

Welcome to Our August 2013 Newsletter



A Note from the group:

The weather seems to be all over the place at the moment, between heat-waves and down-pours! We know changes in weather and extremes of temperature can really affect our M.E symptoms, so we hope you're managing to cope!

Lots of group news for this newsletter. Please pay special attention to our requests for help, and also postal votes for our EGM in September.



She's obviously feeling very bad today. We'd better visit her another time.

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.

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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 there is no Longsight meeting in August!****

Thursday 19th September 7:30pm: Bolton Mountain Rescue will be talking to us about their work. Before their talk, we will be holding a very quick Extraordinary General Meeting, it will only last around 5 minutes:

Caroline Higson would like to join the committee and needs to be officially voted in by members, as she was not able to at the AGM in March. Caroline is happy to assume responsibility of Group Leader duties and be the point of contact for new and existing members. It is essential that as many people attend as possible please and lend your support, just like at an AGM. If you cannot attend in person, please send in your postal/email vote (on the back page) by September 17th. Thank you.

Radcliffe Socials: We meet informally on the first Wednesday of each month, our next will be on **Wednesday 4th September at 2pm**, at **The Sparking Clog, Radcliffe Moor Road, Radcliffe, M26 3WY**. It has plenty of parking, good accessibility, comfortable seating and is relatively quiet. For anyone who fancies 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.

Prestwich Socials: We meet informally on the second Wednesday of each month, our next will be on **Wednesday 11th September at 2pm**, at **The Orange Tree, Fairfax Road, Prestwich, M25 1AS**. Everyone and their carers are welcome and we'll put a newsletter on the table so you can find us.

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 Comic Relief and The Co-operative Membership 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

**Bolton
Council**



Bury/Bolton ME/CFS Support Group Meeting

July 2013

For our July meeting, we had a bring and share supper social like we do in November. It was very hot because of the heat-wave, but it was great to see so many members join us, as we threw Pam a surprise 70th birthday party! Her birthday is August 10th, but we don't have a meeting then, so thought we'd surprise her a month early! The birthday girl looked lovely and we had a wonderful evening!

A note from Pam:

A very big THANK YOU to Caroline for organising and for all of you who helped me to celebrate my 70th, a little early, but it was absolutely wonderful.

I was so surprised to see the Happy Birthday banners and the balloons and all the beautiful food on the buffet, it was a real party.

The *pièce de résistance* was, of course, the magnificent cake made by Charlene, she is an absolute star. It was my favourite lemon cake and she had even made the lemon curd. The decoration on the cake was exquisite, it was a garden, pale green/blue marbled icing and decorated with flowers, a dragonfly, butterfly and pictures of a robin and two ladybirds painted on the side, just absolutely gorgeous.

I believe a fan had been borrowed to keep it cool so that the edible flowers, etc wouldn't melt. To top it all off, it tasted as good as it looked.

There was also the most beautiful card made by Alex, her artistry is fabulous.

Thank you everyone for making it such a special occasion and thank you for all the love and friendship over so many happy years and for all your good wishes.

My love to all of you, Pam.



ME Clinic News:

On the 18th June, Pam, Yvonne and I attended the 6 monthly meeting the group has with the ME Clinic team. Every 6 months, the team do an audit of the service looking at referrals and patient outcomes. The team have had many positive comments and many patients report an improvement in their condition.

We'd like to remind everyone that the clinic service is not just for newly diagnosed patients! You can get a referral to them regardless of how long you have had ME, and you will be seen as soon as possible.

If your condition deteriorates and you want to go back to the clinic, if this is within 12 months of your discharge, you can self-refer back, without the need to go via your GP. If more than 12 months has lapsed since you were discharged, you would need to ask your GP for a referral (this is because the team need up to date tests first).

There is no upper age limit to get a referral; you can be seen regardless of your age. If you would like to attend the clinic, please ask your GP for a referral to:

The ME/CFS Clinic, Brightmet Health Centre, Brightmet Fold Lane, Brightmet, Bolton, BL2 6NT. Telephone: 01204 462 765

If you have any questions for the team, please tell us, and will pass them on. Caroline

Dr Andrew Wright:

I am pleased to report that following a meeting of the Fitness to Practice Panel of the Medical Practitioners Tribunal Service in Manchester in May 2013 Dr Wright has been allowed to resume unrestricted practice when the suspension on his registration expired 5th June 2013.

