



HOPE



C.A.T.S.

SUMMER 2018 NEWS UPDATE

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



Welcome. Hello everyone, welcome to our bumper edition summer newsletter. We hope everyone is keeping well and looking forward to some nice summer sunshine. There is no doubt about it people do feel much better if the sun is shining. For all our members that have summer breaks planned, don't forget to look at our information on going on holiday. If you have any long-term health condition you do need to plan ahead. If you are going away, we hope that everyone has an enjoyable break. For our members who are staying at home don't forget to get out in the fresh air if you can, also please remember to give yourself some 'me' time.

The C.A.T.S. office has been very busy over the last few weeks, with lots of e-mails and phone calls, so there is lots to chat about.

Thyroid Friends / Gold Stars.

During the last few weeks our member database has grown with over 150 members now registered as supporters of C.A.T.S. It always amazes me just how many people suffer from Thyroid problems. When C.A.T.S. first started as a support group our mission was to turn the Thyroid sufferer into a Thyroid manager, with this thought in mind we would like to ask you to help us with this mission, if you can spread the word about C.A.T.S. that would be great, as not everyone knows about us and the support we can give you. Membership to the group is very affordable and only costs £6.00 for a year. This covers 4 newsletters, invites to any special events we organise, access to our helpline, plus free advice and information from our Thyroid advisory team.

Don't forget if you see a gold star form in your newsletter that indicates that your membership is due for renewal. Please consider renewing your membership, if you can, as the membership subscriptions are our main source of funding. Members signed up to receive their newsletters by e-mail will get a reminder in the post.

New Data Protection Laws.

On, May 25th the new General Data Protection Regulations (GDPR) came into effect. This means that you have a greater control over any personal information you share with C.A.T.S. When you first contact us, we do ask for some basic personal information, such as name, address, telephone number. This information is kept confidential and only used when we need to contact you. We will never pass your details on to any third party. Under these new rules We need to ask you if you agree to C.A.T.S. continuing to hold your personal information. If you no longer agree, please can you contact me at the office to discuss this. If you are quite happy for us to continue to hold your personal information and contact you by whichever method you agreed with us, then there is no need for any further action and you will continue to receive newsletters and any other information we need to send you.

Do you ever put something in a safe place, then spend ages looking for it because you just forgot, where you have put it



Petition News.

Any members that have been following our updates on our Facebook page and our website, will have seen the link that Ursula Power from the ITT group posted. Ursula very kindly posted the link to John Woodcock MP asking parliament about the T3 issues. Unfortunately, John wasn't able to use the questions that C.A.T.S. submitted, however, the question that was submitted was answered by Steve Brine (Under-secretary for Health and Social Care.)

In his answer Steve Brine quoted the present guidelines. Put very simply the guidelines are:

- ** No new patients will get T3 prescribed
- ** Patients who have been prescribed T3 will be gradually phased off T3 and eventually be prescribed only T4
- ** Patients who have had their T3 withdrawn can ask their GP for a referral to an Endocrinologist, for an assessment. If patients can show they have a clinical need for T3, the Endocrinologist will write to the GP. Then the GP has to contact the CCG to inquire if they agree that the patient is able to have T3 reinstated. If the CCG are supportive of the use of T3, and can afford to fund it you may be able to get T3 from the NHS.

As you can see the possibility of getting T3 from the NHS depends on a lot of IF'S, AND'S and BUT'S and a lot of luck as well. I recently had a chat with John Woodcock about the unfairness of the situation. Following on from this discussion, John will be interested to know if

- ** Your GP has refused to discuss T3 because they do not support the use of T3. Or your GP has told you that the CCG will not support the use of T3. Or the CCG will not fund T3.
- ** Your Endocrinologist will not support T3, telling you there is no evidence to prove it works.
- ** Your Endocrinologist will support T3, but your CCG will not.

If any of the above situations have happened to you can you please let me know. We would especially like to hear from patients in the Morecambe Bay area. If we can show evidence to prove that patients are still struggling to get T3, John Woodcock will investigate this.

Many thanks to everyone who is supporting our petition and our efforts to get T3 reinstated. Our petition has now got 2,670 supporters. Please help us to increase this total by sharing the petition details with your Facebook friends everywhere. The link is <https://www.change.org/p/the-secretary-of-state-for-health-jeremy-hunt-reinstate-t3-liothyonine-as-a-prescription-drug-available-on-the-nhs>. You don't even need to be a Thyroid patient to support us. If you agree with what we are trying to do, please sign the petition to support us.

