



C A T S
CUMBRIA ADVISORY THYROID SERVICE
BUMPER SUMMER

Newsletter 2017

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

HOPE

Hello Everyone

Welcome to our Bumper Summer 2017 edition of the newsletter. We hope everyone is keeping well and looking forward to the summer sunshine that we will be getting soon. There is no doubt about it a bit of sunshine does make you feel better. Many of you will be heading off on your holidays soon, but before you go away, take a look at our article on "Going on Holiday" you may pick up some helpful tips. For our members who are not going away, we hope you will manage to get a little bit of chill out time. Research has shown as Thyroid patients we do need to be kind to ourselves and not overdo things.

We hope you enjoy reading our newsletter and find something of interest inside. We would like our members to be involved with our newsletters and will welcome any personal experiences, Thyroid news items, or even if you would just like to share any stories, please get in touch with me at the office. Please don't be shy you never know what you can do until you try.

Thyroid Friends. Gold Stars *

Thyroid Friends /Gold Stars *

Thank you to all the wonderful people who continue to support us by being a Thyroid Friend. Over recent weeks our membership database has grown and we now have over 150 members and supporters. However, we will always welcome new members to the group. Some members only join for a short time while other members have stayed with us since the group started. You are free to choose whatever suits you. It is an unfortunate fact that Thyroid disease is on the increase and many people do not know about C.A.T.S. So, if you know anyone who has a Thyroid problem please tell them about our group. You don't have to be a member to access our services, however if you do decide to join us all money we receive from the membership is used to run the services we offer. Membership is just £6.00 for 12 months. This covers 4 newsletters, access to our helpline, invitations to our meeting and public events, plus information and advice from our Thyroid advisory team.

Most members will already know this, but for our new members, if you see a gold star form in your newsletter this is to remind you your membership will be due

soon. Renewing your membership is easy just send back the renewal form with your cheque to the office. If you receive your newsletter by e-mail you will receive a separate reminder in the post.

Petition Update

Our petition to have T3 (Liothyronine) reinstated as a prescription drug available on the NHS was launched last December. I have never run a petition before and it has been a very big learning curve for me. C.A.T.S. are not a political or even a militant group and have always worked within NHS guidelines. However, when the T3 situation started to unfold we felt we needed to act, to tell the Government how unfair their new guidelines were to patients who depend on being able to have T3 as a prescription drug available on the NHS. When we started the petition, I felt that this ruling by the government would not affect many patients. However, I have been surprised just how many people it does affect. I have received phone calls from patients in all areas of the country, who are very annoyed and worried that they can no longer get their T3. Some patients have become too ill to work just because their T3 medication has been stopped. I do not take T3 myself but have seen the evidence personally of what a life changer T3 can be. When your T3 is stopped, you have 3 options available (1) you can pay for your medication by private prescription (this is very expensive) or (2) you can try to order your medication via the internet (this could be risky). Other countries such as, Greece, Turkey, France or the U.S.A. do sell T3 quite cheaply. If you are internet savvy you may be tempted to do this. However, C.A.T.S. recommend that you exercise caution when doing this as there are many bogus firms out there and there really is no way of knowing just what you are buying. (3) The other option available is to get extra T4 from your GP and see if that works for you (this is what the government want you to do). However, for a small group of thyroid patients this option does not work.

Many of our members will have seen the announcement in the press by Simon Stevens (Chief Exec of NHS England) who said T3 can be clinically effective but owing to the cost, NHS England prefer the cheaper alternative. As everyone knows the only alternative the government can offer is extra T4 (Levothyroxine.) C.A.T.S. have stated in the petition the reason why patients need to take T3 is because their bodies do not convert the T4 into T3 in sufficient amounts for their needs. There are many reasons for this to happen:

- * Patients who have had Thyroid cancer are one group of patients that can't convert T3. These patients have already gone through the trauma of cancer and they are now having to fight to get essential medication.
- * Patients who have inherited a faulty gene, or
- * Patients with a high level of Thyroid anti-bodies and
- * Patients who have a damaged Thyroid gland (after having surgery or radio iodine treatments) also have problems converting their T3.