During the period of his suspension Dr Wright has been working full time as an administrator in the NHS and continued with his CPD (continuing personal development).

He has undertaken to move away completely from the field of CFS/ME and will no longer engage in private practice. He is intending to return to full time NHS general practice. We wish him well and send him our love and best wishes for the future. Yvonne Leech

Hydrotherapy:

Bury and Bolton Neuro Voices is delighted to announce that it has received an 'Awards for All' Big Lottery Grant to cover the physiotherapy costs of two further 5-week hydrotherapy courses at the Bolton One Jason Kenny Leisure Centre.

They will run on Wednesdays between 12 noon and 2.30pm and will be mainly for people who have not already been on one of their courses. The first course will start on 14 August 2013 and the second on 25 September 2013. Participants, who will have a 30 minute slot, are asked to contribute £25 in advance to cover the costs of pool hire, lifeguards and volunteer expenses. There are still places available for both courses. You can register by going on to the physio's website. You can then click on the link to register. Anyone who does not have access to the web or who has problems in using it can contact the lead physio, Heather Taylor on 07775 943528 to register their interest: <http://www.neurologicalphysio.co.uk/hydrotherapy/>

Members Successful PIP Application:

For anyone who is wondering what the PIP applications will be like for people with ME, a member has received enhanced care and mobility just from the application form and supporting medical evidence, with no medical or appeal. Of course, your outcome will depend on your own abilities and other medical conditions will also be a factor, but this is encouraging news. Make sure you send in any medical evidence you have, like doctors/consultant reports with your application form! Also remember to photocopy your application form for your records, send your envelope recorded/signed for in the post and put your name and National Insurance Number on any additional letters/sheets, etc that you send. "Fightback" on Facebook advise that the PIP medical is far more thorough and longer, and around 45 minutes to an hour in total. Make sure you take a copy of your form into the medical in case the examiner doesn't have it for whatever reason. Caroline.

Apologies:

Apologies for the oversight, but we neglected to credit, Jeff Glasser with writing the article about going to tribunals that appeared in our July newsletter. Sorry Jeff and thank you for the informative article!

Legal Help With Benefit Claims:

From ME Welfare Benefits Advice and Support Group on Facebook

In April 2013 the rules on legal aid changed. Now, you cannot get help with first tier tribunal appeals, but there is still help in place for second tier appeals (when there was something wrong, legally, with your original appeal). There may be more people who can help, but here are some we are passing on for your information:

<http://www.thefru.org.uk/> **Legal representation when appealing**

<http://www.dls.org.uk/advice/welfarebenefits.html> **Disability Law Service Chief Operating Officer DWP, 0207 829 3364.**

For escalating claims when not happy with decision maker's reconsideration. Independent Case Examiner (ICE). ICE offers a free, impartial resolution service but does not consider matters of law or government policy. ICE can be contacted by Tel: (0845 606 0777), in writing (PO Box 155, Chester CH99 9SA), or by Email (ice@dpw.gsi.gov.uk). Full details are available on the ICE website at: www.ind-case-exam.org.uk

Community Legal Advice - legal aid link Tel: 0845 345 4345 They'll help for free provided you have less than £16k in savings and are on benefits and appealing.

<http://www.turn2us.org.uk/> are a charitable service which helps people access the money available to them – through welfare, benefits, grants, and other help.

“**Fightback**” on Facebook are also an extremely valuable source of information on benefits, appeals, tribunals, etc.

Articles:

Do you have any interesting articles for the newsletter? Please send them to us! We would also like to start printing some of your letters, so if you have any comments on any articles we publish, you have benefitted from information in the newsletter, or you have any useful tips or advice to pass on, please do so! Send us a photo to if you like. Please send to: Caroline@mesupportgroup.co.uk or write to Caroline, 53 Denstone Crescent, Harwood, Bolton, BL2 5DE. Please remember to give your consent to them being printed.

