



MANAGEMENT FILE

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This leaflet is based on an article which first appeared in the ME Association's quarterly *ME Essential* magazine. MEA membership costs £18 a year for people living in the UK/BFPO. For contact details, see foot of this page.

the ME association



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THYROID DISEASE AND ME/CFS

INTRODUCTION

Back in April 2017 we asked about the thyroid gland and thyroid function tests in the MEA website *Quick Survey*. We had 343 responses.

Question: What was the result of your most recent blood test, or before treatment was given, to assess thyroid gland function?

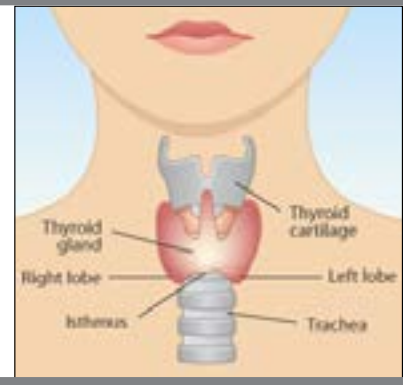
Answers:

- low - hypothyroidism (19%, 66 Votes)
- borderline low (14%, 48 Votes)
- normal (44%, 150 Votes)
- borderline raised (2%, 8 Votes)
- raised - hyperthyroidism (2%, 6 Votes)
- don't know (10%, 33 Votes)
- never done (9%, 31 Votes)
- awaiting results (0%, 1 Votes)

We asked this question because:

- Some of the symptoms of low thyroid function/hypothyroidism overlap with ME/CFS – so this is a condition that **MUST** be excluded before a diagnosis of ME/CFS is confirmed.
- Hypothyroidism is fairly common, especially in older age groups, and the symptoms often develop slowly over time. So some people will have ME/CFS and then develop thyroid disease, and the latter may be misdiagnosed as a slow deterioration in ME/CFS symptoms.
- There is uncertainty over whether thyroid disease is more common in ME/CFS – in our current state of knowledge, research evidence indicates that this is not the case.

Information on the thyroid gland, thyroid function tests, treatment of thyroid disease, and the overlap with ME/CFS



This Management File summarises all the key information that people with ME/CFS need to know about the thyroid gland, testing for thyroid function, and the treatment of thyroid disease.

1 The thyroid is a butterfly-shaped gland that sits in the front of the neck, just below the Adam's apple.

It produces a hormone called thyroxine – also called T4 (because it contains 4 atoms of iodine). This hormone is then converted in cells and tissues into an active form of thyroid hormone called triiodothyronine or T3 (which has 3 atoms of iodine). T3 and T4 are two really important hormones because they are needed for all the cells in the body to work normally.

2 Thyroid disease is common. About one adult in 80 has hypothyroidism – where the output of thyroxine is reduced. Hypothyroidism is much more common in women (15/1000) than men (1/1000) and becomes increasingly common over the age of 50. Hyperthyroidism, which causes an increase in the amount of thyroxine being produced, is less common.

3 Hypothyroidism causes a number of characteristic symptoms – most of which are related to a gradual slowing down in the function of the tissue or organ involved. Common symptoms that overlap with ME/CFS include fatigue, muscle weakness/cramp/pain, cognitive dysfunction, increased sensitivity to the cold, tingling sensations in hands and fingers, weight gain. Symptoms not normally found in ME/CFS include dry and/or puffy skin, hair loss – including a characteristic loss of the outer third of the eyebrows, hoarse voice, constipation, heavy periods and a low pulse rate (bradycardia).

4 Hyperthyroidism causes a number of symptoms that are very similar to anxiety – such as mood swings, irritability and twitching or trembling – and can be misdiagnosed as anxiety. Other symptoms include palpitations, sweating, heat intolerance, weight loss, diarrhoea and sore or gritty eyes. There may be an obvious swelling of the gland in the neck.

Continued overleaf

5 Because hypothyroidism is a common medical condition, some people will have hypothyroidism and ME/CFS. And the thyroid problem may not be picked up because some of the symptoms of hypothyroidism are very similar to ME/CFS. So everyone should have their thyroid function tested before a diagnosis of ME/CFS is confirmed. The MEA believes that periodic checks on thyroid function for people with ME/CFS over the age of 50 is also a sensible precaution to take, especially when there is a deterioration of health for no obvious reason.

6 The output of thyroxine from the thyroid gland is controlled by a hormone called thyroid-stimulating hormone (TSH). This is produced by a small gland under the brain called the pituitary gland. Along with the hypothalamus, the pituitary constantly monitors the level of thyroid hormone in circulation. If the level falls, the output of TSH is raised in order to stimulate the thyroid gland to produce more thyroxine – rather like a heating thermostat in the home.