Our petition had been put on hold during the election. Now we know which party has been elected, we are ready to take up the fight again. We are already finding that many CCG's are following Simon Stevens recommendations not to prescribe T3 to patients. If this situation applies to you, you can ask your GP for a referral to be assessed by an Endocrinologist. You must have 2 sets of bloods done (roughly 6-8 weeks apart) before your assessment. If your assessment shows you have a clinical need for T3, you should be able to get this on the NHS. However, the rules seem to vary in each area and it is a bit of a postcode lottery if you get T3 or not. If you live in the North Cumbria and North East CCG area (see the item on Cumbria CCG) you will be able to get T3 from your GP if you have been prescribed it in the past. However, if you are in the South Lakes or Furness area of Cumbria you will need to have an assessment with an Endocrinologist to get T3. C.A.T.S. are aware the guidelines for prescribing T3 to patients are very tight and you may not be lucky even if you have an assessment. Please let me know if you have recently had an assessment and had your T3 reinstated or refused.

Petition News continued

As I am writing this newsletter our petition stands at 1,235 signatures. This is a fantastic achievement for a small support group like C.A.T.S. However, to get the petition debated in parliament we will need over 10,000 lovely people to sign in support of what we are trying to do. This is a big task but one that we are willing to try to do. However, we do need help from our members and supporters, so first, if you have not signed our petition, can you please consider doing so. Some members have expressed a view that they didn't want to sign the petition because they do not take T3. I can understand how they feel and understand not everyone wants to get involved with petitions. But if you are a Thyroid patient, you never know if you will need to take T3 one day and if we don't fight for it now it might not be there when you need it.

If you have already supported us by signing thank you for your support! Can you please help further by telling your friends, sharing our link on Facebook, or any other form of social media? Please also if you belong to any groups or clubs tell everyone about the T3 situation and how C.A.T.S. are trying to get the decision changed. There are lots of other organisations and individuals working behind the scenes to try to sort out the T3 situation and C.A.T.S will be putting regular updates on our website and Facebook pages so please keep checking these for news of further developments. I feel sure that with all this activity going on we will be able to make an impact and get this ruling changed. The more people we get to shout about this injustice the more likely we are to be heard.

Did you know Pets get Thyroid problems?

Our pets can get Thyroid problems, yes, it is true. Dogs, Cats and Budgies can all get Thyroid problems. Cats generally get Over-Active Thyroids and are treated much the same way as adults are. If the Anti-Thyroid medication does not work to bring the gland back into normal mode, your vet will then consider the removal of

the Thyroid. Dogs quite often develop an Under-Active Thyroid as they get older. Once again, the treatment is much the same as it is for adults. Budgies and other cage birds can become Iodine deficient and can develop an Under-Active Thyroid because of their diet. Vets treat this deficiency by giving the birds an Iodine block to nibble on and this will usually correct the problem.

Going on Holiday

As the holiday season approaches if you are a Thyroid patient, you need to plan. Here are some useful tips to help your holiday go smoothly

** Don't forget Thyroxine needs to be stored in a cool place (below 25c) and must be kept in the original package, otherwise you may have problems at customs

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

** Don't forget to tell your insurance company that you have a Thyroid condition

** If you are on holiday in the UK and you 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 are on holiday in an EU country and need treatment this is still free, but you must have an EHIC card (European Health Insurance Card) The cards are free and to obtain one go to - <http://chq/pages/1073.asp> category ID=70 & sub category ID=172 and follow the links. Or you can ring the EHIC automated application service on 0300 330 1350.

** If you do need treatment no matter where you are you may be asked for a list of all the medication you take. Many Thyroid patients are taking several kinds of medication so it can be difficult to remember them all especially if you are feeling ill. C.A.T.S. have some cards available that you can use to list all your medication. The cards will fit into your purse, handbag or pocket and are available free of charge from the office. Please contact me if you would like one.

** Don't forget to tell all medical staff who treat you, that you have a Thyroid condition as certain drugs administered in emergency situations can cause an imbalance in your Thyroid

** Lastly if you go away and forget to pack your Thyroxine pills don't worry, if you are only away for the weekend you can safely miss taking your Thyroxine for 1 or 2 days without any bad effects. If you are away for longer than a weekend you will need to go to a doctor for an emergency prescription. Some pharmacies may also provide emergency medication. It will be helpful if you have a copy of your prescription with you. Under-active Thyroid patients get free prescriptions but you will most likely have to pay if, you are getting an extra emergency supply