Mecure Bolton Georgian House Hotel & Spa Discount for Our Members:

Just a reminder for any new members who might not be sure, or indeed any long-standing members who have forgotten, the Mercure Bolton Georgian House Hotel & Spa have kindly arranged a discounted fee for our members, where we (and a carer) can use the pool and sauna for the reduced price of £3.50 each (usually £8). There won't be any charge for the carer if they don't use the facilities. You just go up to the desk at the health club and say you're a member of our ME Group, it really is that simple. The pool is small, quiet and warm, and the changing rooms are very close, with a good disabled changing room. There are woggles (long sections of rubber that are used in hydrotherapy to improve core stability) available on request. There's a dry sauna in each of the male and female changing rooms, plus a shared steam room opposite the desk where you book in. Their address is: Mercure Bolton Georgian House Hotel, Manchester Road, Blackrod, BL6 5RU. Tel: 0844 8159029.

Library News:

We now have a copy of this year's Disability Rights Handbook for members to borrow. The Disability Rights Handbook 38th Edition (2013-2014), provides all you need to know about the entire benefits system and comprehensive guidance on these critical changes. It covers everything

from housing benefit, to PIP, to community care assessments and is essential reading when claiming to know what your rights are.

We have been given a grant by CVS to enable us to buy a few library books. Please can you give Carole suggestions of books to purchase on Tel: 01942 810 320 or

Email: caroles4@virginmedia.com. A lot of people end up having a book for many months, so please be aware other members are waiting to borrow them. Last year, we had to replace 10 books that we could not get back, some of which were new. This was because people moved, their numbers changed, they lost them, or they would not return them. We know people genuinely forget to return books, but please try to return them promptly, they cost a lot to buy and replace and many people find them helpful. Thank you.

Radar Keys:

The National Key Scheme (NKS) offers disabled people independent access to 9,000 locked public toilets around the country with the use of RADAR keys. The group has ordered some of these keys in bulk, to re-sell to members at cost, to make it cheaper and easier for you to obtain them. We have large headed keys (for those who struggle with grip and dexterity) and small headed keys. **The keys cost £2.35 each.** We will sell them at the Longsight meetings for you to pick up, or we can pop them in the post (plus extra 50 for postage please). You can pay by cheque, cash, or online by bank transfer. If you would like to purchase a key, please Tel: 01204 525 955, or pick one up at our meetings.

Alternatively, they keys can be purchased for £4 each from <http://www.radar-shop.org.uk/> as well as Shopmobility shops. There is a National Key Scheme Guide book, which gives the location of all the relevant toilets. (be warned, there is an iPhone app costing £5, which locate these toilets for you when you are out and about, but it's not very good according to the reviews!).

They are proposing to relaunch the key later in the year, due to widespread piracy (we know these are genuine keys), but not much is known about it and it would be quite a while before all locks changed if they did so, so it may still be worth getting a key.

NHS Online Clinic:

From **14 - 20 August 2013** NHS Choices and talkhealth will team up with ME Association, Action for ME, AYME, CFS Research Foundation, FibroAction and Fibromyalgia Association UK to present an Online Clinic on CFS/Fibromyalgia/ME where you can ask questions in an online forum:

<http://www.talkhealthpartnership.com/forum/viewforum.php?f=451>

To see live posts follow them on Twitter [@onlineclinics](https://twitter.com/onlineclinics)

ME - THE NEW PLAGUE 2 : Reclaiming the Patient's Voice. A New book by Jane Colby

Jane Colby's new website www.methenewplague.net went live just a couple of weeks ago, to launch my new book. As it says on the home page: "Charles Dickens wrote and published his books in episodes. Author Jane Colby is following in the master's footsteps by releasing ME - The New Plague 2 in episodes, free of charge."

The first episode, set in a TV studio, recounts the PR disaster caused by the BBC when ME patients were encouraged to bay at a well-known doctor.

I've taken part in many TV programmes over the years, and it's never clear quite what will happen as a result, or whether it will help or hinder. But as I explain: "the truth of this devastating disease lies with the ME patients themselves" so it is they - we - who must be listened to. However, in this case... well, find out for yourselves. It's a short episode and quickly digested. I hope it'll whet your appetite for more.

In the original 'ME The New Plague', I investigated the forgotten links between ME and polio, and interviewed eminent specialists. When it went out of print, I promised a new version, including key information from the first one. But on top of that, the project's turned into something more - it's a literary call to respect the patients and the clear evidence they have to give.

ALSO

The Great Sock Rebellion: and other revolts. Yes, it's my new Stripesocks blog! Find it at <http://www.methenewplague.net/blog.html>

I hope it'll raise a smile. And encourage you onwards and upwards in living with ME. We don't all have to be clones. Jane Colby, TYMES Trust.

