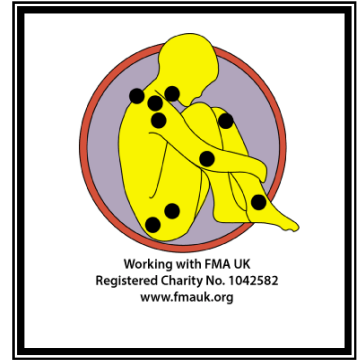




Welcome to Our June 2015 Newsletter.

Note from the Editor Maxine: When will summer arrive. I have read a good few of our members are having a bad time, I hope you improve. I'm slightly better than March and April. Please if possible fill out one of our standing orders to remain receiving our newsletter after the cut off point of the end of May.



Monthly focus.

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

Equipment to Borrow: 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. To trial the SmartCRUTCH's, call Caroline on 01204 525 955.

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 June 18th 7:30pm: James Hall from the Wildlife Trust will talk to us about their work. If weather permits we could go outside to the pond and paths (so dress accordingly). If the weather's not great, or for those who don't feel able to do so, we could perhaps observe the pond and nest boxes from inside, or perhaps view some slides: it really will depend on the weather. They also have a small selection of wildlife greetings cards, key-rings and birdhouses for sale.

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 and 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 a 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 Julia Silver-Wren 01204 394 768 or email juliasilverwren@talktalk.net for details. **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 8th July 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.

Reminders:

Volunteers: We are looking for volunteers who can help with all activities of running the group, if you have a particular skill (or just a pair of hands!) and you think you can help, please contact Caroline. **We are really struggling to keep the group going; we are all**

sufferers, so we need all the help we can get please. Please contact Caroline on caroline@mesupportgroup.co.uk or 01204 525 955 for more information.

Social Media: Please follow us on twitter on: @BBMECFS

Also our Facebook page just for members is www.facebook.com/groups/buryboltonmecfs/
And our new open page

<https://www.facebook.com/bbmecfsopen>

Don't forget our own web page <http://www.mesupportgroup.co.uk/>

Recommended GP's: Don't forget, we have a list of recommended GP's! If you have a sympathetic or helpful GP, please let us know, as people ask us for one in their area all the time. 01204 525 955, caroline@mesupportgroup.co.uk.

Newsletter Articles: Please carry on sending us anything you would like to share with the rest of the group; whether it is a whole page, or just a few lines, it all counts! It could be recipes, tips, experiences, book reviews, etc. Deadline for the newsletter is the last day of the month. Please send your contributions to: maxine@mesupportgroup.co.uk. Via email where possible please.

Benefit and Work guides: Remember, for anyone filling in benefit forms or if you have appeals/tribunals, we have excellent guides available via post or email (saves us funds). Phone Ruth on 0161 766 4559 or email ruth@mesupportgroup.co.uk.

Amazon: The group gets 5% commission when you shop at www.amazon.co.uk, but only if you follow the link from our own website www.mesupportgroup.co.uk.

Appeal to go paperless: A large portion of outgoings is photocopying costs – awareness leaflets, welcome packs, monthly newsletters and several lengthy BenefitsAndWork.co.uk guides. It would help cut printing and postage costs (as well as our volunteer's energy, electricity and time) if you would get the email versions if you are able to. Please contact caroline@mesupportgroup.co.uk / 01204 525 955 to switch to email newsletters. Thank you.

Bury and Bolton ME/CFS and FM May 2015 meeting

Jennifer Gilmour stepped in at short notice, for which we are very grateful. She gave us a brief talk about some of the craft-y activities going on in the area. Jennifer owns Stitch-me-lane Fabrics and Workshops in Harwood, and runs or helps out at various groups. She showed some of the items produced, such as 3-D models and quilting.

The new social enterprise she is part of, Brightmet Long Arm Quilting Studio will be part of this year's MakeFest at the Museum of Science and Industry. They will be working on a social media quilt project where they will teach how to do English Paper Piecing (hexagons) and having people write a positive secret message on the under-side of the paper which will be revealed when the quilt top is complete. When the quilt is complete, and the paper is removed, I will tweet the positive messages daily and do regular Facebook and



blog posts as the quilt progresses. People can join in the “virtual quilt-a-long” or visit the studios and work on the project. <http://breightmetquiltingstudio.blogspot.co.uk>

She also told us about some other local groups, including: Breightmet Women's groups, various days, times and locations: Breightmet Film Club, next on 4th June at Elderdale community centre: Men in Sheds, Thursdays 10am-1pm at the Wildlife Trust where we hold our meetings (there is also a new offshoot starting up in Kearsley). If anyone has any spare tools for the project, they would be greatly appreciated. It's a way for retired men to use their skills and reduce social isolation. They have made some wonderful things, like ladybug houses, hedgehog homes, benches for a school and lots more. There's also Knit and Natter, every Wednesday afternoon at HeartLift, Greenroyd Ave, Breightmet. Both beginner and experienced knitters welcome!



