



Getting a Diagnosis and Starting Treatment

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Hyperthyroidism

- The usual first treatment for hyperthyroidism is Carbimazole but some patients do not feel very well on this. Itching can be a side effect that is unbearable. If this happens to you, discuss with your doctor the possibility of trying a different drug. Propylthiouracil (PTU) is an alternative that some people find much better.

Patients are usually kept on Carbimazole or PTU for up to 18 months before other treatment such as Radio-active Iodine (RAI) or surgery is offered. Some doctors feel that patients can actually stay on these drugs for longer than that. If you decide that you would like to wait before RAI or surgery discuss the possibility of staying on the tablets for a while longer.

- Try to work with your doctor. Getting cross or abusive with your doctor is not helpful. If your doctor is not willing to discuss these issues with you, then perhaps it's time to find another NHS doctor. If you cannot find an NHS doctor that will work with you and you are still ill, it might be worth visiting a private doctor (see our Private Doctors and Practitioners leaflet).

If you don't have access to a computer to look at the links in this leaflet, you can use a computer at your local library. Alternatively, these are available from Thyroid UK for a nominal charge to cover administration.

The Thyroid UK leaflets mentioned in this document are included in the Thyroid UK Information Pack available from Thyroid UK for £9.99 plus £2.50 postage and packing.

The article does state, "If no obvious cause is found the patient should be referred to an accredited hospital endocrinologist or general physician." However, many doctors are unwilling to refer patients to endocrinologists for hypothyroidism.

Thyroid UK has often heard that doctors state that "There are no studies comparing natural desiccated thyroid (NDT) with levothyroxine." If your doctor states this, give him a copy of Dr John Lowe's paper - 'Stability, Effectiveness, and Safety of Desiccated Thyroid vs Levothyroxine' which can be found on our website: http://www.thyroiduk.org.uk/tuk/TUK_PDFs/JohnLowe-BTA-Rebuttal.pdf

Thyroid UK has also often heard that doctors tell their patients, "You never know how much of each hormone is in the tablets." This is untrue. NDT goes through the same process that levothyroxine goes through and is tested to ensure that the correct amount of T4 and T3 is in each tablet. United States Pharmacopeia (USP) is the official public standards-setting authority for all prescription and over-the-counter medicines and other healthcare products manufactured or sold in the United States. Thyroid USP state that thyroid tablets should contain not less than 90% and not more than 110% of the labelled amounts of levothyroxine and liothyronine, the labelled amounts being 38ug of levothyroxine and 9ug of liothyronine for each 65mg of the labelled content of thyroid.

The American Food and Drug Administration (FDA) have had concerns about potency and stability in brands of levothyroxine.

In October 2007, the FDA announced that it is tightening its potency specifications for all levothyroxine (sodium) to ensure the drug retains its potency over its entire shelf life.

Thyroid UK wonders if this could be a problem in the UK too but it is very difficult to obtain this information.

Getting a Diagnosis and Starting Treatment

It's quite possible that you have been ill for some time and have visited your General Practitioner (GP) on many occasions regarding some symptom or other.

If you have read our information and if you have a lot of the symptoms of hypothyroidism (Myxoedema/underactive thyroid) or hyperthyroidism (overactive thyroid), think about making an appointment to go back to your GP and discuss some options with him. Your doctor will need all the information about your health that you can give him. Give your doctor copies of anything you have written down so that he can read it and put a copy in your record. It's better to be specific about your symptoms or your doctor may miss something.

For instance, if you have to have the heating up high in your house all the time because you are cold and people make comments about this, tell your doctor. If you find yourself going to bed early, waking up late and sleeping all afternoon because you are so tired, tell your doctor. If you walk around all day in shorts and a t-shirt and have the windows open all the time, even in winter, because you are always very hot, tell your doctor.

