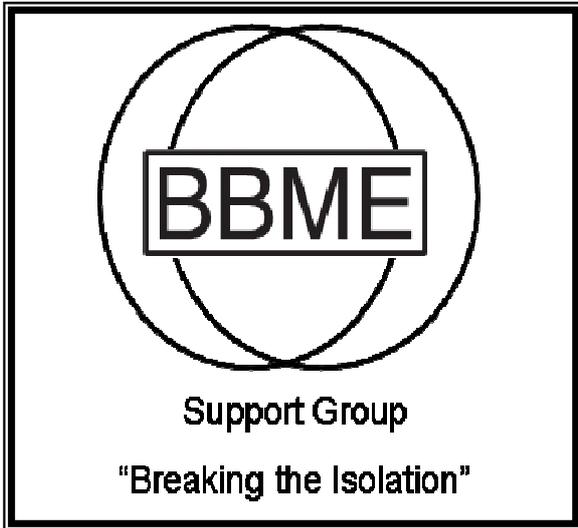


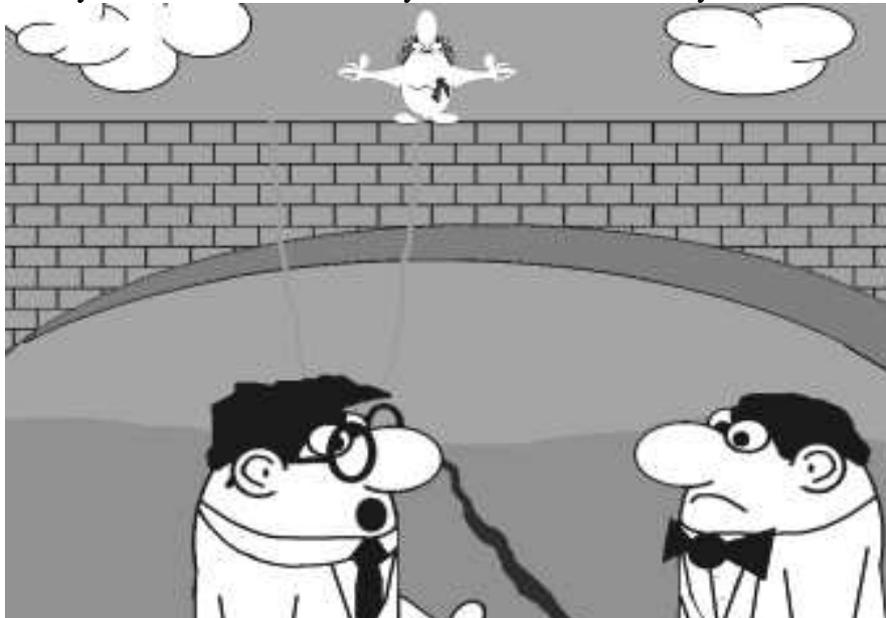
Welcome to Our April 2013 Newsletter



A Note from Alex: This month's news letter is full to the brim and I've had to edit some articles quite drastically to make sure that I have been able to get all of the important and relevant information out to you hence the wording is also smaller than usual. So to read Nom de Plumes full article please go to our website and you will find it there.

Also this month I'm afraid its hands in your pockets time again as our memberships are up for renewal, you will find a membership renewal form in with this month's newsletter with full instructions on the back on how to pay your membership via on line Banking.

There is a very large article starting on page 4 on how to get rid of bedroom tax, for those of our members that this will affect, I think you will find it very useful as the person who wrote it also included a letter that you are free to use. Lastly I'd like to thank everyone who attended our AGM.



Why should she be afraid of bungee jumping? It's just like CFS/ME - after one big leap you always bounce up and down for a while.

With thanks to Invest in ME (www.investinme.org) for their kind permission to reprint this cartoon from the calendar available to download from their website.

