7 July 2021

Simon Pearce Hypothyroidism Part One

Simon/Lorraine, I have added into the document the questions that were asked in chat during the Q&A. Questions answered on 7 July are in blue - Judith. I’ve added my questions - Lorraine

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# General

Lorraine: What is your advice to patients whose GP can’t restore their wellbeing?

# Ascorbic Acid effect on TSH?

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| *1/ Tracey - see vitamin C below*  *In a recent webinar you stated that you prescribe Ascorbic acid to patients with compromised absorption, and mentioned that patients who adopt this regime (measured by their TSH) can possibly go from being initially Hypothyroid to dramatically Hyperthyroid.*  *My TSH was consistently around 4.67 (30mcg T3 & 50mcg T4) until I started taking supplements:*  *Holland & Barratt Elderberry Immunity gummies (80mcg vitamin C, 2.5pg vitamin B12, 3.5mcg Zinc) and Yumi apple cider vinegar gummies.*  *At my next blood test, my TSH had plummeted to 0.07 and the only thing that I had changed are the supplements.*  *I've now been referred for 'referred TFT's' blood tests to determine whether I have antibodies to T4 & T3.*  *Mark Gurnell at Addenbrookes laboratory discusses the phenomenon of these antibodies in a powerpoint presentation. However his results regarding antibodies to T4 & T3 show the TSH rising which is the opposite to my experience.*  *I’d be very interested in your opinion on the sudden change in my TSH and the possible causes.*  Sudden change in TSH could very likely be due to the vitamin C and other acidic compounds in those supplements. Antibodies to T4 and T3 are very rare indeed, but occasionally factors found in your blood called ‘heterophile’ antibodies can interfere with measuring thyroid hormones in several biochemical assays. It generally means you are fine, but the lab results come out wrong. |

# Reversing hypothyroidism

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| Shireen  2. Do you believe and have you heard of people reversing hypothyroidism and what are your thoughts on this?  Yes mild hypothyroidism can reverse, but we rarely test this out in the UK. A recent US study showed that around a third of patients reversed their mild hypothyroidism if they stopped their treatment for 6 weeks and had repeat blood tests. |

# Weight gain/loss

Shireen: Do you know how someone with hypothyroidism should or can lose weight easier?

Ali: If you put on weight, should your dose be increased?

In general, the whole population is putting on weight every year up until you reach 75 or 80, so we don’t expect people with hypothyroidism to be much different. People with severe hypothyroidism, which has been present for a long time do lose weight when they start levothyroxine, but the studies of mild hypothyroidism (TSH<10) don’t show much of a change in weight when thyroid hormones are started. Lots of environmental issues affect your weight and weight gain is rarely due to an issue with thyroid hormone replacement. So no, your thyroxine dose should not necessarily be increased if you gain weight. Of course, if you go from 50Kg to 75Kg, your body is bigger and your requirement for thyroxine will increase.

# Vitamin C

Emma: Would you recommend a soluble vitamin C tablet or just one you swallow?

*In a recent webinar you stated that you prescribe Ascorbic acid to patients with compromised absorption, and mentioned that patients who adopt this regime (measured by their TSH) can possibly go from being initially Hypothyroid to dramatically Hyperthyroid.*

*My TSH was consistently around 4.67 (30mcg T3 & 50mcg T4) until I started taking supplements:*

*Holland & Barratt Elderberry Immunity gummies (80mcg vitamin C, 2.5pg vitamin B12, 3.5mcg Zinc) and Yumi apple cider vinegar gummies.*

*At my next blood test, my TSH had plummeted to 0.07 and the only thing that I had changed are the supplements.*

*I've now been referred for 'referred TFT's' blood tests to determine whether I have antibodies to T4 & T3.*

*Mark Gurnell at Addenbrookes laboratory discusses the phenomenon of these antibodies in a powerpoint presentation. However his results regarding antibodies to T4 & T3 show the TSH rising which is the opposite to my experience.*

*I’d be very interested in your opinion on the sudden change in my TSH and the possible causes.*

Answered above (Tracey’s Q): vitamin C is the same as ascorbic acid. Either soluble fizzy vitamin C or the insoluble tablet work fine.