Try to be clear and precise when you speak to your doctor. It might be an idea to take someone with you if you can, not only for support but also so that they can remember what has been said. How often have you come out of the doctor's surgery and forgotten nearly everything that was said to you? This person may also be able to confirm what you are telling the doctor.

Undiagnosed hypothyroidism or hyperthyroidism can cause a great strain on the heart. Hypothyroidism can cause coronary atherosclerosis (furring up of the arteries) due to high cholesterol levels. Dr Rowan Hillson tells us in her book, "Thyroid Disorders", "Lack of T3 and T4 alters fat metabolism... and this can lead to furring of the coronary arteries (coronary atherosclerosis) and reduction of the blood supply to some of the heart muscle.

This causes angina... - pain in the chest on exercising, which is usually relieved by rest. Coronary atherosclerosis can cause angina, a heart attack or coronary thrombosis.”

Hyperthyroidism causes the heart to beat faster and increases the risk of stroke as well as atrial fibrillation (fast and irregular heartbeat).

It is therefore very important not to miss a diagnosis of hypothyroidism or hyperthyroidism.

Thyroid UK suggest a step by step approach:

Before you make the appointment

Find out whether you have had any previous thyroid tests done. If you have, find out exactly which tests you have had done and make a note of them. The most common thyroid tests are Thyroid Stimulating Hormone (TSH), Free T4 (FT4) and Free T3 (FT3). Sometimes the thyroid antibody tests will be done – Thyroid Peroxidase (TPO) and Thyroglobulin (TgAb) - but not often. Sometimes the receptionist will give them to you over the phone but you will probably need to go into the surgery and ask for your test results. You have a right to see your medical records under the Data Protection Act 1998. Guidance on The Data Protection Act 1998 can be found at: <https://ico.org.uk/for-the-public/personal-information/>

- Do not just accept “normal”. You should always ask for the actual figures of your test results – your level as well as the ranges. Be aware that different areas in the country use different test ranges so one TSH test range might be 0.5 - 5.0 but in another area the TSH range might be 0.4 - 4.0. You could be “borderline” (near the bottom or top of the range) or have “subclinical hypothyroidism” (high TSH and normal FT4) or “subclinical hyperthyroidism” (low TSH and normal FT4) and not be aware of this because you have not been given the ranges of the tests. Subclinical thyroid disease is not usually treated although treatment may be useful.

Thyroid UK is now working with a laboratory that does this test – Regenerus Laboratories Ltd. For more information on the DIO2 test and how to get tested go to: http://www.thyroiduk.org.uk/tuk/testing/DIO2_test.html

- Some people feel better taking natural desiccated thyroid (NDT). This is what was used before synthetic levothyroxine came on the market. It is available on the NHS on a normal prescription on a “named patient basis” but some medical bodies do not like patients being prescribed this even though patients may feel better on it.

On 19th November 2008 The Royal College of Physicians, in particular its Patient and Carer Network and the Joint Specialty Committee for Endocrinology & Diabetes; The Association for Clinical Biochemistry; The Society for Endocrinology; The British Thyroid Association; The British Thyroid Foundation Patient Support Group and The British Society of Paediatric Endocrinology and Diabetes issued a statement, endorsed by the Royal College of General Practitioners, entitled “The Diagnosis and Management of Primary Hypothyroidism”. This statement was also mentioned in the BMJ Editorial entitled, “Diagnosis and treatment of primary hypothyroidism - New guidance highlights how to do it in primary care”.

This Statement includes a statement in the “Conclusion”, “The College does not support the use of thyroid extracts or thyroxine and T3 combinations without further validated research published in peer-reviewed journals. Therefore, the inclusion of T3 in the treatment of hypothyroidism should be reserved for use by accredited endocrinologists in individual patients.”

Dr John Lowe published a rebuttal to this Statement where he discusses various papers in respect of direct comparisons of levothyroxine and natural desiccated thyroid and which showed that the effects were similar on hypothyroid patients. One of them states, “a daily dose of 100mcg of T4 was on average equal in biologic activity to 101mg of desiccated thyroid; 60mg of desiccated thyroid was equal to 60µg of T4.”