We hope these tips help you. Have a nice holiday everyone

Getting an Under-Active Thyroid Diagnosis

Many patients do struggle to get their Thyroid condition diagnosed. I think the main reason this happens is because Thyroid conditions do mimic many other health conditions. There are over 300 health conditions and symptoms that link in with Thyroid dysfunction, so it's not surprising that Doctors get it wrong. Many ladies find when they reach the menopause, they have developed unpleasant symptoms. When they go to see their GP, they are told it is only the menopause, when in fact many of the symptoms are Thyroid related. GP'S often prescribe HRT and in many cases this does help some of the symptoms, but further investigation will often show a lower Thyroid hormone level. Another group that can struggle to get a Thyroid diagnosis are teenagers or young mums, but again many of these patients will be told they are stressed or they are just over-tired or need anti-depressants. Tiredness, Depression and Anxiety can be one of the first signs that your Thyroid is unbalanced. C.A.T.S. feel that more routine testing for the Thyroid would help cut down on the suffering that many patients go through before they get a diagnosis.

Another problem Thyroid patients face is the blood test ranges. In South Cumbria, the T4 (Thyroxine) levels go from 8 to 18 and our TSH (Thyroid Stimulating Hormone) goes from 0.02 to 5.60. (other area's use a different range) The lower your T4 is the higher your THS levels should be. The ideal range if you are already diagnosed is a T4 level around 15 (South Cumbria ranges) and that should give you a TSH reading of around 1. With this sort of reading you should be feeling reasonably well. However, everyone is different and if you have other health conditions to deal with alongside your Thyroid condition you may still be under-par. Many patients will never reach these levels no matter how they try. There are many reasons for this and if you would like further information please contact me at the office.

If you are still struggling to get a diagnosis it is a little more difficult because the blood test ranges that apply to patients that have a diagnosis are different from the range used for undiagnosed patients. Your TSH will need to be at least 10 and your T4 levels will be well below the normal range. Once your TSH goes above the 5.6 level you are classed as having a border-line under-active Thyroid dysfunction. Up until a few years ago this used to be treated with a very small dose (25mcg) of thyroxine. However, the guidelines have recently been altered and doctors now wait until your TSH levels reach at least 10. During this time patients will have lots of distressing symptoms and feel very unwell. C.A.T.S. feel that this is unfair for the patient as the longer your Thyroid condition goes undiagnosed, the longer it will take to get to get it balanced. Consequently, the more likely you are to develop other health conditions. I did read the other day that if you have high levels of Thyroid Anti-bodies and a TSH reading of above 6, you may be able to get Thyroxine prescribed. However, I have not managed to get this information confirmed yet. This could be like the T3 situation (another postcode lottery) but

once I am able to confirm these details we will be able to advise patients on the correct course of action.

Cumbria Clinical Commissioning Group

Our Clinical Commissioning Group (CCG) has recently changed with patients in the Furness and South Lakes area of Cumbria have now joined patients in the North Lancashire area and have formed the new Morecambe Bay CCG. Patients in other areas of Cumbria have joined with the North-East regions and are now part of the new North Cumbria and North East CCG. This reorganisation within the NHS is all part of the government plan to streamline our care, with more specialized care available in the bigger cities. In some way's this reorganisation could be good for us (the patients). However, as Cumbria is a very rural area with very poor transport links I feel many patients will struggle to attend important hospital appointments in the larger cities. A hospital transport system does operate in most areas, however the guidelines for you being eligible for this service are very strict, owing to the cut backs the NHS are being forced to make.

Thyroid Brain Fog

You often see the phrase "Brain Fog" but what does it mean? Well Brain Fog is very common in Thyroid patients. How many times have you gone into a room only to forget what you went into the room for? or put something in a cupboard (or you think you have) only to later find it is sat in your fridge? Or met someone, and you can't remember their name? Yes, folks this is Brain Fog. When we have any health condition that reduces the blood supply to the brain, (heart problems and diabetes are just two conditions) this will be a contributing factor. Many Thyroid patients have poor circulation and a slow metabolism which contributes to poor memory and poor co-ordination skills. Some Thyroid patients can go undiagnosed for several months or in some cases years. During this time, undiagnosed changes in our brain chemistry can occur. This can lead to poor concentration and forgetfulness. Once we are diagnosed with a Thyroid condition and treatment is started, many patients find that memory skills do improve. However, I have always said that Thyroid dysfunction is complex and no 2 patients are the same.

