

<u>Hope</u>

C A T S

CUMBRIA ADVISORY THYROID SERVICE Christmas 2016 - Bumper Newsletter

Long may C.A.T.S. continue to give hope to Thyroid patients everywhere

Hello Everyone

Hello friends, welcome to our bumper Christmas newsletter. We are sending a warm welcome to everyone who has recently joined us. The office has been very busy over the last few weeks with lots of phone calls and e-mails to answer. Thyroid problems are ongoing and as we get older new symptoms seem to arise. Did you know there are over 300 health conditions/symptoms that can occur when your Thyroid does not work properly. Most patients will only ever have a few of these problems and over time some may disappear leaving room for other symptoms to come along. As new research and information comes to light, we can only hope that one day a cure will be found for this often overlooked and often life changing health condition.

Thyroid Friends.

Thank you to everyone who continues to support us by renewing their membership and sending extra donations to support the work we do. Without this help C.A.T.S. would struggle to continue to run as a support group. Our membership database is continuing to grow with over 140 members however, we always welcome new members, so if you know anyone who may like to join us please tell them about C.A.T.S. We would like to think that after running this group for nearly 20 years we would have managed to reach everyone with our news but still people tell us they had never realised that a group such as ours existed so with your help to spread the word we hope to reach many more people in the future. Our membership is £6.00 for 12 months. You will receive 4 newsletters, access to our helpline, invitations to any meetings and special events we organise, plus information and advice from our Thyroid advisory team. C.A.T.S. are a not for profit community group so any money raised by the group is used for the benefit of Thyroid patients.



T3 Withdrawal by the NHS

By now all our members and supporters will have received the letter/e-mail I sent outlining the situation regarding T3 and the NHS. Thank you to everyone who returned the questionnaire. From the replies received, it looks as though only a small number of our group members are affected by this decision. If you have not returned your questionnaire, please can you do this as soon as possible. This is an important issue as far as Thyroid treatment is concerned and we would appreciate your questionnaires to be returned. Then we can work out what the next step should be. You can telephone or e-mail me if you prefer. C.A.T.S. are not a militant group and have always worked within the NHS guidelines, so any action we decide to take about this issue needs to be thought out carefully. I do not take T3 myself but do understand how important T3 is to the small number of patients who do take it and I feel this situation is unsatisfactory and needs to be highlighted. C.A.T.S. understand that T3 is still available in this country but only by a private prescription issued by your Endocrinologist. This is taken to your pharmacist who will give you your T3. However, as this is a private prescription you will have to pay for this service. £329.20 was quoted by Boots Chemist today (24th October) but the price seems to be rising as each week goes by. One chemist even quoted £516.00so you will need to shop around. This development is not just in Cumbria but is all over the country, as part of an NHS drive to save money. I understand that the NHS has to save money, but feel it is unfair to target Thyroid patients this way. Thyroid patients in general get a bad deal in life as it is without adding extra pressure.

In order to get a clear picture of the situation I have been in contact with PALS (Patient Advice Liaison Service) who say this is an NHS matter. I have also sent letters on behalf of C.A.T.S. to the MP for Barrow and Furness (Mr John Woodcock) and the MP's for Lonsdale and Westmorland (Mr Tim Farron) and Morecambe and Lunesdale (Mr David Morris) to see if they can offer any advice. Letters have been sent to the Westmorland Gazette. Gill and I were also very lucky to have an interview with Caroline Barber from the Evening Mail. They have followed up the interview with a very good article on the issues Thyroid patients are facing. I have also been in contact with the British Thyroid Foundation and the Cumbria Clinical Commissioning Group. Once I have received all the replies back, I will up-date everyone. T3 is widely available without prescription from other countries (via the internet), however as C.A.T.S. have said many times before that great care must be taken when ordering goods this way as not all firms are reputable. A lady phoned to say that she regularly goes to France, the last time she was there so took her NHS prescription for T3 to the doctor in France and was able to get another prescription for T3. The lady told me that the cost from the Pharmacy, was just over 3 euros (about £3.00 for 30, 25 micro-gram pills) on top of this there was the cost of seeing the doctor (23 euros) This is maybe something that patients could think about if they travel abroad

regularly. However, C.A.T.S. are not sure of the legal aspects of bringing medicines into this country so please check the rules out carefully before doing this.

