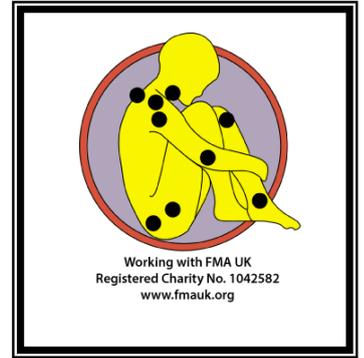




Welcome to Our September 2015 Newsletter.

Note from the Editor Maxine: Summer! What Summer? It's now turning into Autumn. The nights are drawing in and if you qualify please fill out a form with your energy supplier for your Warm Home discount.



Monthly focus.

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

For winter 2015 to 2016, you could get £140 off your electricity bill through the Warm Home Discount Scheme.

The money isn't paid to you - it's a one-off discount on your electricity bill, usually between September and March.

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 17th September 7:30pm. Marie Oxtoby will be talking about the established Bolton Neuro Voices hydrotherapy project. As we are subscribing members of the organisation, members of our group can sign up to these sessions. They are five-week course for new users and there are continuation programmes for previous participants. It takes place at the Jason Kenny Leisure Centre (Bolton One) with professional support from Susan Pattison Therapy Services.

**Thursday October 15th 7.30pm: Hannah Carrington Bolton CCG's
Engagement Officer**

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Thursday November 19th 7.30pm: Bring and Share Supper Our very popular pre-Xmas supper. Please bring a dish to share with fellow members. Don't worry, as there is always plenty of gluten, wheat and dairy free dishes and you won't go hungry!

No main meeting in December, but please join us at Prestwich!

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.**

PLEASE NOTE: There will be no yoga class on Tues 29th September due to teacher training. Apologies for the inconvenience.

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 14th October 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.

Help for your Yoga group

Our yoga teacher , Lisa Heaps ,has asked us if we can get some yoga balls, the size a bit smaller than footballs and quite soft. I have two in the garage, but too big. I thought others might have some put away gathering dust, so would ask to save us valuable pennies please?

She also requested blankets please? I gave all mine to the animal shelter, so I'm all out. If anyone has any, please could you bring to the meeting on Thursday, or to yoga? You could also drop off at my house, or if I am passing your way when out and about, I may be able to collect. Many thanks, Caroline.

REMINDER: RESEARCH...please can you get family & friends involved if you can.

ASSISTANCE NEEDED FOR NEW DIAGNOSTIC TECHNIQUE FOR CFS/ME

Wrightington, Wigan and Leigh NHS Foundation Trust/ Salford Royal NHS Foundation Trust. In conjunction with: University Of Central Lancashire

We are conducting a research study to help us test a new method of diagnosis regarding patients who have symptoms of Chronic Fatigue Syndrome/M.E. This new technique will involve a physical examination of the head, back and chest. The complete process will take about an hour and it will be conducted in Wrightington Hospital, Hall Lane, Appley Bridge, Wigan, Lancs, WN6 9EP

To participate in this research you must be:

- Between 18 – 60 (Inclusive)
- Been diagnosed with CFS/ME in Wrightington, Wigan and Leigh NHS Foundation Trust or Salford Royal NHS Foundation Trust

OR

- A Healthy individual with no immediate family member who has CFS/ME

All travel expenses will be reimbursed. For more information please contact us on the email or phone number below:

Email: abradley6@uclan.ac.uk

Tel: 01772 894549

Free Smoke Alarms:

Do you have a working smoke alarm? The extra seconds that one gives you should a fire occur in your home could make the difference between living and dying.

Call Greater Manchester Fire and Rescue Service on

0800 555 815. They're completely free and will be fitted by a local firefighter.

BACME launches first of its kind guide to practical management of CFS/ME

New guidelines to be used by all therapists and clinicians caring for patients with CFS/ME to improve effectiveness and quality of patient care and meet the need for unified, concise professional guidance

The British Association for CFS/ME (BACME) has published a pragmatic guide to the management of Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME). Developed through collaboration of experienced healthcare professionals, expert patients and patient organisations, the aim is for the guide to be used by therapists, GPs, hospital physicians and healthcare professionals, regardless of their training.

“Until now, there has been very little literature available in this area, so much existing guidance has relied on consensus and expert opinion,” says Alastair Miller, Chair of BACME.