If you check in your local area you will probably find similar activities. A good way of finding out would be through your local library, school, church (you don't need to attend) or neighborhood team at the council, or if you're online through local Facebook pages. I have joined a local online (not Facebook) group called Streetlife, through which I've found loads of activities....now to find the energy to do some of them! I'm going to join a cross-stitching group, to do the beautiful kit that Lynda Marney gave me for my birthday

:) You don't need to live in the area, either, for many of these groups.

We then did some drawing exercises, starting with a 1 minute exercise, which is longer than you think, then a 5 minute exercise, then free drawing. Some of us were more successful than others (cough)...I was intimidated by sitting next to two people who were really good, one of whom revealed later that she had done A Level Art. However, the point was to have fun, and I think it helped our new members to chat easily to "old" members. Drawing is a good activity for relaxation, as you can do as little as you have energy for, and can go back to it later.....unless you're doing a still life of fruit. A lovely evening.
Maria Sale

GMPTE Travel Voucher Scheme

I have been using the travel voucher scheme for many years now, it's a good service that's saved me quite lot of money. The scheme renews every April, so we're reminding members about possible entitlement. Have you used the scheme? Tell Caroline what you think of it for a future article?

I can't get on the bus with my scooter, or walk far enough from any bus stop, so if I need to go to an appointment and can't get a lift, I will take a taxi.

Travel vouchers are for people who are not able to use ordinary buses, trains or Metrolink and who have serious walking difficulties or are registered blind. They can be used to pay for taxis and for travel on accessible bus services such as Ring and Ride and community transport.

You may qualify for travel vouchers if you are a resident in Greater Manchester and:

- you are registered blind with your local authority, or
- you are in receipt of DLA (Higher Rate Mobility Component) or PIP enhanced mobility component or
- you are in receipt of Higher Rate (formerly known as 24 hour) Attendance Allowance, or
- you are in receipt of the War Pensioners Mobility Supplement, or
- If you do not receive any of the above benefits, you may still be entitled to travel vouchers if you are not able to walk 400 metres (440 yards) or more, or climb steps of 300 millimetres (approximately 12 inches) or more, however, this must be certified by your doctor on your application form.

Where can I go using Travel Vouchers?

You can travel anywhere in Greater Manchester and the neighbouring counties using travel vouchers. However, you can only use travel vouchers with taxis, community transport schemes and accessible bus services, such as Ring and Ride, which are authorised. If you use transport that is not part of the scheme your vouchers will not be accepted. When you phone up to order a taxi, you must state that you will be using the vouchers and again once you get inside the taxi itself.

Hackney carriages (black cabs) also should take them, again be sure to ask before you get in, but as these cost more than the local firms, this will use up your yearly limit of vouchers quicker, so I would only use these if I had no alternative.

They will send you a list of all authorised taxis, community transport schemes, and accessible bus services in your area when they send your vouchers; if you would like lists for other areas of Greater Manchester, they will provide these on request.

How do Travel Vouchers work?

When you join the scheme you will be given a travel voucher ID card that shows your name, your photograph and a user number; you need the membership number to order vouchers and you must show this card when you pay for a trip using Travel Vouchers (however, in approximately 10 years of using the scheme, not once have I been asked to produce this ID card). Vouchers are not free but are substantially discounted. Travel Voucher Users can buy up to £120 worth of vouchers for £30, which is just one quarter of the full value, a very good saving.

Vouchers can be used instead of cash, which means that if your journey costs, say £6, then you will hand to the driver 6 x £1 vouchers, but remember, as you have only paid a third of their full value, the journey has only cost you £2 really.

Vouchers change colour every year and you will not be able to use them after the date printed on the voucher (31st March), so don't buy more than you need, as they won't refund or exchanged unused ones. Each voucher has a number on it and they keep a record of which vouchers you have bought in case they are lost or stolen.

