

Press Release

7/2/19, for immediate release



Thyroid Support
Group Norfolk



Thyroid
UK

New report highlights shocking NHS postcode lottery for thyroid patients.

The authors of a major report published in 2018, 'The Liothyronine Dossier', have issued a shocking update today, 7th February 2020.

'The Liothyronine Dossier' led to NHS England clarifying their prescribing guidance for liothyronine (L-T3), which is a decades old generic treatment for the common health condition, hypothyroidism.

Specialists and the NHS in England and Scotland recognise that liothyronine is vital for some patients, but due to historic price rises, unclear guidance and some, unproven, safety concerns it has become controversial and many CCGs are restricting or refusing prescriptions.

[The T3 Prescribing Survey Report](#), published today, shows that, even after NHS England's prescribing guidance was clarified, at the behest of the Health Minister, at least 46% of local health authorities in England are restricting access to this treatment, for those patients who require it, in some cases refusing to allow it to be prescribed at all and telling patients it is not available on the NHS.

An unfair postcode lottery is condemning some patients with hypothyroidism to a severely restricted quality of life. Patients who need liothyronine rely on this treatment in order to be able to live a normal life. Many have had to give up work, or resort to desperate measures to source their medicine outside of the UK.

In some cases patients who have been established and well on liothyronine for years, are having their prescriptions withdrawn, against the wishes of their doctors and are left with no option but to travel to other countries, where it can be a tenth of the price in the UK and is sometimes available over the counter.

Others are turning to websites to purchase unlicensed versions and many more are either having to pay to see private consultants, or simply sinking into increasingly poor health, with poorly managed hypothyroidism.

The Survey asked patients to report what they are being told, regarding availability of liothyronine in their local area.

403 respondents reported that prescriptions of liothyronine are being denied or reduced, in 63 CCGs.

168 respondents said they are now sourcing liothyronine outside the NHS:

- 29% via a private prescription
- 55% without a prescription, either from overseas or via the internet.

The report includes additional quotes from patients affected by the postcode lottery:

“Kirklees CCG does not allow T3. I’m prescribed by endocrinologist in Salford (a different CCG). I have been on T3 now for 10 years.”

“Medway, Kent CCG - GP has told me T3 is no longer allowed to be prescribed on the NHS.”

Lorraine Williams, Director of The Thyroid Trust says

“The report highlights a dire situation and the unresolved pricing situation appears to lie at the heart of it, along with a lack of apparent accountability in the system. CCGs have created an unfair postcode lottery for patients who need liothyronine, or who wish to try it. We need the NHS to end this unfair discrimination against a very vulnerable group and we don’t understand why the Department of Health is, on one hand, agreeing to pay so much more for liothyronine than other countries do, yet at the same time, tolerating this ongoing situation, where vital treatment is being withheld for cost reasons” .

This matter is urgent. It is anticipated that the report will be reviewed and acted upon by NHS England and the Department of Health as well as the individual CCGs who have been found to be harming patients, by denying access to liothyronine, counter to national guidance and the NHS Constitution.

Notes for editors.

The report authors are a consortium of six thyroid patient organisations: The British Thyroid Foundation, Improve Thyroid Treatment Campaign Group, Norfolk Thyroid Support Group, Thyroid Patient Advocacy, The Thyroid Trust and Thyroid UK. Contact details and registered charity numbers below.

Background

Lord Hunt of Kings Heath called a Regret debate about access to this treatment on the 20th June 2018, which Lord Borwick, and a number of other peers spoke in, after which Lord O’Shaughnessy, then the Parliamentary Under-Secretary of State for Health and Social Care, called on CCGs around the country to ensure that liothyronine should be provided on the NHS when it is required.

He also asked patient groups to prepare a dossier of evidence of where national guidance was not being adhered to, which they did. The liothyronine dossier was published in November 2018 and in response, NHS England revised their prescribing guidance to CCGs, to make it clearer, in July 2019.

Due to a sharp rise in the cost of this generic medicine between 2006 and 2016, the NHS had included it in the first wave medicines optimisation programme consultation, the outcome of which consultation was a recognition that there is a cohort of patients for whom liothyronine is vital, for them to be able to have a reasonable quality of life.

The Competitions and Market Authority have provisionally found the original sole licence holder for liothyronine, Advanz (previously known as Concordia) guilty of abusing their dominant market position. Two other manufacturers have since been granted a licence (Morningside and Teva) and the price has come down, but it is still far higher in the UK than in any other country. Liothyronine can be bought over the counter in Greece, for example for just a few Euros, yet the UK Drug Tariff Price remains disproportionately high, currently £168 for a single month's supply of 20mcg and £98 for 5mcg, having previously risen from under £5 a packet in 2006 to over £250 a packet in 2016.

References

HL/Deb/(volume/column(20/6/18) Available at: <http://bit.ly/2vPBSq>

The Liothyronine Dossier: bit.ly/LiothyronineDossier2018

NHS England liothyronine prescribing guidance: <https://www.sps.nhs.uk/wp-content/uploads/2019/07/RMOC-Liothyronine-guidance-V2.6-final-1.pdf>

NHS England medicines optimisation programme, wave one:
<https://www.england.nhs.uk/medicines/items-which-should-not-be-routinely-prescribed/>

Competitions and Markets authority liothyronine investigation: <https://www.gov.uk/cma-cases/pharmaceutical-sector-anti-competitive-conduct>

High Res images available to download.

The Report Authors with Professor Krishna Chatterjee, President of the British Thyroid Association, pictured at the House of Lords. (no credit required)

https://drive.google.com/open?id=1JdjCUZSvc51BvqUHqiYRaCHC3n_7FJQ2

Professional handshots with liothyronine pack (D & M Photography)

<https://drive.google.com/open?id=150HATG4QLGTAJYkdK4RKwsC6TLukit5O>

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