I often get phone calls from patients who are very worried because they are experiencing memory or concentration problems and they think they are starting to get Dementia or Alzheimer's disease. It is true these conditions are on the increase, or maybe it could be that the medical profession is getting better at diagnosing these conditions. However, many patients that get tested for Dementia or Alzheimer's are found not to have the condition. So, what can we do to reduce this problem of Brain Fog? Here are some tips to help you:

* First always make sure your T4 (Thyroxine) levels are up to the optimum level (see our article on Page 5.) We talked about the importance of T3 in our petition, if your T4 level is low, your T3 will probably be the same (low T3 causes memory issues.)

- * Dehydration (not enough fluid intake) can cause confusion, so make sure your fluid intake is good.
- * Sleeping pills, anti-anxiety and anti-depressant medications can all slow down the mental processes, causing poor concentration. If you do have to take this type of medication, please try to take the lowest dose possible to minimize these side effects.
- * It is also important to make sure that your diet contains plenty of fruit and vegetables to get the maximum levels of the A, C and E vitamins.
- * The mineral selenium is very good for brain health and good for Thyroid patients.
- * The B complex vitamins also help to boost mental capacity.
- * Don't under-estimate a good night's sleep to aid brain function.
- * Research has shown that patients who smoke have reduced memory function compared to non-smokers.
- * Other ways of improving our memory is to keep it active by doing crosswords, word searches, jigsaw puzzles or reading a book.
- * Exercise has also been shown to improve memory, so if you are feeling brave, why not join a keep-fit group or take a walk in the summer sunshine!

Weight and Diet

If you ask an under-active Thyroid patient what they would like most, many of these patients would say "to lose weight". We are often asked what is the best diet for Thyroid patients, well to be honest there really is not any one diet that will work for everyone because, as I have said before, we are all different and what will work for one person, will not work for someone else. Under-active Thyroid patients usually have small appetites. So, 6 small meals or snacks can work better for some patients, rather than 3 bigger meals. However Under-Active Thyroid patients normally have a slow metabolism, so we don't burn off the calories as easily as we should. Therefore, we should be careful not to eat high fat or high sugar foods. As these of foods will only add weight instead of helping us lose it, high fibre foods are a good idea as they stay in our body for longer helping us feel full for longer. This can help prevent us being tempted to over-eat. Many Thyroid patients have gastric issues and find animal proteins difficult to digest. Fish, Chicken, Eggs or vegetable proteins are good choices as they are easy to digest. You only need small amounts of protein, but you can fill up you plate with vegetables. Most vegetables are quite low in calories so you need not feel guilty. Potatoes, white bread, white rice and white pasta are all starchy Carbohydrates so we need to limit the amounts we eat of these foods or they will add on extra pounds. We do need some Carbohydrate foods in our diets as these helps to keep our blood sugar levels stable. However, the higher fibre kinds are better so for a healthier option choose wholemeal bread and brown rice or wholemeal pasta. Again, you only need a small portion of these foods. If you like to have a dessert to finish off your meal you can choose a piece of fruit or a low-fat yoghurt but many of these yoghurts do contain high levels of sugar, so please read your label first.

Weight and Diet continued

Here are some other tips that may help you lose weight:

- * Use a small plate for your meals to help you cut down on portion sizes
- * Don't forget to drink plenty of fluids
- * Always eat breakfast as this will help stop those mid-morning hunger pangs
- * Cut out cakes, sweets and biscuits as they only add on the pounds
- * Limit fizzy drinks as most of them contain high levels of sugar
- * Tea and Coffee can dehydrate you (to replace the lost fluid, your body will start to store fluid and you end up becoming bloated and gaining extra weight) so limit the amount of tea and coffee you drink.
- * Alcohol puts on weight so only have a treat now and again
- * Regular exercise does help weight loss
- * Another useful tip is to stop eating 5 minutes before you feel full. Our brains take at least 5 minutes to register our stomach is full
- * We need to chew each mouthful of food carefully, if we don't, we will find our stomach will fill with gas from the undigested food and our brain still thinks we are hungry so we overeat and become bloated this will add up to extra weight

Helping us save the pennies

One of the biggest cost for running C.A.T.S. is our postal costs, so if you would like to help us save money. Why not sign up to have your newsletters by e-mail. To sign up just contact Peter at richjon51@talktalk.net. You can return to paper copies any time, so why not give it a try and see how easy it is.

Did You Know? Thyroid Awareness.