# When to treat? Subclinical hypothyroidism

June: Would you treat subclinical numbers if thyroid antibodies were high indicating Hashimoto’s disease?

Antibodies tell you something about the rate of decline in thyroid function, but not whether someone will feel better with treatment. So antibodies don’t really help in making the decision.

Julie: Perimenopause and hashimotos have similar symptoms- so difficult to know which is causing it - could be both. If TSH is raised (6 monthly tests) but less than 10, normal T4, TPO antibodies positive and patient has bad fatigue would levothyroxine help? If your TSH is raised and you have positive TPO antibodies will it definitely develop into overt hypothyroidism over time?

Around 50% of people with positive antibodies and raised TSH will go overt over a 20 year period. If the TSH was 7 or 8 and was persistently like that for 3 or 4 months, I would recommend a trial of levothyroxine (at least 3 months and at least 75mcg daily) to see if bad fatigue improved. If it didn’t then you could/should stop it. What we would definitely recommend against is trying T3 for mild hypothyroidism when symptoms didn’t improve with T4. In this case it is most likely that the symptoms didn’t improve because they weren’t caused by hypothyroidism in the first place. Doctors need to know when to back out and not keep pursuing mild hypothyroidism as the cause of symptoms because it is easier then otherwise engaging brain to work out what is going on, or addressing weight management and/or lifestyle issues: doctors are not good at improving lifestyle behaviours long-term, and patients often find this very difficult to achieve and so are dissatisfied by the advice.

Julie: Should patients with continually raised TSH , positive TPO antibodies and symptoms wait until TSH is over 10 [before treatment]?

Not necessarily, a trial of treatment is warranted in younger people (ideally <60/65) once other causes of the symptoms have been considered. If the symptoms aren’t improved, then you should stop it.

Julie: If your TSH is raised and you have positive TPO antibodies will it definitely develop into overt hypothyroidism over time?

No only 50% over 20 years follow up will go to overt hypothyroidism.

Jane: several of the gp guidelines I have seen eg BMJ best practice define subclinical hypothyroidism as raised tsh & normal ft4 and include tsh>10 & normal ft4 as subclinical - so i'm interested to see you define anyone with tsh>10 as properly hypothyroid. the BMJ recommended treatment for subclinical hypo is pretty limited so I worry there's a lack of clarity about the difference between subclinical and primary hypo which affects treatment? (raising because this is the range I fall in)

Yes, I think this is harsh and driven by a primary care research group in Switzerland. I think any TSH persistently over 10 counts as overt hypothyroidism, and few real thyroid specialists would argue about this.

Lorraine: What is the evidence for saying most subclinical patients won’t feel better on treatment ( you may have covered this in the talk but if so I missed it) - is it possible that patients with subclinical hypothyroidism might be more likely to need a very fine tuned dose to feel well?

There are 7 randomised studies looking at slightly more than 450 people less than 65 between them (average age around 50). 4 showed marginal benefits, two showed nothing, in one people felt worse with thyroxine. Marginal benefits were improved memory in one study and improved fatigue in another. There are 4 studies in people over 65, and these show no benefit.

# T4

Mercedes: does t4 not always work because people really have no thyroid problems or because it's not the right med for them?

T4 most often doesn’t work because either the dose is wrong, or that they don’t have a significant thyroid problem. In my opinion (which is not everyone’s opinion) it is very rare to find people who have a dramatic response to T3 which is sustained for several years. Most people feel better initially because it feels good to get a special medicine with a lot of hype around it, but this initial effect wares off in many people over time.

Pili: Apart from taking Thyroxine on an empty stomach and not eat or drink for approx half an hour - do you recommend anything else - eg Vitamins, minerals etc...