- Some people do not convert their thyroxine adequately into T3. This could be due to lack of certain vitamins and minerals or possibly due to a faulty gene. The DIO2 gene was researched in 2009 and the results were published in the paper entitled, *"Common Variation in the DIO2 Gene Predicts Baseline Psychological Well-Being and Response to Combination Thyroxine Plus Triiodothyronine Therapy in Hypothyroid Patients"* by V Panicker, P Saravanan, B Vaidya, J Evans, A Hattersley, T Frayling & C Dayan - <http://jcem.endojournals.org/content/94/5/1623.full.pdf+html>

The researchers found that patients on levothyroxine (T4) alone felt worse if the faulty DIO2 gene was inherited through one parent and worse still if they inherited the faulty gene from both parents.

The patients on this study were given T4 only for a set period and then combination treatment of both T4 and T3. The patients who had normal genes did not feel any different on combination treatment. However, those who had one faulty gene felt better on the combination treatment and those with both faulty genes felt better still.

This means that there is a possibility that patients who are on levothyroxine alone and still have symptoms may improve with the addition of T3.

Because this faulty gene causes a deficiency of T3 within the cells, the usual thyroid hormone function tests will not show up a problem. This means that your TSH, FT4 and FT3 blood tests will look normal.

The researchers concluded, "Our results require replication but suggest that commonly inherited variation in the DIO2 gene is associated both with impaired baseline psychological well-being on T4 and enhanced response to combination T4/T3 therapy, but did not affect serum thyroid hormone levels." This means that some people do not convert but this doesn't show in their blood tests.

The 2006 Thyroid Function Test Guidelines state, "There is no evidence to support the benefit of routine early treatment with thyroxine in non-pregnant patients with a serum TSH above the reference range but <10mU/L." which in layman's terms means that patients who have a TSH of less than 10 need not be treated because it doesn't help. However, they also state that, "Physicians may wish to consider the suitability of a therapeutic trial of thyroxine on an individual patient basis."

If your TSH test is above the range but less than 10, it might be an idea to discuss these Guidelines with your doctor as it may persuade him to give you a trial of thyroxine. In our experience, patients with signs and symptoms of hypothyroidism who have a normal TSH and low normal FT4 also benefit from a trial of thyroxine.

Your FT4 could be nearer the top of the range usually and therefore with a low normal level, you feel quite ill. As you probably did not have your thyroid tested when you were well, you will never know if this is the case. Discuss the possibility of a trial of thyroxine with your doctor if you have low normal FT4 levels.

- TSH has a circadian rhythm (24 hour cycle) and levels peak between midnight and 6am. T3 has a similar circadian rhythm. It is therefore a good idea to have your thyroid tests done at the same time of day each time as your levels may differ at different times of the day.
- Start to keep a diary and include your thyroid test dates, thyroid test results and their ranges, any other tests such as B12, folate, ferritin, cholesterol etc that you have had done recently, pulse rate and weight. Your diary will soon start to show a picture of your health and whether things change or not.

- Tick off all the symptoms you have on our Hypothyroidism or Hyperthyroidism Symptom List, adding any symptoms you have that are not listed and rate them on a 1-10 scale with 10 being the worst. Do this at regular intervals – at the same time as you have tests done is a good idea and then you can see how you are feeling and tie this in with test results. This will also help you know at which level you feel best for future reference.
- Find out as much as you can about the thyroid before your appointment so that your doctor can see you are well informed. Copy information from our Information Pack or from thyroid books and highlight the relevant areas so that you can show these to your doctor.
- Make a list of questions you want to ask your doctor. Make sure you have space for your answers. Add to the list as you remember things.