**Please note that if you take T4 (Thyroxine) you will still be able to get this on the NHS as this medication is not yet affected by the new rulings.

Celebrating the Queen's 90th Birthday

It was a surprise phone call from the office of the Lord Lieutenant of Cumbria that started the chain of events that led to C.A.T.S. being invited to the Queen's 90th Birthday Lunch Celebrations in the Mall. The Queen supports many charities and voluntary groups but for our group to be selected (only 4 groups were selected from Cumbria) to attend such a memorable event was indeed a great honour. Sunday 12th June

The sun was shining as Terry and I left our hotel to travel to the Mall, where the celebrations were being held. As we travelled along it started raining, just fine drizzle at first but as we reached the Mall it became heavier. The gates opened at 10 o'clock and there was already a long queue when we arrived. For security reasons we were not allowed to have any umbrellas, but we were all given plastic macs which kept off most of the rain. Slowly the queue edged forward, by now the rain was much heavier, but everyone remained in a very jolly mood despite the rain.

As we entered the Mall we received our picnic hampers, bottled water, a goody bag and celebratory cup and saucer, plus some other celebratory souvenirs to help us remember this memorable day. From our seats we had an excellent view of the festivities, and entertainment that was provided. An added bonus was at about 1pm, it stopped raining and we were rewarded with brilliant sunshine.

Around 3pm the Queen and the Duke of Edinburgh drove down the Mall. The Queen wore a beautiful pink outfit with a lovely hat to match. They joined several members of the Royal family on the stage for the speeches. When the speeches finished the Queen and the Duke of Edinburgh joined Prince William and Prince Harry to return back down the Mall in the royal car. As the party came to a close Terry and I made our way back to King's Cross Station for our journey home. It had been a fantastic day and I am sure this memorable occasion will stay with us for many years to come. Thank you to all concerned for giving C.A.T.S. this wonderful opportunity.









Preparing for Winter

- *As winter approaches we need to prepare our bodies for whatever winter throws at us.
- *Many Thyroid patients feel the cold so wrapping up well is essential.
- *Wearing several thin layers of clothing is much better than just one thick layer. As the heat from our bodies gets trapped between the layers helping to keep us warm.
- *We lose heat from our heads so a hat is must, even indoors, as this can help when it is very cold.
- *Cold hands and feet are another problem so warm gloves and socks are the answer. I often wear 2 pair of socks as my feet are always like ice-blocks.
- *Keeping our homes heated is often a problem especially for our older members, C.A.T.S advisors always say that if you can't heat your whole house do try to keep one main room heated and stay in this room as much as possible. The guidelines are that the ideal room temperature should be 21c.
- *Having plenty of hot drinks also helps keep your body temperature stable.
- *Hot nourishing food is also essential as this will provide us with essential vitamins and minerals to strengthen the immune system. Casserole meals, soups, stews, and one-pot meals are ideal.
- *Keeping active is also important as moving about makes the blood circulate better. Under-active patients generally have poor circulation so this can be beneficial even if it is just walking around your living room.
- *If your diet is poor taking extra supplements is a good idea. Vitamin C, Vitamin D3, Zinc, Selenium, and Magnesium are all beneficial to Thyroid patients and will also boost your immune systems. The herbs Echinacea and garlic are also great immune boosters. However, great care must be taken when using supplements as some do react against thyroid medication causing extra unpleasant side effects. So please check with your doctor before taking any supplements. Also, please buy the best brand you can afford as some of the cheaper supermarket versions are very poor quality. If you do take a multi vitamin and mineral supplement, please be aware that some brands contain 150 micro-grams of Iodine and this is the maximum daily dose anyone should be consuming. However, most people will get an ample supply of iodine from many of the foods they eat. Our Thyroxine also contains Iodine atoms, so without being aware of it we could be unintentionally overdosing on Iodine. High levels of Iodine can be toxic to our Thyroid glands.
- * Sleep is also very important as your body repairs itself while you sleep.
- * Research also shows that a positive mind helps to maintain our general well-being, so keep on thinking those positive thoughts.
- * Last of all don't forget to have your flu jab. They are usually available from the beginning of October although not all health practices send out reminders so check with your surgery when they are available.