I would avoid kelp, seaweed, iodine. Selenium in moderate amount probably is of benefit for Hashimoto thyroiditis if you rarely eat nuts, but too much is associated with a risk of diabetes so go easy; 100-200mcg daily is recommended. You can get this amount from one or 2 Brazil nuts daily. Most people in the UK are borderline insufficient for vitamin D in the winter, particularly if you work indoors, have darker skin or live further north. I take 800-1000 units (20-25 mcg) daily vitamin D3 in winter (October to March).

Lyn: does Levothyroxine work for everyone ?

As above.

Jane: I don't think you said what the aim is when treating with levothyroxine, would you recommend a tsh range to aim for or more symptom based?

My next talk will show the evidence that despite what you might think, most people can’t tell the difference between different doses of levothyroxine. If a person feels great, I’d pretty much be happy with any TSH in the normal range 0.3-4.5, but if they didn’t feel good, I’d more aim for 0.3 to 2.0.

Andrea: Is the ideal range for TSH still 0.3-4.5 when taking levothyroxine? Can it be lower, does that depend on symptoms?

Yes, some people might still get symptoms with a TSH of 4.4, so we would aim for lower. The average TSH in the younger population is around 1.6, so that’s a reasonable place to aim for. Although in the long-term, large epidemiological studies show that keeping a TSH below 0.3 is bad for you (increased risk of heart problems; atrial fibrillation, osteoporosis, fracture, dementia), the individual risks are small and a few people do seem to feel much better when their TSH is around 0.2. I would try to avoid a TSH less than 0.1 as a long-term thing.

Emma: I was medicated about 4.5 years ago originally on 50mg now 75mg. I still feel exhausted all the time. How often should my levels be checked?

Consider a trial off treatment to see if you feel worse. You may be in the situation where thyroid hormone isn’t helping you, or conversely, it can cause slight sleep disturbance and make you feel worse. We would usually recommend once or twice yearly TSH monitoring.

Andrea: Should you be symptom free if you are taking the right dose of thyroxine? Would this be true especially if you were diagnosed when pregnant? (I have never felt well on levothyroxine and now on citalopram for chronic anxiety.)

As people without hypothyroidism on average have two or 3 symptoms of hypothyroidism, I wouldn’t expect everyone to feel 100% perfect and symptom free on levothyroxine. Most of the population feels tired due to the stresses of life, long working hours, long commutes, financial anxieties, job insecurity etc.

Kath: a young man at a northern university who had just been diagnosed with hypothyroidism. He was feeling very unwell and wondered how long it would take to feel better on levothyroxine? I showed a study showing that you should feel back to normal in 16-20 weeks (Roos).

Lorraine: How can you be confident that T4 in the blood reflects tissue T4?

We are not confident of that. As well as measuring TSH which reflects pituitary T4 concentration, we can measure a liver protein called SHBG which reflects thyroid hormone action on the liver. But short of putting your brain or heart in a blender, we can’t accurately measure tissue T4 levels, so we don’t really know.

# T3

June: My endocrinologist can’t test for FT3 even though I take T3 only because the lab will only do TT3. Why is the lab driving this rather than the doctor who knows more about the patient than the lab? Which is best to ascertain function on T3 only?

I did answer this in the Q&A. The problem is that T3 lasts for only 3 or 4 hours in the blood and we don’t know when best to measure. A pre-dose level is expected to be low, and a peak FT3 level just reflects that you recently took T3 and is normally higher than the blood reference range. So measuring FT3 in people who take T3 is generally not useful as it fluctuates wildly across a day.

Tara: If a patient has T4 consistently in the upper range, TSH is consistently normal, and T3 is consistently at the bottom of the range, would that indicate poor conversion in the body of T4 to T3? Would it indicate a need to trial T3 medication?

No I don’t think so. A lowish blood FT3 is normal as you get older, like the healthy reference drops once you are over 70 or 75. A low FT3 can indicate that you fasted for the blood test as it goes down with a few hours of fasting. A low T3 can also mean that you have an inflammatory or infectious condition developing, such as rheumatoid arthritis, psoriasis, it could almost be anything-numerous different non-thyroid diseases cause a low FT3.