Contents of April's Newsletter

Dates for Your Diary & Sponsors	Page 2
Bury/Bolton ME/CFS Support Group AGM March 2013	Page 3/4
Bedroom Tax – How to get rid of it quickly and simply.	Page 4/7
New Prestwich Social	Page 7
Nom De Plume	Page 7
Late Edition	Page 8
Raymond Perrin Update	Page 8
ESA Tip	Page 8
Road Tax/Vehicle Excise Duty	Page 8

DISCLAIMER: Anything expressed within this newsletter may not necessarily represent the views of the editor, the Committee, nor the Bury/Bolton ME/CFS Support Group. Any products, treatments, or therapies featured are for information only and their inclusion should not be considered an endorsement.

Dates For Your Diary

Longsight Meetings: Our main meetings, often with guest speakers, are held at Longsight Methodist Church, Longsight Lane, Harwood, Bolton, BL2 3HX, on the third Thursday of each month from 7.30pm until 9pm (except in April, August and December). Entrance is £1, tea, coffee, water, biscuits, etc provided.

Please note that there will be no meeting in April.

Thursday 16th May: Lucy and Heather, Neuro-physiotherapists, will talk about the hydrotherapy pilots we took part in, along with others with neurological conditions, between August 2012 and January 2013, and show some very embarrassing slides of some of us in the pool.

Thursday 20th June: Staff from the local Millercare shop will give a talk about various aids and equipment. If anyone has anything in particular they would like them to cover, please let me know (as soon as you can e-mail maria@mesupportgroup.co.uk or Tel: 01204 575613). Thanks Maria.

Radcliffe Socials: We meet informally on the first Monday of each month, our next will be on **Monday 13th May** at **the new time of 2pm**, at **The Sparking Clog, Radcliffe Moor Road, Radcliffe, M26 3WY**. It has plenty of parking, good accessibility, comfortable seating and is relatively quiet. They serve very tempting chips that we just can't resist! For anyone who does fancy a snack, these start at just £1.50, with main courses from £3.50. We usually meet at the oval table next to the bar.

Yoga Classes: Are **3:00pm-4:15pm on Tuesdays** at the **Jubilee Centre, Darley Street (off Eskrick St), Bolton, BL1 3DX**. Designed to cater for the average ME sufferer, classes are free and yoga mats are provided. Please wear loose, comfortable clothing. Contact Olivia on 07746 197511, or olivia@oliviayoga.co.uk for more information. **Our yoga classes are currently being funded by the Comic Relief/Community Fund.**

Neuro Support Groups: These groups, run by Greater Manchester Neurological Alliance, provide information, advice and support for people with any type of neurological condition and/or their carers. Call 0161 743 3701 or visit www.gmneuro.org.uk for information about meeting times and locations.

If you are thinking of attending any of our socials, whether you are a new member or a member who hasn't been able to attend for a while, please remember that you can bring along your carer or a friend. We don't bite, but we understand that meeting new people or if you have been house bound for a while, it can be quite daunting going out by yourself and we look forward to seeing you.

PLEASE DO NOT WEAR STRONGLY SCENTED TOILETRIES WHEN YOU ATTEND OUR MEETINGS, AS SOME MEMBERS ARE VERY SENSITIVE TO THESE PRODUCTS, THANK-YOU.



Supported by:
**Health for Bolton and the
Big Bolton Fund via Bolton CVS**



Funding Bolton's future

Bury/Bolton ME/CFS Support Group Meeting

March 2013. by Caroline

Yvonne Leach

Before the AGM business started at our March meeting, we paid tribute to our wonderful Yvonne, who has dedicated herself to helping our members for three decades! Thanks to your generosity, we were able to present Yvonne with some plants and the donations, as well as a beautiful thank-you card made our very own Alex! Pam then told the group just how much Yvonne has done for us over the years. Yvonne was very surprised and moved, thanking everyone for the gifts and good wishes. We are certainly better off as a result of all her hard-work, but she deserves to put her feet up now!