The maximum amount of vouchers you can buy is £120 in a year. They will not carry over unused amounts onto the next year. You don't have to buy the full amount, so if you don't think you will take that many journeys, maybe only buy a couple of sheets worth, as you can always buy more later on, but they won't refund any ones you have not used

If you already have a Free Travel Pass or Concessionary Travel Permit, which provide free or cheap travel on buses, trains and Metrolink in Greater Manchester, you must hand it in when you join the Travel Voucher Scheme. You cannot have both a bus pass or permit

and Travel Vouchers; however, the travel voucher user card provides free or cheap travel on trains and Metrolink in the same way as your pass or permit.

If you do qualify for travel vouchers you are not obliged to have them. Some people who would be entitled to buy travel vouchers may choose not to do so, preferring to keep their free pass or concessionary permit.

They will send you booklets (on request) of local firms signed up to the scheme. This helpfully lists the ones that have vehicles that can take people sat in their wheelchairs or carry folded chairs. I do occasionally come across drivers who are extremely reluctant, or even refuse, to accept the vouchers, despite being the firm being in the booklet, and the booking operator saying vouchers are accepted. Some don't like to take them as GMPTE take a fee off when they exchange the vouchers for cash. Unfortunately, if they are signed up to the scheme, and I disclose how I am paying beforehand, there is not much they can do about it, especially as I usually carry very little cash on me, unless I know I will need it, so always pay with vouchers. They always get enough vouchers to cover the commission fee, and I also give a tip with change. I have tried to approach GMPTE about this issue previously, but did not receive a reply.

For an application form and further information please write to or phone:

Concessionary Travel,
Transport for Greater Manchester
2 Piccadilly Place
Manchester
M1 3BG
Phone: 0161 244 1050

In my experience, the GMPTE staff are fast and efficient at sending your vouchers out and you can pay by card over the phone, or cheque/card/PO via the post.

New Overnight Crisis Sanctuary for Bolton

Mental health charity Self Help Services launched a specialised overnight crisis centre in Bolton on Tuesday 3 February.

Following the overwhelming success of its existing all night service mental health crisis services, The Sanctuary Manchester, and The Sanctuary Wigan & Leigh, Self Help Services has been commissioned by NHS Bolton Clinical Commissioning group to bring the same provision to people in Bolton.

Operating all night, every night, The Sanctuary Bolton will be a place of safety and support, welcoming people experiencing anxiety, panic attacks, depression and / or suicidal thoughts outside of usual office hours, providing an important alternative to people who, in the past, have gone to Accident and Emergency services when experiencing a mental health crisis during the night.

Bolton residents, or those registered with a GP in the area, can access the service by calling The Sanctuary on 0300 303 0581.* Following a conversation with trained Sanctuary staff, people will then either be offered telephone support or they will be invited to come to The Sanctuary for one to one support.

Alongside this, the Sanctuary offers a calm room and staff ensure people are signposted to other services after their Sanctuary visit, including daytime services offered by Self Help Services.

Bolton Clinical Commissioning Group commissioned Self Help Services to run The Sanctuary from Bolton Young Persons Housing Scheme's (BYPHS) building, Trinity House in Bolton. The Sanctuary complements the work of BYPHS, who work to meet the needs of single young homeless people in Bolton.

Project Manager of Mental Health Care at North West Ambulance Service, Mark Parker, commented: "The Sanctuary projects provide essential help to patients living with primary mental health conditions in their time of need. Overnight crisis relief enables patients to get through the hours of darkness and is an invaluable asset".

"Innovative services such as The Sanctuary are crucial as they greatly relieve pressure on accident and emergency (A&E) departments and medical staff by preventing unnecessary hospital admissions."

"The North West Ambulance Service NHS Trust supports these projects by offering a direct referral for patients who present with the eligible criteria to improve the care and experience of patients with mental health needs".

Since its opening in 2013, The Sanctuary has given support to more than 650 people. A report by the University of Manchester revealed that 7% of people who had used The Sanctuary would have self harmed or attempted suicide if they had not had access to it. In addition, the report found that 43% of people would have gone to A&E, called an ambulance or the Police had it not been for The Sanctuary.

The Sanctuary Bolton contact number: 0300 303 0581

The Sanctuary Manchester contact number: 0161 637 0808.

