



## HYPOTHYROIDISM

Guest Author: Sara Peterson, MD

### A patient survey of hypothyroid individuals demonstrates dissatisfaction with treatment and their managing physicians

#### BACKGROUND

Hypothyroidism is a common endocrine problem that requires lifelong treatment with thyroid hormone. The standard treatment for hypothyroidism since the 1960s has been daily administration of levothyroxine (L-T<sub>4</sub>) at doses that keep blood levels of thyroid stimulating hormone (TSH) normal. Outside the thyroid gland, many tissues have enzymes (deiodinases) that activate T<sub>4</sub> to triiodothyronine (T<sub>3</sub>), the active form of thyroid hormone. The current viewpoint is that a dosage of L-T<sub>4</sub> that makes the blood levels of TSH normal also treats most/all hypothyroid symptoms. However, in some studies, L-T<sub>4</sub>-treated patients report not feeling as well as with individuals without hypothyroidism. In any clinical practice it is clear that, despite being on L-T<sub>4</sub> at doses that return the T<sub>4</sub> and TSH levels to the normal range, some patients may continue to complain of sluggishness, lethargy, sleepiness, memory problems, depression, cold intolerance, hoarseness, dry skin, body weight gain, and constipation. They may switch physicians multiple times and may use unconventional therapies, such as dietary supplements, nutraceuticals and over-the-counter products as well as alternative thyroid hormone therapies.

The fact that some L-T<sub>4</sub>-treated hypothyroid patients have symptoms despite normal blood levels of TSH has led to questions as to whether therapy with L-T<sub>4</sub> alone (*monotherapy*) is adequate for all patients. Some have suggested that low levels of T<sub>3</sub> in the blood contribute to residual symptoms and suggest that therapy with both L-T<sub>4</sub> and T<sub>3</sub> (liothyronine or cytomel) (*combination therapy*) may be a beneficial alternative. A total of 14 trials have examined this and it is not clear that combination therapy is better than monotherapy in managing hypothyroidism, although there was a patient preference for combination therapy in some of the trials. Finally, animal-derived natural thyroid preparations (*desiccated thyroid extracts, DTE*), the original thyroid hormone therapy, has historically been widely used as an option for thyroid hormone replacement therapy.

DTE was replaced by L-T<sub>4</sub> in the 1960s once L-T<sub>4</sub> was able to be produced widely and cheaply. Currently, American Thyroid Association (ATA) guidelines do not recommend the routine use of either combination therapy or DTE.

The goal of the present survey was to find out about the perceptions, other medical conditions, and treatment selections of patients with hypothyroidism who responded to our survey.

#### THE FULL ARTICLE TITLE

Peterson SJ, Cappola AR, Castro MR, Dayan CM, Farwell AP, Hennessey JV, Kopp PA, Ross DS, Samuels MH, Sawka AM, Taylor PN, Jonklaas J, Bianco AC. An online survey of hypothyroid patients demonstrates prominent dissatisfaction. *Thyroid* 2018 [Epub ahead of print]; DOI: 10.1089/thy.2017.0681.

#### SUMMARY OF THE STUDY

The Hypothyroidism Treatment Survey was created by the program committee members of the Satellite Symposium on Hypothyroidism that was held in the spring of 2017, a meeting organized by the American Thyroid Association. In the two months before the symposium, patients with hypothyroidism were invited to complete the online survey with the intent to disseminate its results at the meeting. The survey was posted on the ATA website, emailed to patients in the ATA database, distributed to members of the ATA Alliance for Thyroid Patient Education, and further distributed on the websites and social media of multiple patient advocacy groups.

Respondents were asked to provide demographic data and types of treatment used (L-T<sub>4</sub> monotherapy, L-T<sub>4</sub>+L-T<sub>3</sub> combination therapy, DTE, other supplements). Patients were asked to rank satisfaction with their treatment for hypothyroidism and their treating physician. They also ranked their perception regarding physician knowledge about hypothyroidism treatments, need for new





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treatments, and life impact of hypothyroidism on a scale of 1 to 10. Additional questions included the number of times they changed physicians due to unsatisfactory treatment of their hypothyroidism, aspects of their life affected by hypothyroidism, and attempts to seek alternative forms of hypothyroidism treatment.