At the appointment

- Give your doctor a copy of your diary and list of symptoms and explain some of them if necessary. Explain exactly how your symptoms are affecting your quality of life and your work – explain the things you used to be able to do but can't now. "Before" and "after" photos sometimes help too.
- Ask your doctor if you can have all the thyroid tests available if you have not had these done. Many doctors only do the TSH test. However, some doctors believe that all the tests need to be done i.e. TSH, FT4, FT3, TPO and TgAb. This will ensure that other thyroid problems are not missed such as non-conversion of T4 into T3, Hashimoto's disease, central (secondary) hypothyroidism or Graves' disease. Be aware, though, that your GP may ask for FT3 to be done but the lab that the test form goes to may refuse to do it. You could try asking if your GP will add something to the test form to say "Thyroid function test including FT3 & FT4, regardless of the TSH reading." as this may help.

- You may not actually be on enough levothyroxine. Dr A Toft writes in the BMA book "Understanding Thyroid Disorders", "The consensus is that enough should be given to ensure that levels of T4 in the blood are at the upper limit of normal or slightly elevated and those of TSH at the lower limit of normal, or in some patients undetectable." He also states, "Although, by taking excessive thyroxine, a sense of well-being, increased energy and even weight loss may be achieved in the short term, there are long-term dangers to the heart and a possibility of increasing the rate of bone thinning and therefore encouraging the development of osteoporosis.

This book is available from pharmacies, bookshops, www.amazon.co.uk (use the link on our home page) and can also be borrowed from our library.

However, there has been recent evidence to show that it may be safe for patients taking long-term thyroxine replacement therapy to have a low but not suppressed TSH level. The patients who took part in the study who had very high (more than 4.0mU/l) or suppressed (less than 0.03mU/l) TSH levels more frequently suffered from heart disease, abnormal heartbeat patterns and bone fractures compared to patients with TSH levels in the normal range (0.4-4.0). Patients who had a slightly low TSH level (0.04 - 0.4mU/l) did not have an increased risk of contracting any of these conditions.

Take the booklet and details of the above study to your next appointment with your doctor and discuss the possibility of a further increase of levothyroxine. If you experience signs of over-replacement such as feeling very hot and sweaty, have a tremor and fast heartbeat, you should contact your doctor as soon as possible to discuss going back to your previous dosage.

- Other drugs that have been reported to reduce levothyroxine absorption include ciprofloxacin (Cipro), raloxifene (Evista) and Orlistat/Alli (Xenical) so be aware that it may be better to take these drugs away from your levothyroxine.
- Proton pump inhibitors, statins and oestrogens may reduce the effectiveness of levothyroxine.
- Coffee can also interfere with absorption of T4 so do not take your levothyroxine at the same time as drinking a cup of coffee – it's probably best to wait at least an hour before you drink coffee.
- Try taking your levothyroxine at bedtime as there was a small study that showed this benefited some patients.
- If you still feel ill it could be for various reasons. Some people do not feel well on a particular brand of levothyroxine. The main brand in the UK used to be Eltroxin and some people felt better on this. However, this is no longer produced. The other brands are all called generics (copies). Some people feel better on one generic than they do on another. Try to work out if you feel better on a particular generic and ensure that this is the brand given to you by the pharmacy. If one particular pharmacy does not have it in stock, try another pharmacy. Pharmacies may be purchasing whatever is cheapest at the time of ordering so you may need to insist on health grounds.
- Some people have a lactose intolerance. Levothyroxine contains lactose. There are brands of lactose free thyroxine available on a "named patient basis" – see our "Named Patient Basis" leaflet. Discuss with your doctor the possibility of being prescribed lactose free thyroxine instead. Contact us for details of these medications.

There is a paper discussing the fact that early treatment of euthyroid (normal thyroid hormone levels) Hashimoto's Thyroiditis with thyroxine may slow down the disease process. There is also evidence that shows that anti-thyroid antibodies can cause infertility and miscarriage. It is therefore a good idea to find out if you have high thyroid antibodies and discuss treatment with thyroxine with your doctor.

