

Summary of Results of the Thyroid UK Medication Survey 2008

We are very pleased to say that we had an excellent response to our survey. 329 surveys were returned although two had to be discounted because the people were only taking glandulars, which didn't count for this survey.

Our survey shows many different facets, not only in respect of thyroid medication being taken but, due to the many comments made by the participants, the sheer frustration that patients with thyroid disease are feeling about their treatment generally.

In respect of which medication people are taking, the survey shows that although 76% of people are taking the "gold standard" levothyroxine, 25% are taking T3 and 29% are taking natural thyroid hormone, many people are actually taking a mixture of all types of thyroid hormone medication. The most common dosages are (Levothyroxine – 100mcg; T3 – 20mcg and natural thyroid hormone – 2 grains).

84% of people taking Levothyroxine are taking the same dosage every day although 10% are alternating their dosages i.e. 125mcg one day and 150mcg the next, 7% splitting the daily dosage i.e. taking half the dosage twice a day. 26% people said they would like a smaller strength i.e. 12.5mcg.

92% of people taking T3 are taking the same dosage every day with only 7% alternating their dosages and 3% splitting the daily dosage. 56% would like a smaller strength i.e. 5mcg.

84% of people taking natural thyroid hormone are taking the same dosage every day; 12% alternate their dosages and 40% split the daily dosage. 18% would like a smaller strength i.e. 7.5mcg (1/8 grain).

A surprisingly large amount of people (53% for levothyroxine; 36.5% for T3 and 18% for natural thyroid hormone) were not at all happy with the blister packs their thyroid medication comes packed in stating that they were difficult to open, especially for people with problems with their hands. People would prefer that tablets were in bottles or pots of some kind. In respect of the blister packs, people felt that it would be much easier to remember if you had taken your tablet if they had the days of the week on them.

Quite a few people wanted a clear distinction between packs of their medication (38% for levothyroxine; 27% for T3 and 26% for natural thyroid hormone) i.e. different colours for different strengths.

Less people seemed worried about having larger text for the drug name (13% for levothyroxine; 12% for T3 and 10.5% for natural thyroxine).

Very small numbers wanted Braille on the packs (4.5% for levothyroxine; 3.5% for T3 and 2% for natural thyroid hormone).

Larger numbers of people wanted larger text on the packets for the strength of the tablets (26% for levothyroxine; 14.5% for T3 and 25% for natural thyroid hormone). Only 16% wanted larger text for the dosage of the medication in respect of levothyroxine (11% for T3 and 13.5% for natural thyroid hormone).

In respect of the actual tablets, 16.5% of participants on levothyroxine would like larger tablets as it would be easier for them (19% for T3 and only 7% for natural thyroid hormone).

27% of people wanted tablet scoring on their levothyroxine tablets. A much larger proportion of participants wanted tablet scoring on their T3 tablets (27%) and 44% of those taking natural thyroid hormone would prefer this.

A large 49% of people wanted a clearer distinction in respect of the dosage on the tablets for levothyroxine (27% for T3 and 23% for natural thyroid hormone.)

There were many comments with regard to the tablets with most of them asking for different strengths to those already available. Interestingly, only one person responded that they were taking liquid thyroxine, especially as we receive many enquiries about lactose free thyroxine.

Other changes people would like to see are a consistent supply with the same manufacturer - Levothyroxine (62%), T3 (47%) and natural thyroid hormone (28%); Liquid form – levothyroxine (8%), T3 (8%) and natural thyroid hormone (3%); Soluble – levothyroxine (8%), T3 (6%) and natural thyroid hormone (4%); Lactose free – levothyroxine (22%), T3 (27%) and natural thyroid hormone (19%).

There were many suggestions regarding changes such as gluten free; no maize starch; sugar free; no colourings; slow release for T3 and being available on the NHS for natural thyroid hormone.

We then went on to ask questions about who prescribed the medications. The survey showed that 74% of people get their medications prescribed by their NHS GP, 15% of whom are prescribed natural thyroid hormone. This shows that at least some NHS GPs are aware that this is much better for some patients.

14% of those surveyed were receiving medication from more than one source – some people were “topping up” their regime with either more levothyroxine; T3 or natural thyroid hormone from either another doctor or purchased on-line. This reveals that a lot of people are simply not happy with the treatment they are receiving, needing to add to what they are allowed to be prescribed.

When asked whether people received Patient Information Leaflets with their medications it seems that most people did:

Usually - Levothyroxine (28%); T3 (18%) and natural thyroid hormone (22.5%)

Sometimes - Levothyroxine (3%); T3 (15%) and natural thyroid hormone (13.5%)

Always - Levothyroxine (67%); T3 (48%) and natural thyroid hormone (47%)

Never - Levothyroxine (3%); T3 (48%) and natural thyroid hormone (17%)

We asked if people read the PIL (77% said yes); found it useful (66% said yes) and would they like larger text (39% said yes).

When asked if they would like more information on the PIL, 66.5% said yes, 99.5% of those wanting more information on food, medications and supplements that affect the medication. There were 38 comments about the PIL including things like symptoms that may indicate too high a dosage; what to do when experiencing side effects and the best way to take natural thyroid hormone.

With regard to how often people are given prescriptions, 32% of you told us that you only received your prescription on a monthly basis (26% said two monthly and 26% said three monthly). There were many “other” comments ranging from annually to 16.5 days. Some people were self medicating and therefore ordered when necessary.

We asked you if you were happy about the prescription ordering and around half of you weren't. It seems that most people would like 3 monthly ordering although some would prefer annual ordering.

Prescriptions are being dispensed from a number of sources with 52% coming from a High Street pharmacy and 26% coming from their surgery.

We then asked for additional comments with regard to the questions in the survey and it is very clear that you are not completely happy with and have a lot to say about your treatment of hypothyroidism generally.

There were many statements regarding Armour thyroid (a brand of natural thyroid hormone) not being prescribed on the NHS; quite a few statements about the different brands of medication and how difficult it is to get the same brand each time; several comments about how it would be helpful to have different strengths to those available at the moment; some comments about self medicating; and some more comments about the blister packs.

You also told us that you had concerns about prescription ordering, mostly saying that you wanted longer time spans and informed us of your thoughts about how you are treated (or not) by your doctors.

There were various other comments too including *“I would like more info available to patients about the management of this condition plus options available, what can one expect?”*; *“Good luck!! Would like opportunity to ask for (and get!) same manufacturer as neither doctors nor chemist seem to think this is important... Also to try T3/NTH as these are just not really on offer so hope you do well with these survey results. Why do I have to have two different tablets to make up my dosage of 125mcg? Why don't they make tablets this size and why can I only get three months supply at a time!”* and *“What happens to the results of the survey?”*

We can answer the last question here! We used the information from the survey for a Press Release and we will also be sending a report to all relevant bodies, such as pharmaceutical companies, endocrinologists etc. to show them that changes need to be made before thyroid patients will be satisfied with how they are treated in respect of diagnosis and treatment.

We would like to thank all who participated in this, our first proper survey. We look forward to doing more surveys in the future, possibly more focused on one subject at a time in order to show exactly what changes need to take place.

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