Wigan & Leigh Wigan & Leigh contact number: 01942 410 522

*(Calls to 03 numbers cost no more than a national rate call to an 01 or 02 number and must count towards any inclusive minutes in the same way as 01 and 02 calls, according to Ofcom.)

For more information about The Sanctuary Bolton visit

www.selfhelpservices.org.uk/sanctuary or email sanctuarybolton@selfhelpservices.org.uk

Follow Self Help Services on Twitter: @selfhelpservice

"Like" The Sanctuary on Facebook: facebook.com/SanctuarySHS

Bolton and Bury Home Library Services

If you can't get out to your local library, Bolton library offer A Home Delivery service where library service staff or volunteers will deliver up to six books to match your chosen interests, every two weeks. You can request large print and audio books too. They can also delivery to residential homes.

Visit <http://www.bolton.gov.uk/website/pages/Homelibraryservice.aspx> or call 01204 332345 (it is centrally organised from Farnworth library). If you, or your friends or family would like to get involved in delivering the books, they can apply to be a volunteer.

Bury Home Library Service (Social Inclusion Unit). Works very similar to the Bolton one. The home delivery library service is available to people who find it difficult to visit a library whether this is due to age, infirmity, ill health or a caring commitment. The service provides a doorstep delivery of books, talking books, compact discs, videos or DVDs. Call them 0161 253 5973

Renewals

It's that time of year again. Please send in your renewals. We are not sending renewal requests to those who already pay via Standing Order. Most have already paid, or set up Standing Orders so thank you. To make sure you receive your monthly newsletter, and it doesn't go missing in Spam, please add "maxine_fairhurst@hotmail.com" to your contacts, or trusted senders list.

Health and Well Being days

Health and Well Being days are held twice a month at Time Out For U - Holistic and Well Being Centre, 2 St Edmund Street Bolton BL1 2JR on the second and last Saturday of the month. All treatments/readings are for 30 minutes each and cost just £10.

They offer: Reflexology, Indian Head Massage, Foot Massage, Face, neck and shoulder massage, Seated acupressure massage, Luxury facials - using natural organic products called Tropic, Angelic Usui Reiki, Reiki, Oriental face massage, Back massage & Angel card readings. Hopi ear candles - (small donation towards cost of candles as the candles cost £5 a pair),

We usually have 6 therapists at each event offering a range of the above treatments in a large communal room, but it is very discreet. If the treatment needs you to remove clothing, you are given a towel and can go into the toilets to change into the towel. The angel card readings are given in a private room.

Appointments do get booked up very quickly so it is essential to book. You can email or phone lynnmeadowcroft@googlemail.com, 07513770404, or email via the website www.timeoutforu.co.uk.

Save on Your Water Bills

Hippo: A small plastic square bag that fits in your toilet cistern. It retains some water in the bag, so that it isn't flushed, saving around 2-3 litres per flush. There are two versions of it, one for 13L tanks and 6-9L tanks. It lasts for many years and you just place it in the tank, no plumber needed. Mine cost £2.99 off eBay. <http://www.hippo-the-watersaver.co.uk/>

United Utilities Save-a-Flush: This saves about 1 litre of water every time you flush your loo. It won't fit in dual flush toilets, or toilets installed after 2000. Only available to United Utilities customers. You can also order other items here (for free), such as a shower-save, tap aerator kit, shower timer and tooth-brushing timer for kids. Also other water saving items available at reduced cost. <http://www.unitedutilities.com/SaveaFlush-orderform.aspx>

Consider Changing to a Meter

A fixed standing charge for our 3 bed bungalow with garden was £55 a month. We never wanted a meter, as we used to have lots of baths, and I was scared of being charged for a leak. Turns out that based on just two of us in the house, water was estimated at only £32 a month! Since we've had a meter put in last month, that estimate seems not far off, at about £35 a month. We don't use more in Summer for the garden, (we are not green fingered by any stretch of the imagination). After you change from a standing charge to a meter, if it turns out to be the same, or more expensive, you have 24 months to switch back to a standing charge. So it's a good idea to try it and see if you may save money, even more so if you qualify for WaterSure (below). Our meter was fitted within a week, and that was as special order job too, as we have so much plumbed in under our sink.

WaterSure

The WaterSure scheme is available for certain customers with a water meter. It allows them to have their bills capped. This is to make sure that these customers don't cut back on how much water they use because they are worried about how they will pay their bill.