A total of 12,146 individuals completed the survey. The vast majority of patients gave a score of 10 on a scale of 1-10 as to how hypothyroidism has affected their life. Overall degree of satisfaction with their therapy was rated a 5. Among the 3,670 individuals who did not report depression, stressors or medical conditions, those taking DTE reported an average treatment satisfaction score of 7, followed by the L-T<sub>4</sub> + L-T<sub>3</sub> combination therapy treatment group with a satisfaction score of 6 and the L-T<sub>4</sub> monotherapy treatment group with a satisfaction score of 5. Patients taking DTE were also less likely to report problems with weight management, fatigue/energy levels, mood, and memory, compared to those taking L-T<sub>4</sub> monotherapy or L-T<sub>4</sub> + L-T<sub>3</sub> combination therapy. All patients gave a score of 10 to the need for new therapeutic options for hypothyroidism.

## WHAT ARE THE IMPLICATIONS OF THIS STUDY?

In summary, some patients with hypothyroidism are not satisfied with their current therapy, or with their physicians. Higher satisfaction with both treatment and physicians was reported by those patients taking DTE. While the way our study was designed does not allow us to provide an explanation for this observation, future studies should investigate whether preference for DTE is related to T<sub>3</sub> levels in the blood or other unidentified causes.

There is a distinct subset of individuals with hypothyroidism who are dissatisfied with their thyroid hormone replacement therapy and managing physicians. Compared to patients taking LT<sub>4</sub> or LT<sub>4</sub>+LT<sub>3</sub>, those taking DTE were generally more satisfied. The reasons for the high dissatisfaction rates, particularly among individuals taking LT<sub>4</sub> monotherapy, are unclear and deserves further investigation. The vast majority of patients surveyed expressed a strong desire for the development of additional hypothyroidism treatment options.

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### ATA THYROID BROCHURE LINKS

Hypothyroidism (Underactive): <https://www.thyroid.org/hypothyroidism/>

Thyroid Hormone Treatment: <https://www.thyroid.org/thyroid-hormone-treatment/>

### ABBREVIATIONS & DEFINITIONS

**Hypothyroidism:** a condition where the thyroid gland is underactive and doesn't produce enough thyroid hormone. Treatment requires taking thyroid hormone pills.

**Thyroid hormone therapy:** patients with hypothyroidism are most often treated with Levothyroxine in order to return their thyroid hormone levels to normal. *Replacement therapy* means the goal is a TSH in the normal range and is the usual therapy. *Suppressive therapy* means that the goal is a TSH below the normal range and is used in thyroid

cancer patients to prevent growth of any remaining cancer cells.

**Levothyroxine (T<sub>4</sub>):** the major hormone produced by the thyroid gland and available in pill form as Synthroid™, Levoxyl™, Tyrosint™ and generic preparations.

**Thyroxine (T<sub>4</sub>):** the major hormone produced by the thyroid gland. T<sub>4</sub> gets converted to the active hormone T<sub>3</sub> in various tissues in the body.





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**Triiodothyronine (T<sub>3</sub>):** the active thyroid hormone, usually produced from thyroxine, available in pill form as Cytomel™.

**TSH: thyroid stimulating hormone** — produced by the pituitary gland that regulates thyroid function; also the best screening test to determine if the thyroid is functioning normally.

**Desiccated thyroid extract:** thyroid hormone pill made from animal thyroid glands. Currently desiccated thyroid extract is made from pig thyroids and is available as Armour Thyroid™ and Nature-Throid™.

**Deiodinase enzymes:** these enzymes convert T<sub>4</sub> to T<sub>3</sub> on the cellular level by removing an iodine molecule from T<sub>4</sub>.

APRIL

# Hashimoto's Thyroiditis Awareness Month



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## Thyroid Awareness Monthly Campaigns

The ATA will be highlighting a distinct thyroid disorder each month and a portion of the sales for Bravelets™ will be donated to the ATA. The month of April is **Hashimoto's Thyroiditis Awareness Month** and a bracelet is available through the ATA Marketplace to support thyroid cancer awareness and education related to thyroid disease.