Lenovo: does reverse T3 affect how much T3 is absorbed to where it is needed in your body?

Reverse-T3 is a degradation product of levothyroxine in the tissues that overspills to the blood. Some private labs claim to be able to measure it, but it is analytically very difficult to measure so the reported measurements partly reflect blood thyroxine unless it is done by a specialist lab. Also, no NHS lab measures reverse-T3 because it isn’t a helpful measurement clinically.

Lesley: did you say that you never measure T3 and you believe it is irrelevant to any decision you would make about prescribing? I may have got that wrong.... would appreciate clarificatiion.

Never measure T3 in hypothyroidism as it isn’t a helpful measurement. You body tries to keep every last thyroid hormone molecule as T3 so even in severe hypothyroidism, blood T3 can be normal. In contrast, FT3 is a really sensitive indicator of hyperthyroidism and I feel quite dependent on knowing FT3 if I am treating a patient for hyperthyroidism.

Jim : Measuring fT3 is essential to confirm that the axis is working. A TSH of 100 with normal fT3 shows successful compensation. A TSH of e.g. 2.3 with low normal fT3 and fT4 shows an axis problem and possibly severe clinical hypothyroidism.

Normal is normal. In other words a normal TSH of 2.3 with a normal FT4 of 12 (10-22) and a FT3 of 3.7 (3.5-6.8) is normal. A higher TSH in the normal range doesn’t have to go with a lower FT4 or FT3 level in the normal range, or vice versa. Individuals have different balances between TSH and FT4, FT3 and normal for each is normal.

Stephanie : How do you know if the patient is taking adequate/ too little/ too much T3 ( liothyronine ) if you never measure it?

By measuring TSH and asking about symptoms of overactivity and underactivity.

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| Most T3 (85%) comes from conversion of T4 to T3 in tissues such as the brain, and skeletal muscles which finds its way to the blood and is measured as total T3 or free T3. If a patient has conversion problems, is it not very silly to presume that a little liothyronine (normalising fT3) will adequately replace T3 in the tissues that rely on local generation of T3?  The “T3 conversion problem” is largely mythological. If you had a genetic T3 conversion problem which is what some people think might explain their symptoms, you would have learning difficulties due to poor brain development in early childhood (in fact what used to be known as cretinism). It is inconceivable that someone who could not convert T4 to T3 would have normal intelligence. Most of the people who believe they have a conversion problem are highly articulate and bright, but misinformed.  If the brain could get its T3 from the blood, why would it bother with local conversion of T4? Based on this analysis should we not conclude that all the T3 / T4 combination therapy studies are worthless?  Well the whole thyroid system (‘axis’) evolved to allow amphibians to keep stable levels of thyroid hormones in the blood as they moved (evolved) away from the sea which is the source of iodine. So at every level a system adapted for stability of thyroid hormone levels has been ‘naturally selected’ 1: your thyroid has follicles which are big pools of stored thyroid hormones 2: your blood carries both T3 and T4 bound to other plasma proteins (mainly albumin) to give a big buffered pool of thyroid hormones, from which about 1% is available as free thyroid hormone for the tissues to use. Meaning 99% of thyroid hormone in blood is a stable storage pool and blood total T4 is very stable; 3: each indvidual cell can take up either T3, T4 or both and activate and inactivate them as necessary so the cell get exactly the required amount for it’s function. So in rodent studies at least, many (including brain) but not all tissues can maintain tissue levels of T3 through a wide range of blood T4 concentrations, from too low to too high.  Can we look forward to better science in the future?  Yes, definitely we should look forward to more studies, but 1: we can’t ignore that 13 of 15 clinical trials of combined T3/T4 showed no effect or a deleterious effect. Good science is about accepting the results for what they are and 13 of 15 studies is a highly reproducible result, done by different teams on different patient groups in different countries. If adding T3 worked in most people, the results would be startlingly obvious from the work already done. So we have to accept this as a valid result which is going to be representative of the clinical benefit for most patients and not ignoring these studies because the results are not what we expected or wanted to see. 2: we can only learn about what will work for patients from more clinical trials, more rat experiments aren’t going to help know what will make people feel better. So trials of long-acting T3 would be great. Trials recruiting people with a certain DIO2 genotype are probably worthwhile but my knowledge of thyroid hormone metabolism tells me that the common variation in DIO2 accounts for 1 or 2% difference in serum FT4/FT3, so this is less than the difference between 2 different brands of levothyroxine tablet or taking your medication on an empty stomach or with a cup of coffee, so yes, let’s look at that but I’m not holding my breath (could be famous last words from me!). 3. Endocrinologists are a group of doctors who are programmed to believe that if you get someone’s blood hormone levels perfect, that person will feel perfect, and that is one reason that the whole T3 thing has got out of control. Endocrinologists are blinkered in their thinking and if it isn’t to do with hormone levels, they are a bit stumped. If you ask the military to resolve a conflict, they’re gonna fight, not negotiate. So an endocrinologist’s default position is ‘lets try and get the hormones perfect’ (that’s 90% of our job), but what if the hormones are as perfect as they are gonna be already and something else is the answer. We can’t walk around with our head in the sand and pretend it must be to do with T3, when the evidence so far shows that T3 is a good solution for a minority only.  Jim Harwood. |