Normal Blood Tests

Many patients often ask why they still feel ill despite their blood tests being normal. First there is no such thing as a normal blood test. What your doctor means is your bloods are within the normal ranges. However, as C.A.T.S. have said before the normal range is quite wide so your readings may be up at the top or down at the bottom and you will still be classed as in the normal range. In the Morecambe Bay Area T4 ranges are 8-18 so if you aim for around 15 (this figure could be lower if you take a T3 supplement) this will indicate that your Thyroid is balanced. Your T3 should be around 5 as the range goes from 3.8-6.0. The T5H range goes from 0.34-5.6 but with this you need a lower reading as this indicates there is plenty of Thyroxine in your body. A reading of around 1 is recommended for your T5H. Other important factors are your levels of Ferritin and Folate, Vitamin B12, and Vitamin D3. These all need to be at the maximum levels or your Thyroid will not function properly. Another thing to consider is if you have other health conditions it could be they are the cause of not feeling well. One example of this is Diabetes which can make you feel ill and often mimic Thyroid symptoms.

Please note the above ranges are for the Morecambe Bay Area, other areas may have different ranges so please check which ranges are being used in your area. Remember, if you have had a virus infection shortly before your blood tests were done this can result in an incorrect reading. Also, certain medications and foods can alter your blood results .Please contact me for more details.

On the subject of blood tests; a member rang me to tell me she'd had to pay £5.00 in order to receive a print out of her blood tests results. My own doctors do not charge me but this started me wondering if any more of our members are charged for this service. If this has happened to you, please let me know.

Our local Cumbria Clinical Commissioning Group (CCG), have now informed me that health practices can charge up to £10.00 for print outs of blood tests, but most practices will not charge you.

<u>Gluten Free</u>

There has been lots of research done recently on the effects of a gluten free diet on patients who have auto-immune health conditions. Patients who took part in the trial reported a decrease in the symptoms they normally experienced and an increased feeling of wellbeing.

Gluten is a protein that is found in grains such as Oats, Wheat, Rye and Barley along with many other foods. When gluten is mixed with liquid if forms a glue-like consistency. This gluey liquid is difficult to digest and will just stay in your gut much longer than it should. This leads to inflammation causing gut pain, bloating and other distressing symptoms and with patients who have gastric issues because of other health problems this will just add to the problems they are already experiencing. In the auto-immune condition Celiac disease, patients are intolerant to foods containing

gluten. Medical experts now advise these patients should have a gluten free diet, however many people are not intolerant but simply sensitive to gluten so gradually cutting down on these foods makes more sense. There are many gluten free products available in the major supermarkets. Thyroid problems are also auto-immune and many patients do suffer with gastric problems, so why not give this a try just to see if it works for you.

Crash Dieting v Eating Healthy

If you ask a Thyroid patient what would make them happy many will answer to feel well again and to lose some weight. However, for many patients these two goals are almost impossible to achieve. Thyroid patients usually have a very slow metabolism and don't use up the calories they consume as easily as other people. If you cut down on your calories this can leave you feeling hungry and prone to snacking on unhealthy foods a short time later. Cutting out the starchy carbohydrates that are high in calories and replacing them with low calorie vegetables is an idea that works for some people. A portion of vegetables is around 50 calories, so you could put 3 portions of vegetables with a small amount of protein and you will have a meal that will fill you up without adding to many calories.

Research shows that crash dieting is a very bad idea for anyone with Thyroid issues. This is because when the body is deprived of food it simply shuts down to conserve the energy supplies. Under-active patients' bodies are already running in a 'go slow' mode so if you add crash dieting to the situation patients will start to feel very ill in a short space of time.

Visiting your Doctor

A visit to the doctors is not something most of us look forward to so here as some simple tips to make your visit go smoothly:

- **Doctors are not mind readers so please give a clear description of the problem you want to discuss
- **If the problem you want to discuss needs longer than the standard 10 minutes ask the receptionist if you can book a double appointment
- ** Thyroid patients often have poor memories so make a list of the things you want to talk about
- ** If you are finding life difficult to cope with, you may find it will help to take a close friend or relative with you
- ** Your doctor is there to help you so please show some respect by being good mannered, arriving on time for your appointment and listening to his advice
- ** Don't forget as a patient you have a right to access your medical records, ask at your surgery for the correct procedure to do this
- ** Thyroid disease can be complicated and will often need lots of tests to arrive at the correct diagnosis, however if you feel you are getting no-where arrange to see another doctor in the practice