Samantha Cameron Hosts Reception for AfME from Action for ME KMU Email July

Samantha Cameron hosted a reception at **10 Downing Street** in support of Action for M.E. The illness is close to her heart as she has known people affected by it.

We used the occasion to say a very special thank you to many of our supporters and the Prime Minister's wife was able to meet many of the 100-plus guests gathered in the State Rooms at the prestigious event held on 18 June.

Among those attending were yachtswoman turned internationally best-selling author Clare Francis, who is President of Action for M.E., and the charity's Ambassadors, leading businessman Robert Cathery, a long-term supporter of the charity, and six times world champion and double Olympian Anna Hemmings, who became an Ambassador last month.

Other guests included community fundraisers, long term supporters, health professionals and leading researchers who have been funded by the charity. National TV and print journalists also attended and were able to meet key players in the M.E. arena.

Action for M.E. Chief Executive Sonya Chowdhury said, *"This was a fantastic opportunity for us to say thank you to some long standing friends and hello to some new ones. When Samantha offered to host the event, we were absolutely thrilled.*

"There can be few places in the world as iconic as 'Number 10' and we were delighted to be able to celebrate past successes, highlight the much that still needs to be done and share some of our exciting plans for the future at such a high-profile venue.

"Numbers had to be limited, but we were also able to also invite some of the eminent researchers and experts in the field of M.E. who we are funding to this very special event. Bringing people together and working collaboratively to achieve joint aims is a major part of our strategy going forward."

Volunteers Needed

Last month we sent out a request asking if anyone can help us with writing up what happens at our Longsight Socials and the editing of the newsletter, Caroline and I have had no response to our asking for help.

We know that you like us suffer a lot with ME/CFS symptoms, but the committee is really running low on help. On average every year we have 160 members and out of all of the members, including the committee, the group is being run by 12 members!! Which doesn't average 1 person in 10 helping, if you think you can help us please, please get in touch with Caroline or myself, as if we don't get the help the group will start to suffer. Would suit any members, family or friends who want a bit of volunteering on the CV and we can provide references depending on the task.

The Committee do a lot of work behind the scenes that other members don't see, and we really don't want the group to suffer as we think we give a good service for the £8 membership each year.

So if you think you can help please contact Caroline via Email: caroline@mesupportgroup.co.uk or Tel: 01204 525 955, or contact Alex via Email: alex@mesupportgroup.co.uk or Tel: 0161 761 5493.

What is involved in editing the newsletter:

- Coping and pasting peoples articles in to the newsletter
- Checking for Spelling mistakes and making sure that what has been written makes sense
- Updating the dates of meetings
- Copying articles from Action for ME, ME Association etc and giving them credit for the article
- Writing the intro if you want to
- Update the Contents

- Emailing it to one of our volunteers for printing and also emailing it to Alex so she can email it to our members
- If there is a small space put in one of our reminders
- Formatting the newsletter so it looks consistent (Alex can help you with this if need be)
- There are templates for the newsletter already set out until the end of the year, Alex can set up templates for 2014 if you aren't sure on how to do it

Thank Alex.

Update: Caroline has run our website (www.mesupportgroup.co.uk) since 2002, but does not have the time or skill to develop it further, although basic updates still get done. Are there any budding web-developers out there who want to give it a go? Please also ask your family and friends!

Mandatory DWP Health Advice for ESA

Claimants From Benefit & Works Website on 8 July 2013

From November ESA claimants are to be forced to have regular meetings with DWP doctors, occupational health nurses or therapists to discuss how they can make themselves well enough to work. Failure to comply will lead to having their benefit stopped. The rules will apply to claimants who are in the work-related activity group and who are expected to be able to return to work in 18 months or more.

Initially the new rules will apply to 3,000 ESA claimants in a pilot scheme running from November 2013 to August 2016.

It will run alongside two other pilot schemes in which claimants will receive additional support from Jobcentre Plus or from work programme providers to see which scheme gets the most claimants off benefits.

The length and frequency of the meetings will be variable, so some claimants will find themselves having more meetings than others. The initiative is being paid for by the European Social Fund but no announcement has been made as to whether it will be Atos, Capita or another company who will provide the health professionals for the pilot.