Mercedes: Do u recognise genetic conversion problems?

I’ve yet to meet someone who I could discern good evidence for a genetic conversion problem. If you had a genetic T3 conversion problem you would have learning difficulties due to poor brain development in early childhood. It is inconceivable that someone who could not convert T4 to T3 would have normal intelligence. Most of the people who believe they have a conversion problem are highly articulate and bright, but misinformed.

Mercedes: Is it possible that many of the people with symptoms but normal TSH simply are not converting well? Wouldn't that explain normal blood levels and maybe lack of response to T4?

As shown by the Colorado study, 60% of healthy people have at least one symptom of hypothyroidism. We can’t consider treating 60% of the population with thyroid hormones, and the Pollock study shows this doesn’t improve symptoms even if we did it.

Jane: What about people who have DIO1 mutation stopping T4 conversion to T3?

This person would have severe learning difficulties as their brain would not have been exposed to the right amount of thyroid hormone to develop properly. We can discern that children born to mothers who had subclinical hypothyroidism during pregnancy (that is still normal FT4 levels in her blood) have lower IQ at the age of 3 or 5, so brain development is acutely sensitive to small differences in thyroid hormone concentration. Most people who tell me they have a conversion problem are highly articulate, the exact opposite of people with learning difficulties. IMO, this whole “low converter” construct is conceived by private medical and ‘wholistic’ practitioners in the USA to sell T3 or NDT to people.

Shireen: Can medical practitioners campaign to change the way thyroid conditions are diagnosed and treated i.e NDT and full panel testing. As in the long run the NHS loses out given the long list of chronic conditions that result from purely using T4 for hypo.

The flip side of this argument is that the NHS already loses out, as it is paying upwards of 20 million pounds annually to treat less than 10,000 patients with T3, which has been shown not to work in trials. The NHS drug budget is finite, and I suspect the autumn 2021 budget will make it even more finite. Other patients with cancer, or children needing expensive gene therapies like cystic fibrosis are the losers because these very expensive treatments which 100% work in trials and are life prolonging or life-changing are often not funded (or the person has to wait years for the treatment to be funded) because the money is being spent on T3 or NDT. Literally people do die. I know that isn’t an answer, but it is why there needs to be stronger evidence before medical practitioners can make a hard case for everyone who might benefit to try T3 or NDT. I would love the NHS to have bottomless pockets, but that isn’t the reality.

# NDT

Tare: What are your thoughts on treatment with NDT?

Jane: What are your thoughts on treatment with NDT?