- ** Educate yourself about your condition and ask questions about anything you are not sure about
- ** Don't forget doctors often must work to very tight budgets so don't make unrealistic demands on their services. Many minor health conditions can be sorted out by a simple visit to your local pharmacist
- **Allow your doctor enough time to receive all the results of your tests before you make a follow up appointment

Mental Health Issues

One of the first signs that your Thyroid may be malfunctioning is anxiety and depression. These problems can manifest themselves long before your Thyroid levels drop/rise enough to register on your blood tests. C.A.T.S. find that at this stage, patients are usually treated with anti-depressants or anti-anxiety medication. As your Thyroid gland continues to fail doctors will often test for Thyroid conditions and find the levels are border-line or in some cases still in the normal range. Once your Thyroid hormones go low/high enough for you to be treated you will probably no longer need your anti-depressant medication However, many Thyroid patients do experience recurring episodes of depression and anxiety, so it is important that if this happens you should contact your doctor to ask for their advice and support.

These days many doctors use complimentary therapies such as counselling and cognitive behaviour therapies along with acupuncture, relaxation, and traditional medicines to treat depressive related illnesses. These therapies can be quite successful in helping patients turn their life around and get back to normal. However, every patient is unique in the way they respond to illness and treatments, so if something does not work for you, don't give up, just go back to your doctor and ask about other treatments.

Research shows that 1 in 4 people will suffer at least one episode of mental health issues during their lifetime. This means that even if we do not experience this devastating condition, most of us will have a close relative or friend affected by these conditions at some time in our lives. In the world we live with the hustle and bustle of life, trying to achieve impossible targets, living in fear of losing our jobs and struggling to keep our heads above water it is not surprising that we suffer from anxiety and other related conditions.

Thyroid hormones control every part our bodies and every single action that happens in our body so it is no surprise, to find that if our Thyroid is not balanced properly we will start to feel down often with low moods and sadness. C.A.T.S. recommend our members to have regular blood tests to check your levels are balanced. Many health practices only do routine bloods every year however this gap can be too long in some cases. There are many things that can tip your Thyroid out of balance. Some medications, some health conditions, redundancy, bereavement, menopause, pregnancy,

and stress are just a few examples. So, if you are feeling a bit low please go along and see your doctor to see what they advise.

Vitamins and minerals also play a big part in our wellbeing. Many Thyroid patients have digestive issues which prevent us from eating a proper balanced diet. In many cases, even when we do eat nutritious foods our bodies do not always process the nutrients properly, (some medicines can cause this to happen) over a period this can leave us feeling under par. Thyroid patients need to have good levels of Ferritin, Folate, Vitamin B12 and Vitamin D for our Thyroid to work properly. If you think your body may be depleted of any of these essential nutrients pop along and ask your doctor to run blood tests just to be on the safe side.

Thyroid and Pregnancy

Research shows that many Thyroid patients struggle to get pregnant. In many cases, low Thyroid levels or a Thyroid that is under-performing is often the cause. Our Thyroid hormones are very finely balanced with all the hormones in the endocrine system so if one system is out of kilter quite often other systems will be. If a Thyroid gland is to work correctly we need optimum levels of Ferritin, Folate, Vitamin B12, and Vitamin D. Even when we have these high levels we may still struggle to conceive. Sometimes it may be something as simple as stress causing the problem, stress hormones will throw your body out of balance preventing you from becoming pregnant.

If you have an under-active Thyroid and get pregnant, you will need to be monitored carefully. You must have regular appointments with your GP/Consultant and Obstetrician. It is quite possible that mum will need extra Thyroid hormones during the pregnancy. This is because the developing foetus takes iodine away from the mother and mum will also lose more iodine in her urine while pregnant. Hypothyroid (under-active) patients do seem to run a greater risk of miscarriage and pre-eclampsia more than any other group of patients, however, if you follow the advice of your GP/ Consultant you will be able to look forward to a lovely baby at the end of your pregnancy. If you are taking Thyroxine while you are pregnant, please do not worry as very little of this will pass over to baby. Hyperthyroid (over-active) patients are more complex. They will need close supervision by a consultant. Care must be centred not just on mum but on baby also, as the (TSA) Thyroid stimulating antibodies can cross over from mum to baby. However, with today's modern medical knowledge mum will be rewarded with a fine healthy baby.