C.A.T.S, estimate that 1 out of every 4 patients are likely to develop Thyroid problems at some stage in their lives. Many of these patients will go undiagnosed or even incorrectly diagnosed as Thyroid dysfunction does not get the attention from the medical profession in the same way that other health conditions do. The government say that Thyroid conditions only affect roughly 2 patients in every 100, however we feel the figures are much higher than this. Help us to raise awareness of this complex and often distressing condition.

Thyroid disease - Infertility and Miscarriage

Many Thyroid patients sometimes struggle to get pregnant or carry a baby full term. Patients who have an undiagnosed Thyroid problem are the most likely ones to struggle in this way. However, research has shown that your Thyroid hormones play an important part in the development of your baby during the first three months. Therefore, it is vital that for anyone wanting to get pregnant, to

make sure their Thyroid hormones are balanced for at least 6 months before you try. As even a small imbalance can cause problems.

Hypothyroid Patients

Thyroid patients who are adequately balanced on the correct dose of medication should to become pregnant without too much difficulty. However, it is important to understand that as soon as the pregnancy occurs. Mum will need extra Thyroid hormones (25-50 mcg) per day, to cope with the demands on her body from the developing baby. It is also very important for mum to have regular blood test to confirm the Thyroid is still balanced throughout the pregnancy. Many healthy babies are born to patients with Thyroid problems, so it is not impossible to have children. However, extra care is needed and this extra care will be provided by your GP and Consultant who will arrange extra blood tests and check-ups to ensure the pregnancy is progressing as it should.

Low Thyroid hormones have been linked to the problems some mums have with breast feeding (e.g. low hormone levels equal low milk production.) If you are planning to breast feed C.A.T.S. advise you to have regular blood work done to give yourself the best chance of breastfeeding success.

Hyperthyroid Patients

Once again there should not be a problem trying to conceive, if your Thyroid has been balanced for at least 6 months. However, if you are still receiving treatment for over-activity (anti thyroid medication) and you do conceive it then becomes a more complex issue. You will need to have careful supervision from your Consultant to ensure minimal risk to both mum and baby. However, with the medical knowledge and modern technology that is available in today's world, mums can look forward to welcoming a very healthy baby into the world.

Thyroid imbalances can occur during or just after a pregnancy in patients who don't have a Thyroid dysfunction problem. These imbalances are usually short lived. With the Thyroid balancing itself out within a period of 6 months after the birth. However, if this does not happen Thyroid medication will be used to rebalance the gland.

I found these words on Facebook and I thought I would share them- Hope you like them

Every single day, no matter who you meet in that day - friends, family, work colleagues, or even strangers - give joy to them. Give a smile or a compliment or kind words or kind actions, but give joy.

Do your best to make sure that every single person you meet has a better day because they saw you. This might sound like it is not connected with you and your life, but it is inseparably connected through cosmic law. As you give joy to every person you meet, you bring joy to yourself. The more you can give joy to others, the more you will bring joy back to you.

<https://twitter.com/theseecret>

Feeling Well with Thyroid dysfunction

When you were first diagnosed, your GP most probably told you just take these little white pills every day and you will be back to normal in no time. Sadly, this is not true for many patients. Many patients will have struggled to get a diagnosis for many months, or even years in some cases. During this time, your Thyroid has been used to managing on reduced amounts of T4, now it must get used to having a new supply that is readily available (the little white pills you take each day.) This process takes a while, but there are things you can do to help. To utilize the Thyroid hormones your body needs optimum levels of Vitamin B12, Ferritin, Vitamin D and Folate. If you do not know what your levels are you can ask your GP to take some bloods. Many GP's will say your levels are alright if they are anywhere in the range. However, C.A.T.S. find most patients feel better if the levels are near the top of the range. In some cases, it can take up to 18months before a patient is fully balanced and on the correct dose of medication.

Here are some other hints that can help you to feel well

- * Drink plenty of water this helps to get rid of the extra fluid our bodies store
- * Always pace yourself and don't overdo things
- * Make sure you eat plenty fruit and vegetables
- * Try to limit high sugar, high fat and starchy foods as these add on the pounds
- * Learn as much as you can about your Thyroid condition as the more you know, the easier it will be to understand this complex condition
- * Try to have a short walk in the fresh air every day, walking is an excellent way to help you keep fit and raises your endorphins (the feel-good factor)
- * Don't forget to have regular blood tests, and always keep a record of the results
- * Make sure that you talk to your GP if you have any new symptoms

Facebook Page

Have you checked out our Facebook Page? It's been great to see so many people visit the page. What we'd really love is to get to know more of you. So, let's bring together our thyroid community and share, comment and suggest! If you haven't visited the page yet why not look now: www.facebook.com/pagesCumbria-Advisory-Thyroid-Service-C.A.T.S./1387475768249218. Don't forget to like and share to spread the word further.

