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re thyroid treatment



Thyroid Support  
Group Norfolk



The  
Thyroid  
Trust

Thyroid  
UK

## Press Release

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## Thyroid patients are being harmed by failures in prescribing of drug, liothyronine, says new report

**A widespread failure of local NHS bodies to consistently follow national guidelines on the prescribing of a thyroid drug is causing harm to patients, says a significant new report published today. The report shows that liothyronine, a drug used in the treatment of underactive thyroid (hypothyroidism), is not being routinely provided across the country to the people who need it.**

The evidence gathered shows that vulnerable people have ended up with depression, diabetes, heart problems, weight gain, high cholesterol and exhaustion from having this drug either taken away or not prescribed in the first place. The case studies also show people being unable to work and trying to find ways of funding the drug privately.

This is all despite NHS England approved guidance from last year stating that liothyronine should be provided to those who really need it.

The report, which was requested by the Department of Health, has been produced by a consortium of thyroid patient organisations, with guidance from the British Thyroid Association – the UK's body for thyroid specialists.

The organisations received over 400 patients' stories that showed how local NHS Clinical Commissioning Groups are not following the national NHS England approved guidance.

Patients who have had liothyronine withdrawn said,

***“Like thousands of other UK patients, I cannot have a prescription for T3 from my GP or my endocrinologist. I am left in a frightening place.”***

***“Life without liothyronine for me is no life at all.”***

***“I feel completely abandoned by the National Health Service.”***

The report – “Liothyronine – Case Details with Clear Evidence that NHS England Guidance on Prescription of Liothyronine is not Being Followed by CCGs”, follows the House of Lords debate led by Lord Hunt of Kings Heath [3], when Lord O’Shaughnessy, Parliamentary Under-Secretary of State for Health and Social Care, requested clear evidence that NHS England Guidance is not being followed by CCGs. The report has now been handed to NHS England.

Dr Krishna Chatterjee, Professor of Endocrinology and president of the British Thyroid Association states, ***“The current uncertainty, with liothyronine-treated individuals either being denied ongoing prescriptions or needing to source the treatment themselves at their own cost, seems very much against patients’ interests.”***

Lord Hunt stated, ***“The evidence is clear that there are some NHS patients who need to have access to liothyronine. NHS England have accepted at a national level but the message just isn’t getting through at a local level. It’s not acceptable that vulnerable people are getting caught up in something that should have easily been avoided.”***

The authors of the report are now calling for NHS England to exercise its formal powers to intervene on behalf of patients and ensure that those who need liothyronine have clear access to it through the NHS, regardless of which CCG they come under.

**Ends**

**Notes for editors:**

### **About hypothyroidism**

- Hypothyroidism is a lifelong condition requiring daily thyroid hormone replacement. The standard treatment is with a synthetic version of the thyroid hormone, thyroxine.

- Thyroxine is normally converted into the active hormone, liothyronine, in the body, but some patients need to take synthetic liothyronine when that conversion process does not work properly.
- Treatment with liothyronine, a completely different thyroid hormone replacement to levothyroxine, is often more effective in a minority of patients - either alone or in combination with levothyroxine - although the reasons for this are not yet fully understood. If levothyroxine does not resolve symptoms, then the addition of liothyronine is the only alternative.
- Levothyroxine is the second most prescribed item by the NHS (2017).
- Hypothyroidism is ten times more common in women than it is in men. In the UK, around 1-2 in 100 people have hypothyroidism. It most commonly develops in adult women and becomes more common with increasing age. However, it can occur at any age and can affect anyone. [4]
- Studies indicate that 1 in 10 patients with hypothyroidism may only be returned to health by the use of liothyronine. [5]

### **Liothyronine, the medicines value programme consultation and guidance**

This story started when Liothyronine was included in an NHS England consultation last year, as part of the medicines value programme work [2], the consultation heard from a large number of patients and professionals about liothyronine and concluded with guidance that patients with hypothyroidism who require liothyronine, because it helps them and the standard treatment of levothyroxine has not worked for them, should continue to have it. Guidance from British Thyroid Association is included in the national guidance, stating clearly that patients deriving benefit from liothyronine should not have their treatment disrupted. Unfortunately many CCGs and Regional Medicines Optimisation Committee have subsequently developed separate guidelines which either exclude or obscure the BTA guidance, causing patients to be denied treatment. The report authors reviewed over 100 such separate NHS documents on this one medicine.

### **Cost**

CCGs have been seeking to limit prescribing of liothyronine since the cost increased by 6000% in the UK. Despite costing only a few euros in other European countries, the NHS is paying significantly more for reasons which are unclear. [6]

### **New Analysis of prescribing data**

A new analysis of NHS prescribing data by Dr Peter Taylor of Cardiff University's Institute of Molecular & Experimental Medicine features in the report and demonstrates that UK prescribing

of liothyronine has dropped dramatically in recent years, particularly in areas of the greatest deprivation. Submitted for publication.

### **Links:**

[1] Report: Liothyronine – Case Details with Clear Evidence that NHS England Guidance on Prescription of Liothyronine is not Being Followed by CCGs [bit.ly/LiothyronineDossier2018](http://bit.ly/LiothyronineDossier2018)

[2] NHS England guidance  
<https://www.england.nhs.uk/wp-content/uploads/2017/11/items-which-should-not-be-routinely-prescribed-in-pc-ccg-guidance.pdf>

Also see British Thyroid Association guidance (linked to in the above)  
<https://www.british-thyroid-association.org/current-bta-guidelines->

[3] Regret Debate: Hansard: Branded Health Service Medicines (Costs) Regulations 2018  
<http://bit.ly/2vPBSqs>

[4] Hypothyroidism information and stats  
<https://patient.info/health/thyroid-and-parathyroid-glands/underactive-thyroid-gland-hypothyroidism>

[5] 2018 Study into patient satisfaction with treatments for hypothyroidism  
<https://www.ncbi.nlm.nih.gov/pubmed/29620972>

[6] 'Drug firm Concordia overcharged NHS with 6000% price rise, says watchdog,' The Guardian, 21 November 2017.  
<https://www.theguardian.com/business/2017/nov/21/drug-firm-concordia-overcharged-nhs-with-6000-price-rise>

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The Thyroid Trust, 15 Great College Street, London, SW1P 3RX (Working towards registering as a Charitable Incorporated Organisation)

Thyroid UK, 32 Darcy Road, St Osyth, Clacton on Sea, Essex CO16 8QF Registered Charity Number 1125270