Thyroid and Men

We don't normally receive many phone calls from the male population, however a few weeks ago I received calls from 2 men in the same week. Both men had an Overactive Thyroid which is unusual as the Underactive form of Thyroid dysfunction is more common. Overactive Thyroids are normally treated with Anti-Thyroid medication, this reduces the level of Thyroid hormones in the body until your levels return to normal. This sort of treatment usually takes about 18 months for your Thyroid to rebalance itself. If after 18 months your Thyroid is still not stable. Radio-active Iodine is often suggested as the next line of treatment. Overactive Thyroids do often stabilize, only to return to the overactive state several years later. If this happens, doctors may suggest surgery particularly if the overactivity is severe. If your Thyroid gland is removed you will become Underactive and need life-long replacement hormone treatment such as T4 (Thyroxine.) For more advice on this subject please contact the office.

Going on Holiday.

We thought it would be helpful to remind our members about these useful tips to help your holiday go smoothly. If you have any long-term health condition planning ahead is wise

****** If you are going abroad for your holiday don't forget Thyroxine needs to be stored in a cool place (below 25c) and must be kept in the original packing otherwise this could lead to problems at customs

****** Thyroid patients often have very dry, thin skin which is easily damaged, so don't forget to pack your high factor sun cream and some skin moisturizers

****** Don't forget to tell your travel insurance company that you have a Thyroid condition. (it is important to declare all medical conditions)

****** If you are travelling to an EU country and require emergency treatment this should be free, however you must have an EHIC card. (European Health Insurance Card) These are free and a quick way to obtain one is to go to, www.nhs.uk/chic and follow the links, or you can ring the automated application service on 0300 330 1350

** If you are going to a hot country don't forget to drink plenty fluids to help keep yourself hydrated

** If you are on holiday in the UK and are unlucky enough to need NHS treatment most areas of the UK will have an emergency GP system or a walk-in clinic/medical centre where you can get treatment.

** If you do need treatment no matter where you are you will be asked for a list of the medications you take. Thyroid patients often take several kinds of medication. It is often difficult to remember the names of all your medications. C.A.T.S. do have some pocket-sized medication cards that will solve this problem. The cards are free, just let me know if you want one.

Your Thyroid and Digestive Problems.

As you know your Thyroid gland controls every part of your body, so it is hardly surprising to find that many Thyroid patients have problems with their digestive system. IBS (Irritable Bowel Syndrome), Coeliac Disease (not able to digest gluten), Diverticulitis (pockets of inflammation that form in the bowel and large intestine), Colitis (inflammation of the bowel) Gastritis (excessive gas often caused by excess acid or poorly digested foods), IBD (Inflammatory Bowel Disease) are all digestive problems that affect Thyroid patients.

New research is showing that if your gut flora (the friendly bacteria in your gut) is balanced you are less likely to have these problems. However, if you are still unlucky and you do suffer from these conditions, balancing your gut flora will certainly help reduce the symptoms. To help balance your gut bacteria you need to add some pre-biotics.

Pre -biotics are a group of complex carbohydrates that can increase the intake of extra dietary fibre to your diet. Bananas, parsnips, garlic and asparagus will help to do this, but you can also buy pre-biotic supplements. Pre-biotics will help the friendly bacteria (Pro-biotics) multiply, helping to digest your food better. If you want to increase your pro-biotics levels further why not add some Kefir or fermented foods to your daily routine. You can make these yourself or buy them ready made from health food shops. Some members have told me that they have been taking digestive enzyme supplements and this has helped their digestive problems so you may want to try one of the supplements that are available.

Don't forget to check with your doctor before taking any extra supplements.

Carpal Tunnel Syndrome and Thyroid.

Carpal Tunnel Syndrome is a very painful condition that affects the hand and wrist area. Thyroid patients have a tendency to store excess fluid in the body tissue. With a Carpal Tunnel condition this excess fluid collects around the wrist area eventually causing pressure on the Median nerve. This extra pressure causes pain around the wrist area but can also cause pain up the arm as far as the elbow, and also the thumb and fingers.

Patients who have hypothyroid conditions or diabetes will often develop this condition. Patients who have arthritic conditions are also at risk of suffering from Carpal Tunnel Syndrome. Some doctors call this Tendonitis or Repetitive Strain Injury. However, Repetitive Strain Injury is usually due to a build up of fluid in the wrist area caused by using machinery or items such as computer keyboards constantly and for too long a period of time. Carpal Tunnel can also be more of a problem in very hot or very cold weather.

Strong painkillers, anti-inflammatory drugs, cortisone injections, physiotherapy, ultra-sound treatment or heat and cold packs are treatments you can use to help you manage the pain and hopefully regain some movement and strength back into the hands.