NDT is really very under-studied and we need a lot more research work before we can consider using it widely. A theoretical problem is also that pig thyroid contains T3:T4 about 1:4, whereas human thyroid it is about 1:14, so giving NDT gives a lot more T3 than is actually ‘natural’. The objective evidence of an advantage is not there at the moment.

# Blood tests

Mercedes: Are you saying - healthy according to blood tests?

I don’t know what this means. One definition of health says it is a state of wellbeing rather than absence of disease. People with healthy thyroids do have normal thyroid blood tests, except if you have thyroid cancer or nodules. So thyroid health is more than blood tests.

Pili: They only do the TSH test in most GP's now - you have said we should have TSH and T4?

Not necessarily, measuring FT4 can lead to inappropriate dose reductions in levothyroxine, but it is essential if pituitary disease is suspected. Most labs use a ‘cascade’ system and this works well.

Derek: The hospital labs will not test for T4 and T3 if the TSH is within the range.

Yes, that is the cascade system. Its enough as long as you are NOT looking for a pituitary problem.

Claire: I was only ever tested once and then prescribed - levels weren’t way out. Do you think it would be worthwhile coming off medication to check what the body is doing?

Yes, definitely worth a pause without medication for 6 weeks followed by a blood test, particularly if you don’t feel good on the current medication.

Mercedes: Did I misunderstand? Did u not say average tsh is about 1.8?

Yes 1.6 to 1.8 depending on age

Mercedes: does ft3 drop during illness because the body needs and uses more during those times? ie less in the blood because used up by cells more?

The pituitary shuts down a little so the thyroid probably relies on stored hormones and stops producing fresh. A little inflammation also causes the liver to make less T3, but this isn’t very well documented whether the cells use it up quicker.

Mercedes: I was asked to take my bloods around 4/5 hours after meds (t4 and t3) to see the peak I assume, but if it stays within ref range at peak time, is it possible that levels go down and I'm still under-treated?

T3 will go down quickly, but FT4 levels vary by only around 4 or 5 in the day, so there isn’t much drop. TSH remains the single most reliable test.

June: How do you know if the patient is taking adequate/ too little/ too much T3 ( liothyronine ) if you never measure it?

Symptoms of over or underactivity plus TSH result.

DEREK: Why do all private labs as standard procedure test all elements of the thyroid TSH, T4 T3 FT3 Thyroglobulin and thyroperoxidase?

So they can charge you £150 for measuring 5 things, when for most people, most of the time the clinically relevant information would come from measuring just one or 2. The NHS tariff is about £15 for TSH about £10 for FT4 or FT3. Private labs and private doctors aren’t a charity. They are like a Mercedes garage, they have prestige and will try to sell you the top of the range. The taxpayer can only afford a second-hand Ford Mondeo with 30,000 miles on the clock. It’s a reliable, decent car and it gets you where you need to be but there aren’t extra frills. IMO this is better than an American-style system where the affluent are all being sold a Porche but some people can’t afford a car at all, and have to walk.

Mercedes : why not measure [i.e. T3] at different times to get at least an idea of how it's working while on it?

Yes, hourly T3 measurements could work, but I don’t know what it would tell you. It would be high for a while, then normal for a while, then low after 8 hours or so. Wellbeing is probably the best way to tell if T3 is right for you. Endocrinologists can always be persuaded that more blood tests are a good idea, but there is no close correlation between your blood T3 levels and how you feel, so more might not be better.

Lorraine: If the average TSH in the population is always 1.6-1.8, might it make sense to consider treating someone with multiple debilitating symptoms who had for example a TSH of 3 or 4?

Well a TSH of 3 or 4 is well within normal (i.e. 97.5% of the population will be within the 0.3 to 4.5 window). So that is one reason to measure FT4 as well, as if your TSH is 4.6 and your FT4 is low we would consider treating if you have symptoms. But as most people get few symptoms with TSH up to around 10, treating symptoms at a TSH of 3 or 4 doesn’t make sense. Comes back to the Colorado study about symptom prevalence.

