



Welcome to Our July 2015 Newsletter.

Note from the Editor Maxine: How has everyone managed with the heat wave? I love the heat makes me feel more alive, where I know some members find it is the other way for them and they find the heat hard. Anyone any tips to keep cool?



Monthly focus.

We are a Registered Charity. Thank you to Caroline for all her hard work. Our charity number is 1161356.

Don't forget we have a well stocked Library which is at Bolton Main Meetings at Wildlife Trust Centre, Bury Rd.

Dates For Your Diary:

Bolton Main Meetings at Wildlife Trust Centre, Bury Rd:

Our main meetings, often with guest speakers, are now held at The Wildlife Trust Centre, 499/511 Bury Rd, Bolton, BL2 6DH.

They occur on the third Thursday of each month from 7.30pm until 9pm (except in April, August and December). The building is past Morrisons/Home Bargains/Brightmet Health Centre on the right hand side as you go into town, very near the junction before you turn onto Crompton Way from Bury Rd.

Entrance is £1, carers are free. Tea, decaf coffee, water, biscuits, orange squash, etc provided. Gluten/dairy free also catered for. Any questions, please call Caroline on 01204 525955, or email caroline@mesupportgroup.co.uk.

Thursday July 17th 7.30pm: Bring and Share Supper. Our very popular supper has now been brought to Summer too. Please bring a dish to share with fellow members. Don't worry, as there is always plenty of gluten, wheat and dairy free dishes so you won't go hungry! It will be the first bring and share supper where you will be able to enjoy the lovely views of the Bradshaw Brook. At the May meeting we could see the baby ducklings and geese below the window, with blue tits flying in and out of the nesting in the boxes at window height.

No meeting in August 2015

Yoga Classes: Are 3:15pm-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. Please contact our instructor Lisa Heaps Mobile: 0770 803 66 36 Email: lisayogatori1@gmail.com. **Our yoga classes are currently being funded by The Big Lottery Fund.**

Prestwich Socials: Our Prestwich socials are now at **The Church Inn, 40 Church Lane, Prestwich, M25 1AJ.** This has level access and free parking outside. We meet on the **second Wednesday** of the month at 2pm, the next meeting is **Wednesday 12th August 2015** The attendance at Prestwich has been doing better lately, but do please try not to turn up too late in case numbers are low.

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.



DISCLAIMER: Anything expressed within this newsletter may not necessarily represent the views of the editor, the Trustees, nor the Bury & Bolton ME/CFS & Fibromyalgia Support Group (Registered Charity Number: 1161356). Any products, treatments, or therapies featured are for information only and their inclusion should not be considered an endorsement.

Welcome new yoga teacher Unfortunately, our lovely yoga tutor Julia has taught her last class with us on Tuesday 30th June.

She has found another replacement though, to take over the class. Her name is Lisa Heaps and she is fully qualified and is already known to the group as she has observed a couple of the sessions already. She has a special interest in Yoga for ME/CFS sufferers and will be a very good asset to the group. Sorry to see Julia go and hope Lisa gets a good welcome.

Indefinite DLA to PIP brought forward to July

The DWP has issued an updated timetable bringing forward the date when claimants with an 'indefinite' or 'lifetime' award of disability living allowance (DLA) will have to claim personal independence payment (PIP). Claimants will now start being assessed for PIP from 13 July 2015, instead of from October.

The decision is a deliberate snub to campaigners and to the courts after delays in processing PIP claims were found to be unlawful just last month.

Although the DWP argued at the time that they had greatly improved the speed with which claims were being dealt with, there are still many thousands of PIP claimants waiting for an assessment.

The first postcodes where DLA claimants with an indefinite award will start to be transferred are a random sample of 3,000 claimants from postcodes:

BB; BL; DE; LE; M; OL; PR; ST; WA and WN.

These postcodes cover parts of the following areas:

Blackburn, Bolton and Bury, Derby, Leicester, Manchester, Oldham, Preston, Stoke-on-Trent, Warrington, Wigan.

Atos carry out assessments in postcode areas:

BB; BL; M; OL; PR; WA and WN.

Capita carry out assessments in postcode areas:

DE; LE; ST.

Thanks to ATOS Miracles.

Fightback have some new telephone numbers

Fightback General Advice line no 01616727444

Advocacy help with forms/form filling booking 01616675258

Recipe Corner:

These are not only cheap to make, but the first base mix is gluten and dairy free too! Add any herbs and spices you fancy, but Cracking Good Food gave us a couple of the recipes that they frequently teach people to make.