If your doctor is not able to do some of the tests on the NHS ask if you could have the blood drawn at the surgery in order to have private tests done by a diagnostic lab such as Genova Diagnostics (see Genova Diagnostics leaflet). Sometimes the NHS lab will do private tests if asked.

- Ask your doctor to check your B12, folate, ferritin and Vitamin D levels as deficiencies of any one of these could be a reason for your ill health. The symptoms for Pernicious Anaemia are very similar to those of hypothyroidism. The range for B12 is quite wide and some patients feel much better at the upper end of the range. The BBC produced a programme regarding this - "Inside Out 30 Oct 2006 - Vitamin B12 Deficiency" - which you may be able to watch online.

You can find more information on the website of the Pernicious Anaemia Society <http://www.pernicious-anaemia-society.org/>

- There has been a lot of research recently, showing that the serum B12 test is inadequate and a new test has now been developed to test for holotranscobalamin only. This is not available generally on the NHS. However, the Nutristasis Unit at St Thomas' Hospital now provides this test. It is slightly more expensive than a standard serum B12 test. To obtain this test you need to get a signed letter from your GP requesting the test and you must attend the phlebotomy department at St Thomas' Hospital.

For more information on the Active B12 (holotranscobalamin) test at St Thomas' Hospital please go to: <http://www.viapath.co.uk/our-tests/active-b12-holotc> or email the Nutristasis Unit at nutristasisunit@viapath.co.uk or phone Denise Oblein on 020 7188 7188. Or you can visit the Axis-Shield website: www.active-b12.co.uk Registration Forms are available from the Nutristasis Unit or Denise Oblein.

- The Active B12 test is also now available as a private home test kit through the private testing company Blue Horizon Medicals. For more info about Blue Horizon, and to download the Thyroid UK list of discounted Blue Horizon tests, go to the Home Blood Test Kit section http://www.thyroiduk.org.uk/tuk/testing/blue_horizon.html
- If your doctor suggests seeing a consultant in a different field to endocrinology, perhaps a rheumatologist, it might be a good idea to do this. It will either show up another health problem or it will rule it out completely. This often happens when patients are referred to psychiatrists.

If you are diagnosed

- Once you have been diagnosed, try to see the same GP/ endocrinologist every time you make an appointment. It makes it much easier to discuss your progress.
- Be aware that if you are diagnosed with hypothyroidism (myxoedema), you are entitled to free prescriptions. Ask your GP or NHS hospital for an FP92A application form. The form tells you what to do. A certificate/card will be sent to you upon receipt of a properly completed application form.
- If your doctor diagnoses you with thyroid disease, he will probably start you on treatment. Information on the different treatments is found in our leaflets, Hypothyroidism and Hyperthyroidism. Treatment is usually started with small dosages. You will probably be told to be tested in two or three months and then make another appointment.

Your doctor will then look at your test results, discuss your symptoms with you again, especially any improvement, and then make a decision as to whether or not to increase or decrease your dosage.

Your doctor will decide when to keep you on a particular dosage. This is usually decided by looking at the blood tests. However, some people still remain ill at this point. If this happens, we suggest the following:

Hypothyroidism

- You will need to be patient as it can take a long time to improve. It takes about 7-10 days for the levothyroxine to enter the body's cells properly so don't expect any improvement before then. Some people do see improvement in two weeks but for many it can take several weeks and even then, only some of the symptoms will improve in the beginning. If you have been ill for a very long time, it can take many months before you are back to normal.

You may find that you have some good days and then some bad days again. You need to be careful not to overdo it until you have found the right level for you (your set point).

- Ensure that you are taking your levothyroxine with water, on an empty stomach. Wait for at least 30 minutes before you eat.
- Ensure that you do not take calcium carbonate (found in calcium and other supplements and antacids) within four hours of your levothyroxine as this affects absorption.
- Ensure that you do not take iron supplements within two hours of your levothyroxine.