Lorraine: Is there any analysis of symptoms in relation to TSH >2/3/4/5/6 etc….? So many patients report having debilitating symptoms for years before being diagnosed and then “get their lives back” once treated

No well-designed studies come to mind here. It is an interesting idea.

# Drug interactions

Mercedes: Can heparin affect the thyroid? The contraceptive pill? Warfarin?

Michael: Does Cortisol have an impact on Thyroid Testing?

is it safe to come off meds after many years of treatment?

Linda: If you have reflux severe indigestion and take omeprazole & thyroxine what drug should have to replace the omeprazole?

Ali: Can I take Iron Tablets in the evening without problems?

All the above queries were dealt with during the Q&A session

Julie : Is it true that Hashimotos patients should not take statins as it can cause myopathy?

True: People with untreated hypothyroidism should not be started on statins as hypothyroidism is a clear risk factor for statin-induced myopathy.

# Hyper/Hypo crossover

Tremeer: Is there a crossover of symptoms in both Hyperthyroidism and Hypothyroidism

Tremeer: How common and why do people go from Hyper to Hypothyroidism including onset of chronic anaemia

As shown, the symptoms can crossover, so symptoms like anxiety, mood disturbance, brain fog, aches and pains, and of course tiredness/fatigue are common to both hyper and hypothyroidism.

Tara: Overtreatment can lead to hyperthyroid symptoms, and possibly osteoporosis or atrial fibrillation. Is it the suppressed TSH that causes this? Or do over range T4 and T3 cause this?

Answered during the Q&A.

# Ageing

Sally: Are you saying that symptoms reduce with age, even if diagnosed when young? if they don't, does that mean you need higher meds?

Older people excrete (metabolise) thyroid hormones (and actually most drugs) more slowly, so levothyroxine doses generally tend to decrease with age. The study showed that at diagnosis older people had fewer symptoms, whereas healthy people had 2 or 3 symptoms of hypothyroidism on average irrespective of age.

# Menopause

Pili : [what about] MENOPAUSE and Hashimotos? regarding all symptoms exasberated eg lethargy, weight gain especially belly fat - terrible hunger pangs etc etc… I have always fluctuated between Hypo and Hyper and it has been and still is a "rollercoaster" Now coupled with MENOPAUSE well, do I need to say much more :) What can you advise? I definitely think that MENOPAUSE has an impact on patients suffering from any Thyroid condition....

When your oestrogen levels drop during menopause, your levothyroxine requirement will also drop so you may need to reduce levothyroxine dose.

Julie : Perimenopause and hashimotos have similar symptoms- so difficult to know which is causing it - could be both. If TSH is raised (6 monthly tests) but less than 10, normal T4, TPO antibodies positive and patient has bad fatigue would levothyroxine help?

This would definitely be worth a 3-6 month trial of levothyroxine. It might not help but is worth a shot; probably 50:50.

# Questions on the studies quoted in the talk

Lorraine: Did the Colorado study do any analysis on patients with more than four “hypothyroid symptoms”? Is there a tipping point where number of symptoms is most likely to be relieved by thyroid hormone replacement?

Fair question, but that wasn’t looked at, as it was just a one-stop ‘questionnaire and have a blood test’ design.

Lorraine: The Pollok study from 2001 had less than 50 subjects in total and all were given the same dose for just 12 weeks. Do you think this issue warrants revisiting or are the results definitive?

Difficult to say. That study had some difficulty getting through ethics, as it was deemed unethical to give ‘normal’ people thyroid hormones, but I agree it was a small study. The power is that is was a crossover design, so each person received both placebo and real thyroid hormones, which cuts out a lot of the ‘inter-individual’ noise from a parallel group study. Also the people who entered the study were amongst a very vocal local group who all had a lot of symptoms and pressurized the Glasgow doctors to do something about it.