According to the DWP: *“The regular discussions will focus claimants on how they can improve their view of their readiness for work by taking steps to manage their health issues. They will not replace a person’s GP, but can promote health support and help a claimant to reengage with their GP if they are struggling to adapt to their condition.”*

It seems unlikely that DWP appointed health professionals could oblige claimants to undertake specific courses of treatment, but failure to engage with the process may lead to benefits sanctions, so claimants may feel under a great deal of pressure to follow ‘suggestions’ made by DWP funded health professionals.

According to employment minister Mark Hoban: *“Many people on sickness benefits want to work, so it’s vitally important that we give them the right help to move into a job if they are able. The help we give people at the moment tends to focus on work-related skills, but doesn’t necessarily address health problems. But by giving people regular support from doctors, occupational health nurses and therapists we can do more to help people manage or improve their conditions.”*

Benefits and Work will publish more information about the location of the pilot and the company engaged to carry it out as it becomes available.

BEDROOM TAX NEWS

From Benefit & Works News Email on 9 July 2013

The evidence that the bedroom tax is a disaster, especially for disabled claimants, is now overwhelming and undeniable unless you happen to be a government minister. **A short BBC video** reveals that housing association three bedroom properties are now lying empty at a time of desperate housing need, because claimants cannot afford to move into them.

Meanwhile, tenants – especially disabled tenants - trapped in properties too large for them are **falling behind with their rent in unprecedented numbers**, according to the National Housing Federation.

All of which leads Iain Duncan Smith to the inescapable conclusion that **the bedroom tax 'is proving a success'**.

Apparently this is because it is "shining a light on the previous government's failure" in relation to housing policy. The fact that thousands of disabled claimants are suffering debt, fear and forced relocation as a result is so small a price to pay for this illumination that it isn't even worth considering, apparently.

ETAG Meetings:

On 12th June, Pam and I attended an ETAG meeting (Equality Target Action Group Network). Both of us weren't really well enough to go, but it's very important to make sure the needs of people with ME are met when designing NHS services.

The meetings are a way of individuals, groups and organisations to inform and guide equality and diversity within local health services and also to feed back information and good practice.

We had previously asked for your input to take to them, regarding barriers to services and out of hours care. The response to our request for ideas was quite poor though, only people on our Facebook group replied with ideas, no one got in touch with us via email, or phone. Please tell us what difficulties you are experiencing, they won't get fixed if they don't know they are there!

Some of the comments were things like not being able to get follow up appointments at the ME clinic, Bolton One parking, local rate GP numbers, waiting times for GP appointments, and difficulties with ambulance transport being on time.

They seemed concerned with many of the points that were raised at the meeting, and I feel they are very responsive to feedback and I feel confident that they are genuinely listening to and interested in our concerns. Most of the people there were representing organisations, like Bolton Healthwatch and other professionals, there were actually very few people representing illnesses like us, so it was quite good to get a lot of the attention and plead/beg for services!

On 1st August, Maria and I attended another ETAG meeting on your behalf to continue to ensure that the voices of those with ME are heard and considered by the new CCG when they are commissioning NHS services. We are currently arranging a date to meet with the CCG to explain about the work of our group.

We both looked rather worse for wear by the end, but it was definitely worth going! We'll send you more news when we hear any, but please Email caroline@mesupportgroup.co.uk, or Tel: 01204 525 955 with any concerns you want raised. We also want to make sure that the needs of carers are taken into consideration, so please get in touch! Caroline

There's a survey out for individuals to complete, online or by paper. It asks about your experiences with healthcare, barriers to services, how you got on with any complaints you had, etc.

The group will submit one of behalf of all our members, using the points you raised, but you can also fill in one yourself: <https://www.surveymonkey.com/s/VZRX8BM>. If you require a paper copy, we have a few and can send you one in the post.

Twitter:

Our group is now on Twitter! Our Twitter handle is @BBMECFS (Twitter.com/bbmecfs). Although our Facebook page is where most of our members interact with each other online, Twitter will be a good way to better interact with relevant bodies, such as Bolton CCG and the national ME organisations, so that they keep us in mind. We can also post links to relevant research that we are involved in, like the METRIC study, to make them aware of any developments.

If you want idea of who to "follow" on Twitter, take a look at who we are following, it contains both local and national bodies.