Below is Pam's speech:

Tonight I would like to pay tribute to and thank Yvonne for all her hard work, patience and kindness over the last 30 years.

Without Yvonne it is doubtful that this ME support group would exist. Yvonne and her husband Russell were founder members of the group, back in the very early days when meetings were held in member's houses. It was only in 1990 that we started to have meetings in Harwood Methodist Hall.

Despite being carer for Russell and one of her sons, who also had severe ME, and working full time until very recently, Yvonne managed to fit in an enormous amount of voluntary work for the group. She was the group leader for many years and has been carers contact, giving vital support to many carers. Yvonne has represented group views at hundreds of meetings keeping the profile of ME high and making sure that service providers did not forget their obligation to ME sufferers. She has lobbied MPs and service providers alike and been part of many working parties looking at the needs of ME patients and carers.

We will always be in your debt Yvonne and cannot begin to thank you enough for your hard work and dedication. We wish you health and happiness and a well earned rest.

We are still taking donations for Yvonne. Please send cheques payable to "Bury/Bolton ME/CFS Support Group" to Pam Turner, 7 Burghley Dr, Radcliffe, Manchester, M26 3XY.

We also take online banking payments, if that's easier. Please pay into: Sort Code: 20-10-71 Account No: 00902179 Account Name: Bury & Bolton ME/CFS Support Group. You MUST put your name/alias and Yvonne as the ref and then email lynda@mesupportgroup.co.uk with the date and the reference (Lynda suggests that you use your name or a pseudonym) you have used so she can identify your payment. Once she has received the bank statement and identified your payment she will then send you a receipt via email.

21st March 2013 Bolton/Bury ME/CFS Group AGM

Minutes

Present: Pam Turner, Susan & John Critchley, Pat McKenna, Tracey Morris, Ann and P Richards, Yvonne Leech, Jeff Glasser, Maria Sale, Alexandra Wootton, Carole Senior, Amanda Gore, Phil Seddon, Lynda Marney, Andrew Levy, Caroline Higson, N, Ruth & Rachel Fryman, Kathleen and Charlene Patrick, Susan Courtney, Melanie Bainbridge, Anne Lindsay, Diane Knowles, Beryl, Johnny and Stacey Barlow.

Apologies: Christine Farrington, Rosalind Smith, Angela Glendinning, Steve and Jean Higson, Karen Ruth Moskovitz, Bill Walsh, Jay Coates, Kate McCarthy, Paula and Sue Stephenson, Linda Tiernan, Carol Oldham-Hobson, Steve Jerstice, Donna-Rebecca Wright, Susan Heath, Margaret Benn.

1. Minutes of last AGM held on 15th March 2012 – Maria Sale proposed the minutes be accepted as correct and Carole Senior seconded the proposal. All voted unanimously to accept the proposal.
2. Matters Arising - There were no matters arising from the previous minutes.
3. Secretary's Report – Carole Senior read out the Secretary's Report.
4. Treasurer's Report - Lynda presented the accounts and report. Pat McKenna proposed to accept them as correct and Melanie Bainbridge seconded the proposal. All voted in favour.
5. Election of Committee – Tom Bridge put forward his name for membership to the committee. Kathleen Patrick proposed and Charlene Patrick seconded the proposal that the seven members standing for the post of committee members be accepted and all voted in favour. The elected members are: Alex Wootton, Carole Senior, Margaret Benn, Maria Sale, Lynda Marney, Phil Seddon and Tom Bridge.
6. Appointment of Honorary Auditor - Sue Critchley proposed and Anne Richards seconded the proposal that the Honorary Auditor should be Lisa Fletcher for the coming year. All voted in favour of the motion.