7 Hypothyroidism is diagnosed by finding an increased level of TSH and a reduced level of T4 in the blood.

Early on, and in borderline/sub-clinical cases of hypothyroidism, both tests can be within the normal range with the TSH moving towards the upper limit of normal and the T4 towards the lower end. The level of T3 is not usually measured but there are people where the problem lies in the conversion of T4 to T3 – not the production of T4.

Thyroid peroxidase antibodies (TPO) should also be measured in borderline cases if the TSH remains elevated.

Thyroid peroxidase (TPO) is an enzyme normally found in the thyroid gland. It plays an important role in the production of thyroid hormones. A TPO test detects antibodies against TPO in the blood. If you have been diagnosed with thyroid disease, your doctor may recommend a TPO antibody test, in addition to other thyroid tests, to help determine the cause.

The presence of TPO antibodies in

your blood suggests that the cause of thyroid disease is an autoimmune disorder, such as Hashimoto's disease or Graves' disease. In autoimmune disorders, your immune system makes antibodies that mistakenly attack normal tissue. Antibodies that attack the thyroid gland cause inflammation and impaired function of the thyroid.

Some people with TPO antibodies may not have thyroid disease. However, the presence of TPO antibodies may increase the risk of future thyroid disorders. If you have normal thyroid function with TPO antibodies, your doctor may recommend periodic checkups to watch for future thyroid problems.

If there are any doubts about either the diagnosis or management of hypothyroidism, I strongly advise asking a GP for a referral to an NHS hormone specialist (endocrinologist) rather than using the private sector for what can be very expensive consultations, tests and sometimes questionable treatments.

UK adult reference ranges for the two common blood tests:

TSH = 0.4 – 4.5mU/L

Ft4 = 9.0 – 25pmol/L

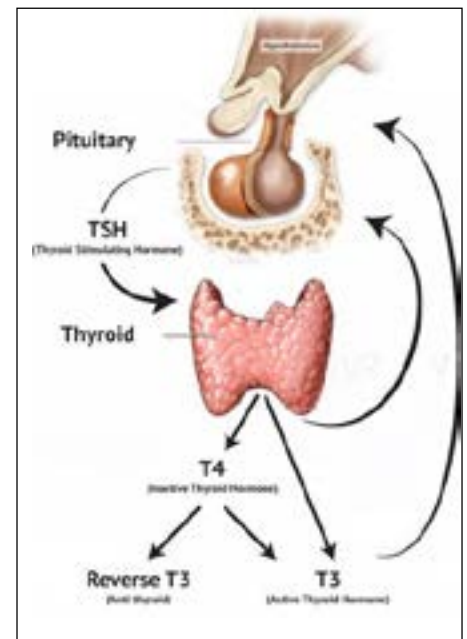
More detailed information on thyroid function tests can be found here:

<http://labtestsonline.org.uk>

8 Hyperthyroidism is diagnosed by finding a raised level of T3 and T4 and a reduced level of TSH.

9 Although there is consistent evidence of dysfunction affecting the hypothalamic-pituitary-adrenal axis in ME/CFS (which reduces the output of cortisol from the adrenal glands), there is no sound evidence to indicate that hypothyroidism is more common in people with ME/CFS, or that is more likely to occur if you have ME/CFS.

10 Hypothyroidism is treated with



(prescription only) thyroxine and this is normally carried on throughout life. The decision on whether or not to treat, or just monitor, someone with borderline thyroid function test results will depend on individual circumstances.

There is no indication to treat people with ME/CFS who have normal thyroid function tests with thyroxine – as some doctors in the private sector have done. This is not only unnecessary. It can also be dangerous, especially when there may be adrenal gland dysfunction present (i.e. low cortisol) as well.

There are also some concerns about the way in which a synthetic version of T4 is almost always prescribed.

Synthetic T4 works in most cases but, as already noted, in some cases the problem does not lie with the thyroid gland failing to produce enough T4 – the problem lies with the conversion of T4 to active T3.

T3 can be taken in tablet form but the cost here has escalated to the point where two months supply of a drug that is fairly cheap to produce is around £300.

Medical information contained in this leaflet is not intended to be a substitute for medical advice or treatment from your doctor. The ME Association recommends that you always consult your doctor or healthcare professional about any specific problem. We also recommend that any medical information provided by The MEA is, where appropriate, shown to and discussed with your doctor.