** Please note that in a few cases patients can develop Thyroid issues during their pregnancy. Again, these patients will need to be monitored carefully, but in most cases the issues resolve themselves once baby is born.

Hereditary Factors

There is a strong connection in some families as regards
Thyroid problems. Inheriting anti-bodies that work against your Thyroid is often the
cause. Anti-bodies either cause your Thyroid to slow, (under-active) or speed up

causing (over-activity). Doctors do not routinely check for anti-bodies, but if they are found to be present it simply means that the patient will probably develop thyroid issues at some stage in their life. However, in some families, a member will develop Diabetes instead of thyroid issues. Some patients are very unlucky and get a double whammy by developing both conditions.

Sometimes we see families where mum, grandma, aunties and cousins all have thyroid issues where in other cases just 1 or 2 members are affected. Thyroid problems are not as common in men but do seem to be on the increase. Not all patients who have Thyroid issues can blame their anti-bodies as many patients who do get tested are found to be negative, so the cause must be put down to other reasons. There are many reason for patients to have Thyroid issues such as stress, redundancy, traffic accidents, menopause, pregnancy, diet and life-style, some illnesses and some medications.

In some cases, no reason can be found and you just have to accept the fact you have been unlucky.

Complimentary and Alternate Therapies

We are often asked about complimentary or alternate therapies and if thyroid patients can use them safely. Well the answer is yes and no, but before we explore this topic we need to separate alternate therapies from complimentary treatments as many patients do get confused about the two treatments.

Put in simple terms alternate means replacing your traditional treatment with something else, so the answer would be no for alternate treatments. Thyroid medication should never be stopped unless your doctor agrees to this. Up to now there has never been any safe licensed alternate treatment proven to work for Thyroid patients. I often see adverts for miracle treatments for under-active thyroid problems. Patients are led to believe that they can stop taking their usual medication and use this miracle cure instead. Patients are told that this cure will fix their Thyroid. These treatments only consist of various herbs and high amounts of iodine and are un-licensed therefore not proven safe to take. As C.A.T.S always say Iodine can be dangerous to thyroid patients, also we all know that once our Thyroids start to fail there is nothing much we can do about it and there is absolutely nothing that we know of that can make your thyroid work again. All we can do is make sure that the Thyroxine we take is the correct dose and is balancing our thyroids properly. If you don't think your thyroid is balanced properly, please go and have a word with your doctor.

Years ago, patients were treated with NDT (Natural Desiccated Thyroid Extract) this is a natural treatment extracted from pigs. However, in the late 1950's this treatment was discontinued by the NHS because the batches were inconsistent in the dosage and would be unsafe to use as a treatment. It is now an un-licenced medicine; therefore, it

could be classed as an alternate treatment by the NHS.C.A.T.S. know that some patients do buy this extract from the internet, because they do not feel well on T4 alone. Some people tell me that they feel very well taking NDT, However the problem you have with NDT is that you have to work out the dosage yourself. C.A.T.S. feel this may be a bit tricky to do. Unless you are very lucky, and have a very understanding doctor to help you. As C.A.T.S. always work within the NHS guidelines, we do not recommend you try this as there are many un-reputable firms out there and you can't be certain you are buying the genuine product **Anyone who does risk taking this medication needs to have regular check-ups just to be on the safe side.

Complimentary means using something alongside your traditional medication. There are many treatments that come into this category. Acupuncture, Reflexology, Remedial Massage, Relaxation, Aromatherapy and Reiki can all be beneficial to Thyroid patients. These treatments all help to re-balance our bodies, and will alleviate many of the symptoms Thyroid patients experience. Other treatments that may help are Physiotherapy, Chiropractic, and Osteopathy. As usual you should always check with your doctor before trying any new treatments. As we said before everyone is different so what works for you may not work for another person, if you don't think a treatment is working for you please go back to your doctor to discuss trying another treatment. You may need to try several treatments before you find one that is beneficial to you

**There are also many herbal and homeopathic treatments available but please be aware that some of the plants these remedies are made from can be toxic to Thyroid patients, so please seek the advice of a qualified practitioner before using these treatments.