Equipment Hire:

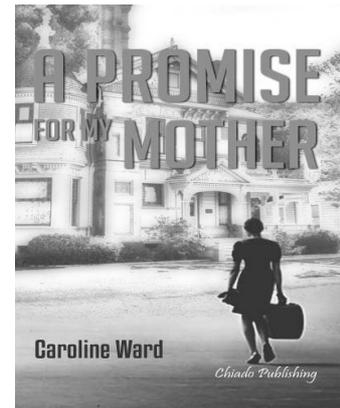
We have a wheelchair and two electric mobility scooters (small enough to fit in car boot for days out or holidays). If you wish to borrow any of these, please phone Pam on 01204 793 846.

Member's New Book:

A member, Caroline Ward, has a new book out, based on a true story.

The launch is on 29th August at the Holiday Inn on Bridgeman Street in Bolton from 4pm - 8pm. Please come along and show your support!

In spite of battling the effects of M.E. and the tiredness that comes with it, she has written her story of a life that has been a bit of a roller coaster ride, made worse by the absence of love and support at crucial times when she needed it most. She has made it through to now enjoy a happy and content life and share's her story with us.



Nom De Plume.

It has taken a great deal of trial and error to get to a place where I can, with a degree of confidence, call myself a baker. Cakes, I have never had a problem with, nor puddings, tarts or pies. But there are two things, one of which I intend to discuss today, have however, demanded much more care and attention than I normally have. Like many of you, I too continue to struggle with the energy I have, in relation to the energy needed to get through each day. Mostly, I exist by holding my breath, willing myself to be better, by being organised, more methodical, and spontaneous. And those are some of the attributes that baking calls upon. You see its biscuits... For me, baking crisp, fully formed, slightly bigger than bite sized biscuits are never an easy prospect. I can blame the oven, M.E, sloppy measurements or poor mixing, but there are many times I just fall short of getting it exactly right. Still, on I try and it is true to say there are as many kinds of biscuits as there are people that eat them.

The same can not be said for tea lovers, as there are those that do, and those that do not. I am of course, referring to dunking, a habit rarely practiced outside of ones home and family circle. Yet when the habit is mentioned it never fails to cause a reaction of some sort or other. Personally speaking, as one who favours crisp and crunchy textures, over all others means that my tea and its confectionary partner, rarely meet. Memories of the loss and subsequent sunken contents of a biscuit, which is then left to lurk at the base of ones cup, evoke an audible gasp.

Still, I have to confess a degree of respect for those skilled enough to get from plate, to cup to mouth, with ease. And so to my recipe, which this month is not inspired by a specific memory, but rather a practical longing to improve ones technique.

Baking in my home, is almost always in response to something emotional, be it an urge to soothe, to celebrate, or to welcome loved ones into my home. And a batch of biscuits, wrapped in my brown greaseproof paper and tied with string, has enough power to move even the most guarded amongst us. I particularly like to stuff my biscuits because it almost always catches the eater off guard, and chosen well, will also help to keep the biscuit moist too. So this month, I salute the crusade of the baker, and raise a toast to all who support us.

Ingredients

- 2 overly ripe large organic bananas
- 3 cups of rolled organic oats
- 1 cup of finely ground organic almonds
- The insides of 1 organic Vanilla pod
- 50 mls of Coconut milk
- 1 tablespoon of Golden syrup, Agava Nectar or Organic Honey
- A generous pinch of smoked sea salt

Method

1. Start by pre heating the oven for 20 minutes, at gas mark 6 (or its equivalent).
2. While doing so peel and mash the bananas into a smooth paste.
3. Combine this with the sea salt, Agava nectar (or it's alternative).

4. Now pour all of the oats and almonds into the bowl and combine by stirring until all the ingredients have been evenly distributed.
 5. Refrigerate for a minimum of one hour until the consistence of the dough is quite firm.
 6. Divide and roughly form the mixture into small balls the size of a walnut shell.
 7. Having done so, pierce with the tips of your finger each ball so to stuff the mixture with a glacier cherry.
 8. Repeat until all of the mixture has been used. Now place each ball into its own mini paper case. One can choose to either bake the biscuits on a rectangular baking tray, straightaway or return the biscuits to the fridge for a few hours until they are needed.
- They will take no longer than 15 minutes to be transformed into rich golden morsels fit for any dunking or non-dunking biscuit queen or king.