They look relatively easy to make compared to other meals, but here are ways to reduce energy/pain further:

- **Get utensils and cutlery with easy grip handles to reduce wrist/hand pain. Oxo GoodGrips range are good.**
- Use a mini-chopper to chop herbs, etc, or a blender to chop up things like onions faster.
- **Use frozen spinach and other pre-chopped vegetables (though it does add water to the dish).**
- Buy pre-grated cheese.
- **Use pre chopped frozen garlic/chilli/herbs.**
- Use lime/lemon juice from a bottle instead of squeezing it by hand.
- **If you've used all your energy cooking, leave the pans/dishes to soak, and wash them up the next day. The world won't end if you leave them for a bit longer. Pat yourself on the back for making a tasty meal!**

Savoury Stuffed Pancakes

With thanks to CrackingGoodFood.org

250g gram flour--sieved
500ml cold water
1 crushed garlic clove
1 red chilli finely diced
Handful finely chopped coriander
Pinch sea salt

Sieve the flour into a bowl and slowly pour in the water, whisking at the same time. The batter should be thin and free from lumps.

Add all other ingredients and mix well.

Leave to rest for 15 mins.

To cook:

In a medium sized non-stick frying pan add 1 tsp veg oil.

Place over a medium to high heat for 30 seconds, add a small ladle of pancake batter and move around the pan until the base is covered.

When pancake begins to bubble and appears less 'wet', carefully flip over, heat other side until golden.

Continue until mixture is used up or you have enough pancakes!

Stuffing Suggestions:

Refried Beans n Cheese

1 can drained borlotti bean
Glug olive oil
1 tsp cumin powder
1 tsp paprika
1tsp chilli (flakes/powder)
Squeeze lime juice
Chopped coriander
Sea salt to taste
Cheese



Mash all ingredients together in a bowl.

Taste and adjust the flavours.

Nicely served with cheese in the pancake!

Note: You can also use "lactofree" if you are lactose intolerant, or vegan cheese (non-dairy cheese). The brand "Violife" is now available in lots of Tesco stores. Available in slices and blocks, it's highly recommended across the vegan and dairy free communities. Holland & Barrett's and independent health food stores sell this and a range of others.

Garlic Mushrooms with Spinach n Feta

2 handfuls mushrooms
2 cloves garlic crushed
glug of olive oil
1 tbsp chopped parsley
Squeeze lemon juice.



Spinach
Feta cheese

Pan fry mushrooms in oil with garlic until brown.
Add parsley & squeeze over lemon & season.
Lay spinach on the pancake, spoon over
mushrooms & crumble feta on top.
Season with black pepper and roll.

Money Saving Tips for the Kitchen:

- Ways to a Healthy Affordable Diet

With thanks to Cracking Good Food. They are a not for profit social enterprise. Visit them at www.crackinggoodfood.org or call 0845 652 2572.

Twitter: @CrackingFood. Facebook: www.facebook.com/crackinggoodfood

- Follow the seasons and eat local food that's in season, it's the cheapest way to buy good food and it ensures a wide variety of food throughout the year.
- Try and buy from a local shop if you can – they're actually much cheaper than the supermarkets for fruit and veg (especially the Asian food shops).
- Eat less meat & dairy – pulses, rice, pasta and a wide variety of vegetables are cheaper and healthier.
- Go to your local shops in the hour before they close and see what's been reduced – especially a greengrocers on a Saturday if they're going to be closed the next day.
- Buy reduced staples like bread and vegetables and freeze what you don't need right away. Chop up vegetables and bag them up before putting them in the freezer, then you've a ready supply of vegetables for stir fries, curries, stews & soups, better and cheaper than commercial frozen veg.
- Cut down on takeaways and make nicer and healthier versions of your favourite takeaway meals at home.
- Reduce the cost of cooking – did you know that if you bring potatoes, rice or pasta to the boil in a pan, it will then cook just as quickly if you turn the heat off and leave the lid on as it would if you kept the water boiling?
- Electricity is 3 times more expensive than gas so cook on gas if possible to save fuel costs.
- Make double quantities of a meal and store the extra in the fridge or freezer for another day. You'll save on cooking costs.
- Buy food staples that don't go off quickly, like rice and pasta, in bulk if you can afford to – it usually works out cheaper per meal.
- Cut down on your food waste – the average British household throws away about £50 worth of food every month!! That's money that most people can ill afford to lose. You can cut down on this & save money:
 - Plan your meals and buy only what you need

- Buy loose fruit and vegetables from the greengrocer rather than a big bag of them from the supermarket – that way you'll only buy what you need
- Freeze any extra that you buy on a special deal or because it's reduced
- Freeze leftover portions if you cook too much – so much cheaper, tastier and healthier than a processed ready meal for those days when you don't have the time or don't feel like cooking
- Take your dinner leftovers to work the next day for lunch – much cheaper and better for you than visiting the takeaway or bakery



Fundraising: Many thanks to **Sue Walker**, manager of the One Stop Shop on Minerva Rd. She raised £167 with a bake sale for us. She is the mum of our eager helper, Angela. Many thanks Sue, it's very much appreciated.

Many thanks to our members **Jeff & Chico** who raised £137 with their round the world adventure! Now over to **Chico**, Jeff's monkey pal.