“The new guidelines meet a considerable need for a practical, clinical, treatment summary for all healthcare professionals working with patients suffering from this complex condition to follow. By bringing together specialists from different services and backgrounds, our guide provides a concise consensus for broader treatment; complementing existing documents such as NICE guidelines to develop something wider-reaching and more practical in everyday work.”

Despite affecting 250,000 people in the UK, CFS/ME remains relatively unheard of amongst the general public. As the range and varying intensity of CFS/ME symptoms are so wide, it remains an illness subject to much debate. BACME hopes that the new guidelines will be used in routine clinical practice, and welcomes further review based on feedback and developments in the evidence base as they are put into practice.

Though the new guide focusses on the treatment of adults, BACME hopes to develop additional guidelines for children and those who are severely affected by CFS/ME; a progression welcomed by Mary-Jane Willows, Chief Executive of leading children’s charity, the Association of Young People with ME (AYME).

“All too often the experiences we hear from our young members and their families are those of being passed from one medical professional to another with very little understanding of what CFS/ME is and what it involves,” says Mary-Jane Willows.

“Sadly, the result is often the condition worsening before the patient receives the treatment they so desperately need, in some cases ruling out recovery completely. But CFS/ME is a treatable condition, and we welcome these guidelines from BACME to provide much-needed practical guidance to all professionals responsible for the care of those in need.”

The guide will be available to all BACME members and clinicians at the organisation’s training events, and is also freely available to view and download online, here: www.BACME.info/

New logo for online shop selling medicines

With thanks to FMA UK. From 1 July 2015, all online pharmacies or online shop selling medicines in the EU must display a new logo to show they are operating legally. This logo was introduced by the Falsified Medicines Directive (2011/62/EU) to protect patients from

falsified medicines – fake medicines designed to look like real, authorised medicines. Falsified medicines might contain ingredients which are of bad quality or in the wrong dose, or they might contain no active ingredients at all.

Any patient considering buying medicines online should look out for the logo on the website of the online pharmacy. The logo should be displayed on every page of the website. When clicking on the logo, you should be taken to the website of the national regulatory authority where the online pharmacy is based, which contains a list of all legally operating pharmacies and online sellers of medicines in that country.

Online sale of medicines in Europe

The sale of medicines online is legal in some EU countries, and not in others. This will still remain the case. The European Medicines Agency has set up a website with more information on the online sale of medicines, and there you will find a list with hyperlinks to all EU Member States' websites.

<http://www.eu-patient.eu>

New:
EU common logo



Recycling Old Spectacles

Do you have a small pile of glasses and cases in a drawer? VisionAid Overseas can recycle these. I took in 14 pairs! 12 of these were my Nanna's going back to the 80's and she'd decided to finally part ways! - Caroline

Vision Aid Overseas runs a nationwide spectacle collection scheme which operates to raise money for Vision Aid Overseas and ensure spectacles are recycled in an environmentally-friendly way. They do not take the cases though.

Optical practices all over the UK and Ireland can collect spectacles for Vision Aid Overseas and send them free of charge. I took mine to Boots Opticians (just dropped them in, wasn't going in for a test), as all Boots Opticians seem to participate in the scheme (but check first).

The Vision Aid Overseas website has details of their work, and you can search for details of participating national and independent opticians local to you.

As they will not take glasses cases, if you have some spare, you can do all sorts of useful things with them! We've put drill bits in one so they're easy to find in the tool box. They also make great sewing kit cases, for concealing person hygienic products, keeping small delicate items safe in your luggage, makeshift manicure set, kids jewellery case (you can decorate the case with things from the craft shops), saving used postal stamps to pass on to us, and storing pill packets and the like for a day out.

To reduce waste in the first place, if your case is still ok, keep using that and decline the new one you get with new glasses. <http://www.visionaidoverseas.org/recycle>
01293 535 016 (9am-5pm Monday to Friday)

Tips for CV's and Finding Work

I recently had to take my ESA50 form into the JobCentre (Blackhorse Street, Bolton) to be faxed over, instead of posting it in, as I was late completing it. I knew I was going to be over the time limit they gave, so I phoned to tell them and that's what I was advised to do.

The forms took a few minutes to scan in and were emailed over (not faxed like they told me, he said they never use a fax now!), and it was received in seconds. The phonenumber said I would be able to get a receipt, but the advisor said they don't give receipts, which I wanted in case it got lost. He wrote notes on my file that my form was sent, with medical evidence and additional notes. Quite painless (apart from having to get dressed, go into town, park, etc).