Auto-Immune Disease

Thyroid dysfunction is considered to be an auto-immune health condition. Research shows that in many cases dysfunctional genes are found to be the cause. Anti-bodies found in the immune system defend the body against disease and infection. In Auto-immune conditions anti-bodies have attacked various parts of the body thinking that the body needs to get rid of this part. This then causes that part not to work properly or in some cases will cause inflammation and pain. There are over 80 auto-immune conditions and sadly there are no cures for this type of health condition. Doctors can only give treatments that can relieve the distressing symptoms that many patients suffer. Some common auto-immune conditions are Rheumatoid Arthritis (inflammation of the joints), Lupus (affects skin joints kidneys and other organs), Celiac Disease (reaction to gluten causing damage to small intestines), Pernicious Anaemia (decreases red blood cells), Psoriasis (skin condition), I B S (inflammation in the bowel and intestines), Grave's Disease (overactive Thyroid), Sjogrens Syndrome (destroys saliva glands), Type 1 Diabetes (destroys insulin production), Vitiligo (destroys skin pigmentation) and Hashimoto's (Under-active Thyroid).

Website News

Our new updated website is proving very popular and during the month of August we had over 3,000 visits which was unbelievable. If you have not visited our site yet, please take a look. There are lots of information sheets which you can download and print out. We also put regular news updates on our Facebook page. There is also a contact us form where you can post any questions you have. This is linked to my email address so you won't need to wait for an answer. We want the website to work for you so if you have any ideas how we can improve our site please let us know.

T3 Update

The latest news on this situation is we now have 3 of our local MP's helping with our mission to have T3 reinstated as a prescription medicine. The Evening Mail Newspaper wrote an excellent article to highlight the situation. The Westmorland Gazette printed the letter I wrote to them but missed an important section out which altered the context of my letter. They have agreed to print a follow-on letter and print the full version on their website postbag section. However, if you missed it you can find a link on the C.A.T.S. website. We are also asking all our members and supporters to help us with the T3 issue by writing to their MP. We have a template letter available for anyone who would like one. T3 has now been given a red card by the NHS making it even harder for patients to access, and also putting it into the same category as NDT.

Contacting us

If you want to contact us, there are several ways to do this

BY POST----- The Old Cottage, Garden Terrace, Baycliff, Ulverston,

Cumbria, LA12 9RP

BY PHONE ------ 01229 869705

By E-MAIL----- moyramm@yahoo.co.uk

VIA OUR WEB-SITE----- www.cumbriancats.co.uk

FACEBOOK PAGE------------<u>www.facebook.com/pagesCumbria-Advisory-Thyroid-Service-C.A.T.S./1387475768249218</u>

** Please note during August and September, we did experience a problem with our phones, and internet so if you contacted us during this time and have not received a reply, can you please contact us again as the problem is now sorted. Please accept our apologies for this inconvenience.

That's all for now Folks

Once again we are at the end of this newsletter, I do hope you find something helpful inside We will be back again next March with our Spring news update, but for now we want to wish all our members and supporters A Happy Christmas and a healthy and peaceful 2017

Many thanks to Peter for all the hard work he puts into the newsletters and to Tony for all his hard work in maintaining our website. Also, thank you to HSC Milners printers for all their support and effort in getting our newsletters ready for us. We couldn't do it without you.

Best Wishes

Moyra

As a foot note I think we should also give Moyra a big thank you for all the hard work she does in producing these informative newsletters, and running the group. Peter



CATS – Information Guidelines FREEDOM OF INFORMATION RULES

Please note that all information supplied to CATS will be treated with the strictest of confidence and will not be passed on to any other source.

ALL CATS VOLUNTEERS WORK TO STRICT CONFIDENTIALITY RULES AT ALL TIMES

Any information produced in this newsletter is to help those suffering with thyroid disease. Whilst every effort is made to provide accurate information, it is impossible to ensure that the information given is relevant to every individual. No responsibility is accepted by C.A.T.S. and it is recommended and essential that if in any doubt about your condition that you should always contact your doctor, specialist physician or surgeon to seek medical advice.



C.A.T.S recommends that you ALWAYS seek your Doctor's advice













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