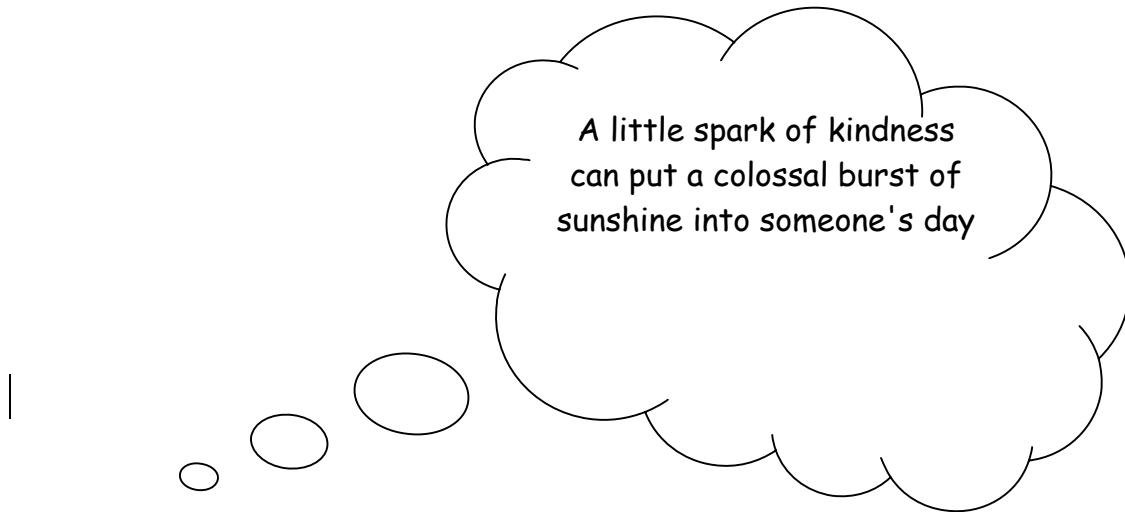
Website

Another source of information for you can be found on our website. Keep checking it for updates on our petition, general thyroid and health news along with access to all our thyroid information. Visit www.cumbriancats.co.uk

That's all for now folk's

As another bumper newsletter ends I hope you have enjoyed the content, but remember the newsletter and our services are for you and so if there is a way that we can improve our services to you please let us know. We are always looking for new information and ideas, better still why not write something yourself for us to include in a future newsletter.

Passing Thoughts



That's all for now folk's

Once again we have come to the end of our newsletter. We hope you have all enjoyed reading this bumper issue and have found some helpful information inside. People often say they always learn something new when they come to our meetings. We would like that to be the same with our newsletters. Gill and I are also looking forward to seeing everyone at our events. However, if you cannot attend the events you can still access Thyroid information and advice via our website. Just log on to www.cumbriancats.co.uk. Our website is constantly being updated so you should find lots of useful information on there. If you want to contact me with any questions you can do so using one of the methods below: email moyramm@yahoo.co.uk or moyra@cumbriancats.co.uk telephone 01229 869705

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Postage Cost

One of the biggest cost for running C.A.T.S. is our postal costs, so if you would like to help us save money, why not sign up to have your newsletter by email. To sign up just contact Peter at richjon51@talktalk.net. You can return to paper copies at any time, so why not give it a try and see how easy it is.

Facebook Page

We recently introduced a Facebook page to our services. This is proving very popular among our members. Once our website is fully updated you will be able to share your experiences, post questions, receive C.A.T.S. news, updates and much more. If you haven't visited the page yet, why not take a look now www.facebook.com/pagesCumbria-Advisory-Thyroid-Service-C.A.T.S./1387475768249218. Please like and share our page to spread the word about Thyroid disease.

We will be back again in September with our mini late summer news update but until then enjoy the summer sunshine, keep well and keep happy.

Best Wishes,

Moyra

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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