Late Edition

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

A new hypothesis suggests that the on-going immune response of chronic fatigue syndrome (ME/CFS) may be the result of infection of the vagus nerve. **Source: Vagus Nerve Infection in Chronic Fatigue Syndrome – About.com – 10th July**

Megan Anne Arroll a psychologist from the Optimum Health Clinic has written a paper on how psychological factors might be the root of CFS/ME. She suggests that physiological mechanisms employed in the body to deal with stress may contribute to the perpetuation of CFS/ME. **Source: Allostatic overload in ME/CFS – ProHealth – 27th July**

A round-table discussion was recently organised by the Simmaron Research Institute involving patients and physicians. They covered new immune drugs as well as one doctor's attitude to treatments. Dr. Peterson of the Sierra Internal Medicine /Simmaron Research Institute found that the 'wait and see' approach so often prescribed by doctors with ME/CFS in hopes that the patient will just get better is a mistake. He's found that, in his group of patients, treating aggressively early is more effective. **Source: The Simmaron ME/CFS Physicians Roundtable Pt. II: Talking Treatments – ProHealth – 30th July**

New research has identified more sleep problems in people with CFS/ME and is recommending routine screening to see if they are the cause. In this research, sleep studies of 343 people with ME/CFS revealed that 104 had a primary sleep disorder that explained their symptoms, and thus didn't have ME/CFS at all. **Source: Are there sleep-specific phenotypes in patients with chronic fatigue syndrome? – Pubmed – 20th June**

Jennifer Brea is a doctoral student in the Department of Government at Harvard University on indefinite medical leave. She's aiming to make a film profiling people with CFS/ME and showing how their lives are led. Although she's interested in people from the US, anyone around the world can also take part. **Source: Harvard Student Begins New ME/CFS Documentary Project – ProHealth – 9th July**

The UK ME/CFS Biobank has been awarded a grant of £1m over three years by the US National Institutes of Health (NIH). A biobank is a large collection of biological samples including tissues such as blood, which provides a valuable database for scientific research. The UK ME/CFS Biobank was launched in 2011, is the only one in the UK and was the first in Europe aimed at the study of the illness. **Source: UK ME/CFS Biobank project awarded £1 million grant – London School of Hygiene and Tropical Medicine – 28th June**

Anyone can register for free email updates from Benefits & Work, just visit their website (www.benefitsandwork.co.uk) and click on the link to 'Free Stuff' on the left hand menu.

E.G.M Postal Ballot (Emergency General Meeting)

Caroline Higson was on the committee for many years, but stepped down a few years ago. She would now like to rejoin, after being unable to in time for March's AGM. Caroline has had various roles in group over the years. She currently runs the website, moderates the Facebook group, gets grants, writes pieces for the newsletter, attends meetings with the ME clinic and other relevant bodies and other bits and bobs (yes, she is very, very tired and spends the day trying to stay upright!) She was diagnosed with ME at 15 (now 27) also has Fibromyalgia and Ehlers Danlos Syndrome, a connective tissue disorder. Caroline actually met her husband Steve, who also has ME, at her first group social, back when the old "18-35 group" met at Middlebrook in 2002! They celebrated their 10th wedding anniversary in July and would never have met if it were not for the group!

If you cannot attend in person, please send in your vote via post by 17th September.

E.G.M Agenda 19TH September 2013:

1. Apologies.
2. Nominations for the committee.

If you are unable to attend but would still like to cast your vote for the committee members please tick next to the name on the list below and return to: Carole Senior, 182 Church Street, Westhoughton, Bolton, BL5 3SX by 17th September 2013. Please can you label the envelope with the words **Ballot Paper** on the left-hand side of the envelope and **also remember to put your name on the ballot paper!** Alternatively you can send an email to caroles4@virginmedia.com stating EGM Ballot in the heading and typing the name that you want to vote for. It is important that you are able to place your vote for electing new or re-electing committee members that have put their name forward to be on the committee, as the rule for running a support group state that we have to vote that we can show that are members are getting a say in who represents them.

Thank You.

✂.....

Postal Ballot.

Postal Ballot: Please tick next the name of the person you vote for to join the committee:

Caroline Higson []

Please send this to Carole Senior, 182 Church Street, Westhoughton, Bolton, BL5 3SX, or email caroles4@virginmedia.com, by 17th September with the words **Ballot Paper** on the left hand side of the envelope.