I also had a chat with him about other services they offer and advice about concerns members had in the past with looking for employment after/during illness. I've written some ideas based on what he said. These are my interpretations based on his information which may differ from that given by another JobCentre Plus employee.

- Some members have said to me "If I am well enough to work in the future, how do I explain the gap on my CV?"

You can't ignore it, they're going to ask, so you've got to put something! If you were comfortable with the term, you could put "Housewife/husband" or "Homemaker" and follow this up with the skills you learnt while you were ill, such as needlecraft, scrapbooking, doing crosswords, or even doing the washing up, etc. You could be straight to the point and put "Unable to work due to illness". If you fit the criteria, they will interview you.

- I became ill at a young age, or last worked quite a while ago, so my CV is old, and rather bare....what can I do about it now that I want to start looking for a job?

Have you done any college courses? Night courses for learning how to play guitar, do sugar crafting or flower arranging or learn to use a computer program? A First Aid or cookery course? That should all go on! Have you been a volunteer for a charity, organisation or group? Anything from running a stall, taking calls, knitting items for charity to skydiving fundraising (the last one is maybe not us lot)? They charities may also be also provide references for you.

Have you taken up any hobbies while you were ill? Did you teach yourself how to sew a dress or knit, or fix things? The advisor said even practical everyday things can go on the CV; if you learned how to wash up, do some DIY, use a computer, taught your mum how to use Facebook, identify birds, etc. It fills a gap and discussing your skills and hobbies might help you come out of your shell in an interview.

- Should I declare my illness on the application form? I'm worried it might go against me and it'll put them off.

The advisor said that people don't realise that many disabilities entitle you to an automatic interview. In some cases, where your employer is a large organisation, it may in fact go in your favour, as they need to hire a certain percentage of disabled people. The interviewers may even know people with ME/FM, or any other conditions you have, therefore can anticipate you needs and how it affects you. Small companies can hire who they like who fits the bill though.

If you have been ill and off sick, if you do have a job position, they should let you have a phased return back, so you can gradually build up hours. If you are struggling with it, you need to talk to your manager/HR/OT about it.

If you don't currently have a job, but feel well enough now to hold one down again, perhaps try volunteering for a few hours a week first to see how you manage. This means that you aren't under any contractual obligation if you find you can't do as much as you thought. If you receive any benefits, you will need to inform them that you are attempting to undertake the volunteer work, with approximate hours, what work is involved, etc. Explain any difficulties you will anticipate and any help from others you will receive. E.g. transport, needing to do activities seated most of the time, having frequent rests and visits to the toilet, etc.

For Employment Support Allowance, unpaid volunteer work is exempt, so should not affect your benefits. You can do paid permitted work on ESA (with conditions on hours and pay), however, they may argue that if you can do this work or volunteer work, you can find regular work, which is why you should write about your anticipated difficulties and any help you will have. I am in the support group and my volunteering was declared exempt and has not affected my benefits.

If you're struggling with updating your CV, or even deciding what career is right for you, the Job Centres have the National Careers Service visit to help you. They have a CV builder, skills checker, course search, action planner, job hunting tools and career advice on the website too. <https://nationalcareersservice.direct.gov.uk> 0800 100 900

Useful Contacts:

Shaw Trust (www.shaw-trust.org.uk), **Breakthrough UK** (www.breakthrough-uk.co.uk) and **Remploy** (www.remploy.co.uk) help disabled people find work and can offer advice and guidance, CV tips, etc. The first two can also represent you at meetings with your employer.

Access to Work offers a grant from the Government to pay for practical support in the workplace if you have a disability, or mental or physical health condition. **M.E and Fibromyalgia are disabilities.** It helps people stay in work, or start a business. The scheme can pay for adaptations, transport to/from work, a support worker, awareness training, a communicator, etc. Open to those in a job, self employed, in work trial or youth contract. Must be over 16. Funding has been greatly cut since the election though.

On the day the Conservatives were re-elected, Minister of State for Disabled People Mark Harper announced changes to the Access to Work Scheme. These come into effect from October 2015. If you already get funding, this will be unaffected until April 2018.

