and other patients who need liothyronine are facing. She says:

"I have been taking this medication for ten years now and my health deteriorates significantly if I stop taking it. I am very concerned that the NHS is being grossly overcharged, but as a patient I feel that I am stuck in the middle of a pricing war between Concordia and the NHS.

I was left with no other option than to buy it online from a supplier overseas. I was very unhappy with the quality of the medicine purchased online and negotiating to buy it is so complex and expensive that I am at a complete loss in trying to understand it...

I am in my 60's and a full-time Carer for my mother. Paying for my medication is an additional financial burden. The situation I've been in has also been extremely stressful. Having to cope with the withdrawal of a medication that I need in order to maintain my health is completely unacceptable and stress causes a worsening of my hypothyroid symptoms which makes it very difficult to cope on a day to day basis."

Maureen's local CCG (Thanet) have commented that the GP practice should not be withholding the drug for reasons of cost and have offered to intervene, so hopefully her case may be shortly resolved. However we know of many other patients facing the same issue who do not yet have any such reassurances.

Another patient, Lorraine Williams, The Director of The Thyroid Trust found that when she first began taking Levothyroxine she initially became very much more unwell and amongst other disturbing symptoms was unable to think clearly for several months, despite her blood test results being brought into range. Thankfully her GP and NHS Endocrinologists followed best practice and after several dose adjustments and ongoing testing to optimise her dose and the opportunity to trial Liothyronine for a period of around 18 months, she found she didn't need the specialist drug and is quite well without it.

Other patients report similar experiences to both Maureen and Lorraine.

Other thyroid patient organisations who campaign very actively for T3 to be made more available and are not in agreement with current treatment guidelines, have many thousands of followers Thyroid UK have 70,000+ on Health Unlocked and 17,000+ on Facebook for example. The strength of feeling - and in some cases desperation amongst patients - must be acknowledged and addressed.

Those who are most unwell at the point of need are the ones least likely to be able to fight the system for the medicine they need and they should not have to.

Notes for editors

Thyroid facts

- About one in 20 people in the UK have a thyroid condition ^{xiii}
- There are several different thyroid disorders including hypothyroidism (underactive thyroid), hyperthyroidism (overactive thyroid) and thyroid cancer.
- The most common is hypothyroidism which is usually caused, in this country, by an autoimmune condition called Hashimoto's disease.
- 8% women over 50 and 8% men over 65 have hypothyroidism^{xiv}. It mostly affects women aged over 40 but can also affect men, younger women, babies and children.
- It is standard procedure to perform a heel prick test for congenital hypothyroidism around five days after birth.
- Thyroid health can be an important factor in successful pregnancy.

What is Liothyronine/ T3 and why is it controversial?

- Liothyronine is the active thyroid hormone, also known as T3.
- Most patients who have an underactive thyroid gland are treated successfully with Levothyroxine (also known as T4 and by the short name, thyroxine) but some may require T3, either in addition to T4 or as an alternative, in order to feel well.
- As many patients who take T3 get it on private prescription or buy it themselves online there is no definitive data to say how many patients take T3 in the UK.
- More research is needed into the efficacy and risks of T3.
- There is a very active patient lobby for both T3 and natural desiccated thyroid (NDT) which is produced from pigs' thyroids and contains both T4 and T3.
- Hillary Clinton is one high profile individual who is known to be prescribed NDT. In the UK, NDT is not licensed, although patients can get it on a named patient basis on a GP prescription.
- In some cases it has been seen that treatment with T3 can be life changing – to the extent that people who were unable to live a full life have been able to 'get their mojo back', go back to work and so on, rather than languishing in a very poor state and having to claim benefits if they were otherwise unsupported.

About The Thyroid Trust

The Thyroid Trust runs regular support and information meetings in central London for anyone affected by a thyroid disorder. Our next meeting is 19th May, details on our website. Friends, family and interested professionals are all always welcome. We are committed to: working alongside the medical profession, providing quality peer support and access to reliable evidence based information, as well as raising awareness of key issues relating to thyroid health.

All sources listed in numbered endnotes on the following page.

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High Resolution Images to accompany this story:

https://drive.google.com/open?id=1BU3vVsAPg8TOkXrLKtnn_AWZaXz4RrbG

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A Voluntary Association

Working towards registering as a Charitable Incorporated Organisation in 2018

www.thyroidtrust.org

- i The debate in the Lords will be instigated by Lord Hunt of Kings Heath (Labour). Lord Borwick of Hawkshead (Conservative), patron of both The Thyroid Trust and The British Thyroid Foundation, will also speak.
- ii <https://www.statista.com/statistics/378445/prescription-cost-analysis-top-twenty-chemicals-by-items-in-england/>
- iii Experts commonly accept that between 5-20% of hypothyroid patients do not thrive on the standard treatment - research is required to quantify this more precisely.
- iv <https://www.thetimes.co.uk/article/concordia-international-drugs-company-faces-huge-fine-after-overcharging-nhs-by-33m-8skqntg68>
- v NHS Consultation response document <https://www.england.nhs.uk/wp-content/uploads/2017/11/items-which-should-not-be-routinely-prescribed-in-pc-ccg-guidance.pdf>
- vi <https://www.patients-association.org.uk/Handlers/Download.ashx?IDMF=3692914d-fb56-4555-b88e-c775109e3ec7> . And http://www.british-thyroid-association.org/sandbox/bta2016/bta_response_to_the_nhs_england_consultation_for_website.pdf
- vii <https://www.change.org/p/itt-campaign-group-improve-thyroid-treatment-for-millions-of-people-stop-the-withdrawal-of-t3>
- viii http://www.british-thyroid-association.org/sandbox/bta2016/information_for_endocrinologists.pdf
- ix Thyromind.info
- x <http://www.british-thyroid-association.org/blog/posts/treating-an-underactive-thyroid>
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- xiii British Thyroid Foundation
- xiv source: Journal of Medical Screening 2011 - <http://www.bbc.com/news/health-12252813>