7. Any Other Business – Amanda Gore mentioned that the Facebook group had been having a discussion on the possibility of setting up regular Manchester meetings for the members further afield. A provisional date has been arranged to meet at The Orange Tree in Prestwich on Wednesday 17th April at 2pm. There were no objections.
8. Lynda Marney asked if the annual membership should be run from January to January, as opposed to March-March, to encourage people to remember. People discussed the possibility of setting up standing orders and using direct bank transfers to make it easier to pay membership fees. It was queried as to whether all those who were able to get the newsletter via email did so, to save us postage and printing costs.
9. Date and Time of Next Meeting - The next AGM will be held at 7.30pm on Thursday 20th March 2014.

The meeting closed at 8pm, followed by a raffle and social evening.

Bedroom Tax – How to get rid of it quickly and simply.

By Joe Halewood

Joe Halewood is the Director of Consultancy Services at Housing Support Management. Who say they have advised over 200 supported housing providers across England and Scotland since 2000. Joe has written a great deal about the bedroom tax and how to challenge it on his blog: **SPeye**, and below is what he has written. Thank you Joe for letting me reproduce this article.

Dear Bedroom Tax Affected Tenant: This is a fully updated post on 16 March 2013 at 8pm and combines two previous articles that together say how you can get rid of the bedroom tax for good and very quickly. Yes it's long but it is worth reading and will only take 5 minutes. It says why you should challenge the bedroom tax with a simple letter and gives a draft of that letter after having described what carnage and chaos a simple one-page letter from every bedroom tax affected tenant will create. It will cost you a stamp or you can simply hand it in to your nearest council one-stop shop.

Please read on: This post looks at **WHY** and **HOW** every bedroom tax affected household should challenge their local council's bedroom tax decision. It also explains using Liverpool City Council figures to illustrate the absolute pandemonium this will cause.

What do I mean by challenge?

Some tenants have received letters from their landlords to say the bedroom tax may apply to them. Any such letter is simply a letter and for the bedroom tax to apply to any tenant you will receive a formal letter from the council HB department – a Notice – with regard to the bedroom tax decision.

When a decision is taken by the Housing Benefit department that the bedroom tax applies you will receive a "Benefit Decision Notice" (BDN) and this by comparison is a legal letter – a Notice. Even if your landlord is the council they will need to send you a formal letter from the Housing Benefit department.

The BDN will say how you can appeal the decision, which is a right, and I copy below what HB decision letters from Liverpool City Council say and wherever you live this will be very similar. It says: -*"If you want to know more about this decision or think it is wrong, you must tell us within **one month** of this letter or we may not be able to help.*

You can either:

1. Ask for an explanation
2. Ask us to look again at the decision
3. Appeal against the decision – this can only be in writing. If you appeal against the decision an independent tribunal administered by the Tribunal Service will hear your appeal."

In short – 'explain', 'look again' and 'appeal' are your basic options. Any or all of these 3 options form the *challenge*. You can write asking for the council to send a more detailed explanation to you which you can then consider with a view to issuing a later appeal within the month or asking the council to look again after they have sent you the more detailed explanation.

Why this will create pandemonium?

1. The scale

- Liverpool has 5 parliamentary constituencies which form the City Council local authority area which issues Housing Benefit decisions.
- The National Housing Federation issued a breakdown of bedroom tax affected households by parliamentary constituency.
- As such we know that Liverpool City Council (LCC) has 12,649 bedroom tax affected households in these 5 constituencies.
- Therefore LCC would need to consider 12,649 bedroom tax 'challenges' if everyone challenged
- **UPDATE (see comments) For the avoidance of doubt Liverpool has 43,460 social tenants claiming HB at latest figures. The 12,649 is the number of those affected by the bedroom tax.**

2. What does each 'challenge' involve?

- The DWP (purported) impact assessment gives an estimate of each 'appeal' as a monetary cost of £200 to the council.
- This gives a cost to LCC of 12,649 x £200 if we accept this extremely low DWP estimate of cost and a cost to LCC of £2,529,800 at face value.
- Yet just as the tenant has a month to issue an 'appeal' or other form of challenge then LCC will need a policy of how long they will take to respond – probably a month as well – to explain, reconsider or refer to appeal at Tribunal.