Fortunately, Carpal Tunnel Syndrome is not usually a permanent condition. It tends to come in phases lasting 2 to 4 weeks then the pain will slowly disappear allowing patients to resume normal activities.

If none of the above treatments work for you, doctors will sometimes suggest surgery. The aim of this, is to release the pressure on the Median nerve, thereby alleviating the pain. However the effect that surgery has may not be long-lasting as Thyroid patients have a tendency to store excess fluids, so this could result in the problem re-occurring.



T3 News update.

Anyone who has been following the updates on our Facebook page will have read that Vince Cable, Leader of the Lib Dems, successfully arranged an adjournment debate in Parliament on the high cost of T3 (Liothyronine) and the CCG's approach to it. The debate was arranged to take place on the 21st May, and it was scheduled as the last item on the agenda for that day. (10pm)

Vince Cable was fantastic and had certainly done lots of research about T3. I felt that Vince covered all the aspects of the T3 situation very well. C.A.T.S would like to say a massive Thank you to Vince for all the hard work, and effort he has put into raising this issue.

Steve Brine, Parliamentary Under-Secretary for Health and Social Care responded to Vince Cable by quoting the present guidelines. I was disappointed at this as Steve Brine only gave a similar answer as he did when he responded to our MP John Woodcock on the 30th April. As we all know the present guidelines do not go far enough and certainly do not cover all the issues about T3.

We can only hope that now the T3 issues have been aired in Parliament, that the government will look into this matter further

The national petition group ITT (Improve Thyroid Treatment) were actively involved with Vince Cable raising the T3 issue, so if you have not signed their petition yet can you please consider doing so.

The ITT petition is an on-line petition and can be found by following this link- <https://www.change.org/p/itt-campaign-group-improve-thyroid-treatment-for-millions-of-people-stop-the-withdrawal-of-t3>. As well as fighting for the T3 issue, this group is also fighting for better care for Thyroid patients so please support them in their mission.



Public Meetings

Over the last few months Gill and I have been busy trying to plan our public meetings. After organising meetings for nearly 14 years I have to admit that we are running out of speakers for the meetings. Unfortunately, we have also found that some of the venues we use have increased their fees. This makes it difficult for us to decide which venues to use.

One idea we'd like to suggest is an informal 'coffee and a chat'. We think it would be nice to do something different, if these events were held in venues such as Morrisons café, Booth's café or Asda café that would be more informal than an event at the Forum. Simply buy your refreshments at the venue's café then join Gill and myself for a chat. If you have any questions you need answers to, we can help by answering them and also have Thyroid information available for you to take home.

Gill and I always enjoy catching up with your news so this would be a lovely way of continuing to do this. If you think this is a good idea please let me know so we can get something arranged as soon as possible.

Did you know?

In Cumbria as many as 3 out of 10 patients have or may have Thyroid problems. Sadly, many of these patients will be misdiagnosed or go undiagnosed for months or even years. In the early stages of Thyroid dysfunction many patients are prescribed anti-depressants. (Anxiety and Depression are one of the first signs of Thyroid dysfunction). However, once the Thyroid hormone levels drop down far enough, patients do need to have Thyroxine prescribed to them. Another common problem is ladies of a certain age are told they are menopausal and need HRT when in fact the real problem is that the Thyroid hormones are low. C.A.T.S. feel that more awareness of Thyroid issues amongst the medical profession is necessary to prevent this sort of problem happening.



Treating patients over 65.

I recently read a report about a study that had been done to consider if patients over 65 benefit from being treated with Thyroxine. The group of patients tested all had low grade Thyroid dysfunction or borderline levels of Thyroid hormones. Consequently they would only require low dose treatment with Thyroxine. As far as I know none of the patients had any other health problems and were not taking any other form of medication, which could have distorted the study results. The group were tested before medication was started and all were found to have slightly raised levels of TSH (Thyroid Stimulating Hormone.) After taking medication the group were found to have very little change in their T4 readings. Most of the group also had very little change in their TSH levels. The group said that they had not felt any great benefit from taking medication. The people responsible for the study concluded that patients over 65 with low grade Thyroid dysfunction may not benefit from having treatment, as the raised levels of TSH may be a natural occurrence as we grow older. I was a little bit disappointed when I read this statement. As we all know the government are trying to get the NHS to save money and I felt that this evidence could be used as proof to stop the NHS from prescribing T4 to over 65's. However, fortunately it was decided that before a decision is made about this more research needs to be done. I am pleased that more research will take place as Thyroid dysfunction is very complex and everyone responds differently.