Lorraine: Roos et all 2005, comparing doses - I think you said that the subjects showed the same symptom relief regardless of blood tests or dose in this study but that blood tests normalised quicker on the “full dose”. How would you explain those patients who have radically different symptom responses to different doses and would you advise clinicians to try adjusting doses in any patient who continues to experience symptoms or are there criteria for deciding when not to do this?

Well my next talk will show that most people can’t tell which dose of levothyroxine they are taking. It is possible that as soon as you start taking levothyroxine for hypothyroidism, the thyroid hormones are passaged out of your blood to the tissues where they are needed so as we often say, blood levels don’t reflect tissue levels, and the Roos study result could be a good example of that, plus possibly some placebo effect too.

In practice, most people who experience ongoing symptoms have room to firstly, consider a trial off levothyroxine to see if the ongoing symptoms are due to the levothyroxine and their thyroid already recovered. And secondly, for some modest dose adjustments. We rarely know the FT4 or TSH level of someone before they got a thyroid problem, so we are guessing a bit when we aim for something in the normal range, which is quite wide. So trying different dose levels does no harm, but the blinded studies show most people really can’t tell.

# Covid

Alison to Everyone : IS there a role for thyroxine in recovering from long Covid

Thyroxine should only be used for people with hypothyroidism. I showed a study showing that people with normal thyroid tests don’t feel better on levothyroxine, so this probably applies to long Covid.

# Other

Xpsi: What is happening when 1/2 hr after taking thyroxine, your breath suddenly disappears and you struggle to get it back?

Sometimes breathlessness at rest and a feeling you can’t fill your lungs is a symptom of hyperthyroidism. I would try splitting your levothyroxine dose in 2 and see if that helps.

Mercedes: Do you think there is a link between thyroid disease and mast cell activation syndrome (mcas)?

MCAS is a rare disease and I don’t know that much about it, but I haven’t heard of a link between this and thyroid disease.

Xpsi: Can it be confirmed 100% that levothyroxine stays in your blood for approx 6 days..

The half-life is 6 or 7 days, so of a single dose on day 1, 50% is gone in 6 days and 75% gone in 12 days etc.

Michael: GP are generic specialists - should patients ask to be referred to an Endocrinologist if wanting more customised treatment?

Problem is most NHS endocrinologists are overwhelmed and treating hypothyroidism is felt to be well within the skill-set of most GPs. I will see a patient with hypothyroidism once and occasionally twice if there are big problems but 3% of the population take thyroid hormones and we need twice the number of endocrinologists if we are going to look after all those people.

Amanda: Are xanthalasmas a sign of thyroid problems?

No, a sign of a cholesterol problem.

Nina : I have been diagnosed with low blood pressure and POTS and adrenaline rushes at night causing sweating and palpitations. How might hypothyroidism relate to this? Or does it. I have Ehlers Danlos hypermobile type.

??? : Is there anything [else] I can do lifestyle wise to ease my symptoms? I am also struggling with my cycle. Instead of 5-7 days on it is more like 10-12 days on.

There is a definite symptom cluster around EDS-3 and POTS. I don’t really understand why that should be, but as far as I am aware, this is unrelated to Hashimoto’s. I would say just try to keep a healthy weight and exercise every day, if only a regular walk for a couple of miles. Sometimes prolonged menstrual cycle can be due to hypothyroidism or too little levothyroxine but if your TSH is OK, (like below 3.5, it’s unlikely to be related).

Ann : I have been told that people with Hashimots often have low acid in stomach but can still have GERD. Is that right?

Yes, I don’t really understand this either but people with low stomach acid (due to ‘atrophic gastritis/ pernicious anaemia’) can get GERD symptoms. My GI colleagues say you can get bile going backwards into your stomach, and bile is quite irritant (biliary gastritis), so that might be a problem for some people.

Kathryn : Can hashimotos cause a low oestrogen level even with levy treatment and can the symptoms be similar to hypothyroidism?

Hashimoto’s does not affect oestrogen levels but menopause symptoms such as tiredness and brain fog can overlap a lot with hypothyroid symptoms.