The changes mean it will now only provide awards up to a limit set at one and half times "average" salary (a limit of £40,800 per person per year at October 2015), to be updated annually in line with salaries. Those who have awards above this limit already, before this cap is introduced can keep their existing support until April 2018.

Other proposals are:

Developing a framework for translation services including British Sign Language. This is aimed at guaranteeing quality standards, from Summer 2015. They will work with deaf people and stakeholder groups (like charities) to undertake this.

In early in 2015/16, they will look to pilot contracted taxi services for employees across the larger towns and cities. Eligibility for eligibility for self-employed awards will be based on the Universal Credit rules, from October 2015.

Personal budgets (aka Direct Payments) to be offered to those with ongoing awards for travel or support needs.

According to Disability Rights UK, this will result in greater flexibility and less form-filling for the employee. As disabled people are more likely to be self-employed, more support in that area is helpful. However, having a cap on funding support could mean employees with disabilities are further overlooked. For every £1 spent on Access to Work, £1.48 will go back into the Exchequer's pocket in tax, national insurance or benefits savings.

Source: <http://www.disabilityrightsuk.org/>.

For advice on getting help to stay in, or get into work, speak with the **Disability Employment Adviser** at JobCentre Plus. They can help anyone in or out of work, whether they are on benefits or not. You may need to make an appointment to make sure the right person is in. They can't answer the phone when they are in an appointment with someone, so best to leave a message, or make an appointment to speak in person, if you're able to. Make sure you have your National Insurance number to hand, or know it.

Your **Union** may also be helpful in negotiations or a dispute about reasonable adjustments.

Look for vacancies which display the "two ticks" symbol on company websites, which means they have signed up to the "**Disability Confident**" campaign for inclusive recruitment practices.

Doing Careers Differently Booklet (Free download):
<https://crm.disabilityrightsuk.org/doing-careers-differently>

Doing Work Differently Booklet (Free download): <http://www.disabilityrightsuk.org/how-we-can-help/publications/doing-life-differently-series/doing-work-differently>
To order paper copies, phone Disability Rights on: 020 7250 8191

NHS Choices Advice: <http://www.nhs.uk/Livewell/Disability/Pages/Disabilityandwork.aspx>

Action 4 ME Helpline: Advice on welfare benefits, Disability Discrimination, employment and insurance issues. Free factsheets online.

Tel: 0845 122 8648

Monday 10am to 12.30pm and 2pm to 4pm

Tuesday 10am to 12.30pm and 2pm to 4pm (for pre-booked appointments)

Wednesday 2pm to 4pm

Thursday 10am to 12.30pm and 2pm to 4pm

The line is always closed on Fridays and Bank Holidays.

They are now offering bookable appointments on a Tuesday between 2pm and 4pm.

You can book a slot by calling the number above or the Information and Support Officer on 0117 927 9551 (Mon to Fri 9am to 5pm). You can also submit a brief question on:

<http://www.actionforme.org.uk/get-help/welfare-rights/welfare-rights.htm>

Factsheets: <http://www.actionforme.org.uk/get-informed/publications>

Benefitsandwork.co.uk have good guides on Reasonable Adjustments and Disability Discrimination. You can also apply for Personal Independent Payment whilst you are employed. Subscription of £20 p.a payable, but free to members of Bury and Bolton ME/CFS & FM Support Group with yearly membership (if posted out, postage costs apply but can be picked up at several locations).

Disabled Entrepreneurs www.disabledentrepreneurs.co.uk

Help is available for disabled people setting up their own business.

The New Enterprise Allowance and Access to Work (previously mentioned)

ACAS (Advisory, Conciliation and Arbitration Service):

<http://www.acas.org.uk>

They provide information, advice, training, conciliation and other services for employers and employees to help prevent or resolve workplace problems.

They have an online chat and text relay also.

Acas helpline: 0300 123 1100 (8am-8pm Monday to Friday and 9am-1pm Saturday).

Equality & Advisory Support Service: <http://www.equalityadvisoryservice.com/>

Expert information, advice and support on discrimination and human rights issues and the applicable law. Phone: 0808 800 0082. You can also live chat on the website or email in, text relay available.