3. Unpicking the LCC response needed

- If we assess each hour of LA time at £25 or so – which is what a few years back the government advised as a cost per hour for councils to use for processing Freedom of Information requests - then the £200 cost of an 'appeal' or challenge (the DWP figure) broadly equates to 8 hours of LCC staff time per appeal or challenge
- The total staff time needed to consider 12,649 challenges becomes 12,649 x 8 hours – a total staffing time of 101,192 hours!!
- 101,192 hours is one month's staff time of 160 hours for approximately 632 full-time workers!

So Liverpool City Council would need 632 staff solely dealing with bedroom tax challenges.

That assumes they need to do this in one month. It further assumes that 8 hours of staff time per appeal or challenge is sufficient as per the DWP estimate. If further assumes each appeal or challenge is looked at by only 1 member of staff and doesn't need 2 for example.

Even if they took a year to respond to each challenge this means 53 full-time staff!!

It further assumes LCC could find 632 or even 53 HB trained staff and LCC would be competing locally with Wirral, Sefton, St Helens, Knowsley, Cheshire West and Chester, and countless other LAs in a commutable area for these ethereal HB trained staff too.

Of course every other council would be in the same boat of searching for HB trained staff. So this is impossible unless IDS can wave a magic wand and produce trained HB decision-making staff out of the ether.

It assumes LCC has budgeted for the cost of 632 HB trained staff and has a spare £2.5m plus recruitment cost or more likely much higher agency costs. Will existing trained HB staff need to be paid more to retain their services? Yes so there's huge additional costs to the public purse involved here isn't there reader?

I don't need to continue at all with this as it is patently obvious that the entire bedroom tax system would come crashing to its knees.

Put simply, if you want to put a figurative bomb underneath the bedroom tax and force the coalition to rethink, and rethink bloody quickly, as they will be heavily pressured from EVERY local authority to do something, then every bedroom tax affected household should exercise their right to challenge their bedroom tax decision does precisely that!

Social landlords would be adversely affected as well. Their pre-existing arrears cases would likely see the tenant saying they are awaiting a decision or payment from HB, but this is taking forever as the system is clogged up with bedroom tax appeals and HB are way behind dealing with their normal workload! The district judge will likely adjourn and more arrears accrue on the rent account until HB decide. The judiciary itself will be concerned over this and also when a huge increased number of formal appeals is sent to tribunals. Will these need to be sitting 24 hours a day like magistrates courts did during the riots? More public purse costs anyone?

So the government would also have social landlords and the judiciary lobbying hard with all the councils too and all of a sudden all of the actors (councils, landlords, tenants and the judiciary) on one side and all lobbying the coalition. Remember this is an absolute right of appeal or challenge to a HB decision and perfectly lawful. The government would have little option but to think again and very quickly.

There you have a lawful plan to rid the pernicious bedroom tax and quickly. All it needs is a small effort and free contribution from some experts well versed in drafting arguments and experience of the HB appeals system – a couple of hours each would do it wouldn't it?

One wonders why social landlords and particularly their lobby groups such as the CIH and NHF and others who, after all, are paid handsomely by their members the same social landlords to lobby on their behalf, hadn't thought of this simple idea!

Anyone would think that social landlords wouldn't benefit from transferring back to government the £500m per year financial risk of arrears this government imposed on them with the bedroom tax.

Let's be clear that is what the bedroom tax policy is a massive transfer of financial risk to social landlords and a thinly veiled attack on social housing – and why hasn't the CIH or NHF or other sector lobby shouted that from the rooftops? Just another tale of incompetency of the housing response to the bedroom tax anyone? Yes just like a worker in private housing needs £6,000 more in gross salary than a social housing tenant for the same job in order to pay the average £80 per week cost of private rent? No that argument has

never been put out either by the social housing sector either! No argument that this means high private rents are a barrier to the take up of employment compared with social housing. No argument that the taxpayer gives £1bn or so more in subsidy per year to private landlords than it gives in total to social landlord through this HB added benefit cost to privately rented housing either.