"Hello everyone, I was quietly planning my next outing when Jeff said he had some work for me to do. It seems that we did not reach our target of £200 from my posts, we only have £137, so that's err umm, gosh wish I had fingers £67 more to find. Therefore, here is an update on my holiday and what I achieved, firstly I travelled to five countries, stayed in 10 cities or towns, travelled over 33 thousand miles by plane alone.

I had my photo taken at Ayres Rock, Tower of London, Sydney Harbour Bridge and Opera House, Brooklyn Bridge in New York as well as visiting the 9/11 Memorial in New York. Oh must not forget Jeff's favourite McDonalds in flashing lights on Broadway, but also the peace and quiet of the Grand Canyon, when we got away from all the people taking Selfies, at least I being a model was able to show how to pose for photos, in fact we met some nice people along the way as a result of this. Not sure how many photos there were of me in different locations, maybe will get Jeff to count them.

We visited many other places but please go and have a look at my Facebook page (search for Gulliver Chico Glasser on Facebook) or visit Jeff's Blog at <http://francisthefearless.blogspot.co.uk>, if you do not have the internet then for a reasonable contribution I am sure Jeff would post you the contents of the blog. Well think that's enough for now, at present we are planning a trip to Ireland in June and Scarborough in August, plus a trip to Blackpool again in September, so I will try to give you all some information on these trips, but sadly Jeff has not mentioned any abroad at present, so I hope the weather is warm this year. Don't forget it's still not too late to help with the running costs of the group and sponsor us and help reach our target!

Late edition - June 2015

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

To prepare for the NIH Pathways to Prevention Workshop in the US, Researchers identified 9 sets of clinical criteria which were used to diagnose CFS/ME. They found none of the methods were tested enough to identify patients with ME/CFS in cases where diagnostic uncertainty existed. They recommended more definitive studies in broader populations are needed to address these research gaps. - Diagnostic Methods for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: A Systematic Review for a National Institutes of Health Pathways to Prevention Workshop – Prohealth - June 20

Another study to support the NIH workshop, studied the effects of 35 different treatments used on CFS/ME patients. They found that trials of rintatolimod, counselling therapies, and graded exercise therapy suggest benefit for some patients meeting case definitions for CFS, whereas evidence for other treatments and harm caused is insufficient. More definitive studies comparing participants meeting different case definitions, including ME, and providing subgroup analysis are needed to fill research gaps. - Treatment of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: A Systematic Review for a National Institutes of Health Pathways to Prevention Workshop – Prohealth - June 17

A piece on singer Avril Lavigne showed how she struggled with a diagnosis once she became ill. Doctors thought it was CFS/ME at first, but after trying other avenues she was diagnosed with Lyme Disease. Avril recommends that your physician should be “Lyme literate”. - Brave Avril Lavigne breaks down as she opens up about Lyme Disease battle – Closer - June 29

Ex World and Olympic kayaking champion Anna Hemmings recently spoke to a business conference describing the highs and lows of her life. Winning gold medals was the culmination of an early ambition set after watching the 1984 Olympics. However, that all changed when she contracted CFS/ME. Anna said, “I couldn't do anything. I literally had no energy. However, the emotional symptoms were even worse. I imagine it was a bit like going through the worst recession ever and seeing everything you have worked so hard for just swept away. This was my livelihood at stake and it's something that people simply didn't understand.” She realised she had to reset herself and adopt some of the Olympic lessons to her recovery. “There is always one thing that you can control. You can choose your attitude, choose to stay positive and choose to stay focussed. The attitude is the difference that makes the difference.” Anna’s recovery was mainly down to Reverse Therapy and she subsequently recovered enough to win more titles. - BMF Conference: Making the boat go faster – Builders Merchants’ Journal - June 30

NOTE: Reverse Therapy is an educational process that teaches people to identify the triggers which prompt the body to create distress signals, which are symptoms such as fatigue and unexplained pain. As soon as a person understands the reasons for these alarm signals, their awareness is raised and they start to 'listen' to Body-mind. From that point on a subject will work towards eliminating the causes of bodily distress.

Mid-Sussex M.E. charity reMEMber has been honoured with the Queen’s Award for Voluntary Service. “We are thrilled to receive this award,” says the charity’s founder Janice Kent. “Our dedicated band of volunteers – all M.E. sufferers or carers – have worked tremendously to help others over the last sixteen years.” The charity gives information and advice, arranges consultations by expert doctors, holds social and fund-raising events, campaigns for better services, arranges talks by experts, supports research, provides self-management courses and produces a quarterly newsletter - all for the benefit of patients and carers in Sussex and beyond. Queen’s Award for M.E. charity reMEMber – Mid Sussex Times, online - June 22

Action for M.E. has been named as recipient of the Whitehouse Consultancy’s pro bono scheme for 2015-16. The scheme will mean they receive 12 months of free public affairs and political communications consultancy “We are delighted to be working with Action for M.E. and hope to transform the policy landscape for people with M.E. in the UK,” says Chris Whitehouse, chair of the Westminster-based public affairs and communications specialist. - Whitehouse working with Action for M.E. - Catholic Universe – June 19