Action on Disability Work UK (ADWUK) <http://www.adwuk.org/Individuals/Advice.aspx>

Experienced disabled advisors have provided support to disabled people and people with long term health conditions by giving guidance on effective job hunting; advice on the removal of barriers or difficulties faced, whilst at work or in training; information about approaching statutory bodies for support (for example, Access to Work); and information about how to approach employers when difficulties arise. Dedicated telephone line: 0844 445 7123, email: advice@adwuk.org By Skype: adwuk2013

Evenbreak Matching employers who value diversity with talented disabled candidates.

www.evenbreak.co.uk 0845 658 5717

Leonard Cheshire Disability:

www.lcdisability.org 020 3242 0200

Disabled Students Allowance: <http://www.yourdsa.com/> (also contains good advice about Access to Work and School Support).

Disability Rights UK have a disabled students helpline: 0800 328 5050.

You can get a Disabled Students Allowance grant to cover adaptations, etc.

*Please note the above is for information only, based on experience. We would encourage anyone to seek independent advice.

Late edition - August 2015

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

Researchers from Barcelona studied the different aspects of CFS/ME in men compared to women. They found a number of differences such as men being diagnosed earlier and more women having a family history of chronic pain. Women were also much more likely

to have additional illnesses to cope with, revealing 58% of the females in the sample also had Fibromyalgia compared to 28% of the males. Their conclusion showed that there are many measurable differences between the sexes, although different social and behavioural aspects may cloud the real picture. For that reason, it would be too early to definitely divide ME/CFS into male and female categories called phenotypes. - ME/CFS in Women and Men – Prohealth - August 28

A blog post by Joanna Charnas explores life with CFS/ME as well as facing normal aging issues, but specifically hair loss. At 55, she suffers from 15 dysfunctions or diseases, although the main one is CFS/ME. Joanna says, “As I contemplate my twin bald patches, I have to remind myself that this is life, neither all good nor all bad. Most things are a little of each. Life with chronic illness is like that: tandem success and failure all swirled together.” - “The swirl of life with chronic illness” – Huffington post - August 26

An orang-utan at Blackpool Zoo is trying to win the affections of Hollie Gordon, an amateur photographer who regularly visits the zoo to snap the animals. Hollie, who has M.E., is “flattered” by the ape’s lovesick mooning, despite having a boyfriend. She says she won’t stop seeing her “other man” because she is regularly bed-bound with fatigue and finds an escape in her photography. -Orangutan in love with girl with M.E.–Daily Express- Aug 27

Shannon Spurdens, 17, who has M.E., is in final rehearsals for a professional production of the ballet Coppélia. “I am extremely proud of Shannon,” says her mother, Donna. “As she was diagnosed with M.E. earlier this year this is a huge achievement and we will be very emotional watching her perform.” More than 200 of the best young dancers in the region auditioned. - Young dancer with M.E. twirls to success – Diss Express- August 21

Lizzie Horgan, 25, became ill with M.E. last October and started posting pictures on Instagram to document her struggle with the condition. This sparked an internationally-read blog, viewed thousands of times since its launch in July. Lizzie says the blog is designed for people like her: “Someone who wants to see some positivity and some honesty about what it is like and how it affects you.” Read Lizzie's blog at www.beyond110.co.uk - M.E. blog for people who want positivity – Hertfordshire Mercury - August 13

The University in Taipei surveyed 1,318 patients suffering from migraines. The 10.1% who also had fibromyalgia had higher headache frequency, headache-related disability, poor sleep quality, and were more depressed and anxious than those with migraine only. This group were at a higher risk of suicide than the main migraine group, something which healthcare professionals need to be acutely aware of. - Suicide Risk High in Migraine with Comorbid Fibromyalgia – Neurology Advisor - August 28

Medical marijuana has a strong record in reducing pain and aiding sleep, writes Cort Johnson. According to a survey in the US, fibromyalgia patients find it more effective in treating their illness than approved medications. Now one company is developing synthetic versions of two of the chemical compounds believed to produce marijuana's medical effects, and is expecting to begin a fibromyalgia trial next year. - Medical marijuana and fibromyalgia – Health Rising - August 13

Greg Crowhurst, who was a third-place finalist in the British Journal of Nursing’s Nurse of the Year Award 2015, describes the experience of being a carer for his wife with M.E. “Sadly I wasn’t able to attend the awards in person, owing to my duty of care to my wife,” he writes. “Those involved in the care of people with severe or very severe M.E. have to make these choices every single day. I was proud to make that choice.” - Greg’s duty of care to wife with M.E. - British Journal of Nursing - August 13