Anyone see an argument that the bedroom tax called the ‘spare room subsidy’ by the coalition should be called the ‘cost of room subsidy?’

Yes you’ve guessed the wonderful social landlord not put that argument out there either...and as there are more spare rooms in privately rented housing than in social housing...oh don’t get me started!

Sources:

NHF figures on numbers of bedroom tax households [here](#) by constituency

DWP estimate of appeals [here](#) and section 54 says:

“...if 20,000 claimants chose to appeal the decision made on their Housing Benefit entitlement, DWP estimates the additional administration cost associated with these appeals would be approximately £4m.”

Sample letters of challenge that all 660,000 tenants can use are needed. So come on people get circulating good quality sample letters of challenge and appeal and let’s get rid of this nasty pernicious drawn-up on the back of a fag packet bedroom tax policy.

Let’s each donate 2 hours of time and so every bedroom tax affected household can easily challenge its council for the cost of a first class stamp by simply cutting and pasting into their letter of challenge?

Isn’t the tenants lot stressful enough without having to trawl through the HB Regulations to see that, for example:

- every council needs a policy to include where and when they refer a registered social landlord HB case to the Rent Officer; or
- that this is standard practice for private housing yet the landlord is simply believed for social tenancies and as HB departments are ‘guardians of the public purse’ why do they discriminate against the social tenant here?
- If a bedroom is what a social landlord says but not what a private landlord says cannot be fair can it?
- Is that a blanket policy by HB departments, an unlawful fettering or restraint is the status quo!
- Does the council have a policy on referring unsuitably large social housing accommodation to the Rent Officer?
- What information was sent by the landlord to the HB department for HB to assess the bedroom tax? Did this include unnecessary information outside of any protocol between HB and the social landlord?
- How does the HB department determine what is a bedroom? Is it just the acceptance of the social landlords word and what is the written policy where a claimant disputes that view?

How many separate challenges are there in that off the top of my head far from inclusive challenge list?

UPDATE – BEDROOM TAX MARCH DAY 16.03.2013

This ‘call to arms’ above received many responses for which so many thanks are deserved and resulted in one example of a standard letter to freely share. This is below. **It is a simple and reasonable request for further information from the tenant to the Council so the tenant affected by the bedroom tax decision can then consider whether to lodge a formal appeal based on having much more information on the facts of how the decision was reached.**

The guidance and other official documents released regarding the bedroom tax/under occupancy charge simply say the landlord informs the HB department whether a property has 1 bedroom or 2 or 3 or more and that is it. It does NOT say definitively it is whatever the landlord says. Further, the government and DWP have specifically stated they will NOT define what a bedroom is. Yet how can you tax (or charge) something which you cannot or will not define?

There is no definitive guidance on how landlords share information with the HB department. There are protocols in place that allow the sharing of information and information will have been shared. Yet when did this information sharing take place? And what if the tenant is a foster carer or has a teenage son or daughter in the armed forces that were exempted just this week? Would a social landlord know a tenant is a foster carer or has a teenage son in the armed forces? Probably not so the landlord could have inadvertently misinformed the Council’s HB department. Further, what role the landlord played in this process will differ in Birmingham to Bristol or Bradford or Brent or Brighton. It may well have different arrangements and processes between Landlord A and Landlord B within any town or city.

All any tenant knows is that there is an involvement of their social landlord in the HB department making the bedroom tax/under occupancy charge decision and no more than that. Hence for a tenant to consider whether a formal appeal – the start of a legal process – is warranted or not, the tenant needs to have all the facts and not just assumptions within the bedroom tax decision-making process in their given local authority area.

You will find the Standard Letter on the next page:

Dear Sirs,

I received your decision letter dated INSERT DATE and referenced above that imposed an under occupation charge, or bedroom tax of 14% / 25% (delete as appropriate) on my existing award of Housing Benefit.