This study is interesting as Thyroid dysfunction, normally takes a long time to develop, and the patients taking part in the study may well have been at the beginning of their Thyroid journey. C.A.T.S. always tell patients that the longer patients go undiagnosed, the longer it will take to balance your Thyroid. So even though the patients in the study did not feel any benefit from taking medication, they may have done if they had continued to take the medication, or even tried an increase, as this is often necessary before the Thyroid becomes balanced again. We are all different in the way our bodies respond to treatments, what works for one patient, may not work for another. Rebalancing your Thyroid may need lots of juggling with medication before you achieve a balance. Another thing to remember is that there was no mention of the T3 levels. (These are just as important as T4 levels).

In my previous article I said that many patients are given Anti-depressants in the early stages of Thyroid dysfunction. Some types of Anti-depressants do raise the level of T3, which helps to raise our serotonin levels (this gives us the feel good factor.) Over the years we have been running C.A.T.S. we have found that many patients do benefit from being started on anti-depressants for a short while. Then as their T4 drops further, and replacement Thyroxine is started, the patient is then weaned off the anti-depressants, and the dose of T4 is increased until the Thyroid becomes balanced. Good levels of Vitamin D, Vitamin B12, Ferritin and Folate are also important for Thyroid balance.

Website and Facebook page.

While we are not having meetings, we regularly post news updates on our website and Facebook pages. So, if you have not visited these recently, why not take a look now. Our website does have lots of useful information that you can print out. Our website address is www.cumbriancats.co.uk. You can access our Facebook page from our website or click on this link www.facebook.com/pagesCumbria-Advisory-Thyroid-Service-C.A.T.S./138747576829218. Please like and share our page to spread the word about Thyroid disease

Saving us some pennies.

We are always looking at ways of saving money, and one of our most successful ideas was when we introduced our e-mail newsletters. We now have over 70 members signed up to have e-mail newsletters. So, if you want to sign up just send me your e-mail address, and I will add you to our mailing list. You can opt back to paper copies anytime you wish. Why not give it a try and see how easy it is.

Passing Thoughts

When we die one of the most important things we leave behind are memories.
Please make sure that we leave happy ones

Buying over the counter medicines

In the effort to save money the NHS has taken many of the prescription medicines off prescription and made them available to buy over the counter. As Thyroid patients we need to be careful with any medicines we buy this way. There are a number of medicines that do interact with our Thyroid medication, so C.A.T.S. advise that you always seek advice from your GP or consultant before buying any of these medicines

This advice also applies to any herbal or vitamin and mineral supplements that you might buy from supermarkets and health food stores. Many patients think that natural remedies won't harm us, but it can be dangerous to take these sorts of treatments without seeking advice first

Updating your personal Information

When you join C.A.T.S. we ask for some personal information such as your name, address, telephone number and e-mail address if you have one. The reason we do this, is so we can send you any newsletters or any other information you require. Please can you help us by letting us know if any of your details have changed.

This sounds so simple but it is surprising how many members do forget to do this.

C.A.T.S. GUIDELINES, for FREEDOM OF INFORMATION RULES

All information given to us is treated as confidential and not passed on to any other source. All C.A.T.S. volunteers work to strict confidentiality rules at all times



That's all for now.

Sorry but we have come to the end of this newsletter. I hope you enjoy reading all our articles and news up-dates. I have just worked it out that this is my 15th year of writing newsletters. In that time, I have covered many subjects however, Thyroid issues are so varied and complex, I am sure there are subjects that I have not covered. So, if there is anything you would like me to write about, please let me know. Also, don't forget if you see any Thyroid items in magazines that our members might be interested in reading please let me know about them too. C.A.T.S. try to give a good service to our members however, we do need help from yourselves, so come on don't be shy, let us have any ideas you have on how we can improve our service to you.

We hope everyone enjoys a happy, healthy summer. We will be back in September with our mini news up-date, until then, Take care everyone.

Best wishes. Moyra x

Contacting us.

There are several ways to contact us

By telephone—01229 869705

By e-mail moyramm@yahoo.co.uk

By post—C.A.T.S. Office, The Old Cottage, Garden Terrace, Baycliff,
Ulverston, Cumbria, LA12 9RP

By our website – www.cumbriancats.co.uk and use the contact link

C.A.T.S. information guidelines

Please note that all information supplied to C.A.T.S. will be used in the strictest of confidence and will not be passed on to any other source

ALL C.A.T.S. VOLUNTEERS WORK TO STRICT CONFIDENTIALITY RULES AT ALL TIMES

Any information produced in this newsletter is to help those people suffering with Thyroid disease.

Whilst every effort is made to provide accurate information, it is impossible to ensure that all information 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 consult 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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