I consider this unwarranted yet in order to challenge this in the correct way and potentially by way of formal appeal I require further information to be sent to me within 7 days of this letter and the urgency of that is to ensure I have enough time to formulate any such appeal and in full knowledge of the facts of my case within the time allowed; OR in the alternative I request the deadline for any such formal appeal be moved to 21 days after I receive the request information below:

1. A written copy of the Council's policy and decision-making procedures in relation to referring a socially housed claimant decision to the Rent Officer Service.
2. A full explanation of how the council decided that (INSERT ADDRESS) was determined to be a 3 bed property for the under occupation charge and this to include what involvement if any of my landlord, (INSERT LANDLORD NAME) in this process.

Please state by way of covering letter with the requested information any changed deadline date from above with regard to a formal appeal.

Yours etc

New Prestwich Social

Following on from a discussion on our Facebook group about some members not being able to get to the Radcliffe socials, we are going to trial a new location. There will be an informal social at **2pm** on **Wednesday 17th April** at **The Orange Tree, Fairfax Road, Prestwich, M25 1AS**. Everyone is welcome and in case you're worried you might not recognise us we will put one of our newsletters on the table. If it goes well we will arrange regular socials there, so watch this space for info on future dates and our verdict on accessibility. (Please note that the Sparking Clog socials are continuing as normal).

Nom De Plume. Granola

Ingredients you will need:

- 200 grams of organic toasted flakes of coconut or 200 grams of roughly chopped, toasted walnuts, or any other preferred nut
- 100 grams of mixed, lightly toasted seeds, such as sunflower, pumpkin, flax, hemp and chia seeds
- 1 kg of organic jumbo rolled oats or 1 kg of organic puffed brown rice or 1 Kg of organic puffed quinoa
- 200 Mls of organic vegetable oil
- 2 organic vanilla pods or a heaped tablespoon of freshly ground cinnamon
- 2 teaspoons of freshly ground smoked or Himalayan flaked, sea salt
- 400 grams of organic unsweetened dried cranberries
- 400 grams of organic unsweetened banana chips
- 200 Mls of unsweetened organic rice milk or 200 Mls of organic plain soya yogurt

Method:

1. Begin by toasting the mixed seeds, coconut or nuts, and allow to cool. If using oats, then preheat your oven to gas mark 6 or its equivalent. Should you need to follow a wheat and gluten free diet, then be advised that the puffed rice or Quinoa have no need to be cooked. And therefore once weighed out, can be put to one side for now.
2. Having placed your oats into a deep sided roasting tray of generous proportions; place in the oven and stir occasionally until golden brown for approximately 20 minutes.
3. During the last 5 minutes of the oats being cooked, measure and mix together the oil and your chosen flavourings; should that be from the vanilla pods then add their moist seeds to the oil with a brief stir and pour this onto the oats, when the oil is fully distributed, return your mix to the oven. If you prefer a deeper depth of flavour, you will be much rewarded by grinding a large bark of cinnamon into a fine dust, which is then used in an identical fashion to that of the Vanilla.
4. Leave your coated oats to bake for a further 15 minutes. Ample time to grind your salt, and weigh out the dried fruit. All of which is then stirred into the hot, toasted oats just moments after it has left the oven. This sudden injection of heat helps the salt to dissolve and the dried fruit to plump up.
5. Allow the contents of your baking tray to fully cool; at which point, one can then add the seed, coconut or nut mix. Once all the ingredients are united, decant your granola into a generously sized kilner jar.

If Gluten Free:

Should your Granola need to be gluten free then your method of preparation differs slightly. Begin by combining the dried fruit, seed, toasted coconut, or nut mix together in a large saucepan over moderate heat, stirring occasionally. Pour the infused oil and freshly ground salt onto your fruit, seed, coconut or nut combo. Continue to cook your ingredients until the oil has been absorbed and the cranberries have plumped up in size. Allow to cool, and combine the fruit mix with your gluten free cereal and decant. There are two ways

one can prepare a cereal bowl of granola, it can be mixed 12 hours before you intend to eat it, with a handful of fresh berries, a tablespoon of honey or Agave nectar and 200mls of plain yogurt, this is then covered with Clingfilm and left to chill. Alternatively serve with either cold or hot rice milk.

Late Edition

Here's a brief roundup of some of the recent articles covering CFS/ME during March.

Jessica Taylor, who has severe M.E., talks about celebrating her 22nd birthday by sitting in a chair for the first time in seven years. "I've been bedridden for so many years, fighting to try to sit in a chair means everything to me," she says. - **Thousands watch Jessica's triumph** – **Medway Messenger** – **22 March**

This is the story of 2 physiotherapists who contracted CFS, but used Graded Exercise Therapy to help with their recovery. - **Making the grade** – **Chartered Society of Physiotherapy** – **20 March**

This study attempts to shed more light on definitions of CFS/ME. It identifies 3 different categories which are Chronic Fatigue, Post-Exertion Malaise and Chronic Fatigue Syndrome. The researchers recommend that "future research on this "chronic fatigue spectrum" should, therefore, use these categories and novel tailored algorithms to classify patients into ME, CF, or CFS". - **PubMed.gov** – **27 February**

This blog also covers the definition of chronic fatigue calling it the "Disease of a Thousand Names". It highlights the role of the immune system and the fact that it was ignored in a meta-study, of CFS/ME studies, which has led to more confusion on a universal definition. - **Chronic Fatigue and Immune Dysfunction: Who Took the "ID" Out of CFIDS?** – **March 7**

This one person's story of living with ME and how it's affect her life. "I don't know how long I will suffer my new best friend but I refuse to dwell on the unknown. Instead, I face each day with a blank sheet. The bad day, the day before is behind me." **I have learned it is possible to be happy and sick?** – **Galway Independent** – **March 13**

Dr. Jacob Teitelbaum has developed a new programme called SHINE, after contracting CFS/ME in his early career. "SHINE works for anyone who needs more energy," Dr. Teitelbaum said. "It focuses on five areas: Sleep, Hormones, Immunity, Nutrition, and Exercise." - **5 Ways To Beat The Exhaustion Epidemic** - **March 11**

Raymond Perrin Update

Dr Raymond Perrin, asked me to thank all of our members who for participating in his test run for the new research, and below are his finding:

In total we had 6 CFS/ME patients, 3 healthy controls and 1 'red herring' (a mother of one of our patients who definitely did not have CFS/ME but would be no good for the actual research as she may have all the physical signs without the illness due to genetic links in ME.)

If my system worked the practitioner would correctly identify 6 CFS/ME, 3 healthy and the patients mum would wrongly be diagnosed as ME.

Gail with many years experience identified all 6 ME patients and the 3 healthy controls correctly and as predicted identified all the physical signs on the patients mother and so wrongly diagnosed her as ME. Basically she scored 10/10.

Kerry who is a newly practising osteopath with only 3 days of training correctly identified 5/6 ME patients and the 3 healthy controls she identified correctly and was not sure when it came to the patient's mother.

If results such as this are repeated in the main larger study, then we will be more than happy and the project would be a resounding success.

Once again thank you to all who took part in the study.

ESA Tip

If you've been put in the WRAG and have run out of benefit, try making a brand new claim. I know it's stressful, but it may be worth it. At least one of our members did just that after being in the WRAG for 12 months, and was put in the support group without a medical, and on virtually an identical claim form. Just emphasise that your condition has deteriorated if that is the case (a dead cert, I would think).

Road Tax/Vehicle Excise Duty

Disabled drivers exemption – From 8 April 2013 the Government will extend the current road tax exemption to those receiving the enhanced mobility personal independence payment (PIP, replacing DLA) and introduce a new 50 per cent discount for those receiving the standard mobility PIP.