To qualify for help under the WaterSure scheme, you or someone living with you, needs be entitled to receive one of the following:

- Universal Credit
- Housing benefit
- Income Support
- income-based Jobseeker's Allowance
- Working Tax Credit
- Child Tax Credit (except families in receipt of the family element only)
- Pension Credit
- Income-related Employment and Support Allowance

In addition, you need to either:

- be responsible for three or more children under the age of 19 and in full-time education living in the property, **or**
- have (or someone living in the property must have) a medical condition which requires significant additional use of water. Examples of medical conditions include weeping skin diseases (such as psoriasis), Crohn's disease or ulcerative colitis. (Note: this is not an exhaustive list, conditions such as Irritable Bowel Syndrome, diverticulitis, etc may qualify).

If you qualify for WaterSure, you will pay no more than the average household bill for your company, even if you use more than the average amount of water. You will not qualify for WaterSure if you use a garden sprinkler system or have a swimming pool. If you think you are eligible for WaterSure, you will need to apply through your water company.

Reduced Price Reiki

One of our members/carers has kindly offered reduced price reiki treatment for any group members and their carers. I too am a carer and I know first hand how this illness affects you. Dominic (my son) has suffered from M.E. for the last five years. I am a widow and have very little family support. My friends don't totally understand, as you well know you can look well but feel awful!!! I am so aware how time out for yourself is so important and the therapies I offer can greatly help with anxiety and stress.

I would like to offer Reiki treatments at a discounted price of £10.00 normally £30.00. All of my other treatments half price with the exception of hopi Candle at £15.00.

These treatments are available to people with M.E and their carers. My website details www.petrabarlowholistictherapies.co.uk. I am on facebook also. Contact details (probably best to ring my mobile) 07515 688 528.

*Group note: As always, we are not advocating this as a treatment, just passing on a kind offer from a member. Please seek advice from a medical professional before undergoing any new treatment, diet, etc.

Late edition - May 2015

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

An Australian pilot study on 115 CFS/ME patients has shown links with the Transient Receptor Potential (TRP) super-family. The TRPs, and their channels, are widely found on our cells and in tissues, and have significant roles in most physiological functions.

Professor Pete Smith said that important signalling mechanisms are disrupted as a result of these genetic changes involving the detection and response to threats. "These are primitive genes that are involved in many cellular signals in the brain, gut, cardiovascular and immune systems, as well as in the mediation of pain." Their results will help understand the causes of CFS/ME. - Examination of Single Nucleotide Polymorphisms (SNPs) in Transient Receptor Potential (TRP) Ion Channels in Chronic Fatigue Syndrome Patients – Libertas Academica - May 10

Professor Leonard Jason, and colleagues, have described the difficulties in defining CFS/ME. They also cover definitions which could separate CFS from ME. They say, "In order to progress the search for biological markers and effective treatments, essential features of the disease need to be operationalized and broadly used. This would increase the probability that individuals included in (research) samples have the same underlying illness." - Defining Essential Features of Myalgic Encephalomyelitis and Chronic Fatigue Syndrome – ProHealth - May 18

May 12th was ME Awareness week, and amongst many events and articles was a piece featuring Helen Wood who's had the disease for 10 years. Helen said that many people do not understand the complex symptoms ME can bring, and sufferers are often accused of being lazy. She said: "I have a blue badge and I still get funny looks from people when we are parked in the disabled spaces. I wish people wouldn't judge without knowing the full facts first. Just because I don't look ill doesn't mean I'm not, I still wish I was like everyone else of my own age. ME is a hard illness to live with." - Don't judge without knowing the facts - Bristol ME campaigner speaks out – Bristol Post - May 17

This article features the top 10 lies doctors tell their patients. You may recognise number 1 as it's about claiming the patient's disease is psychological when in fact it's biological. Others on the list include saying, "Any healthcare professional who is not an M.D. (in the UK a GP) is a quack", "the more tests we do the safer you are" and "Don't worry. I've been practicing medicine for 25 years." Sometimes doctors deviate from the truth when presented with symptoms that don't fit what's in the text-book. Other times, they do so out of convenience. Jacob Teitelbaum, M.D. said, "Many times doctors can't see the big picture, your total health, and only look at the symptoms they are familiar with". – Top 10 Lies Doctors Tell Their Patients - May 27

Former world triathlon champion Non Stanford took part in the Vitality World Triathlon London in Hyde Park on Sunday May 31st. She has had many injuries and illnesses, including a form of Chronic Fatigue Syndrome that blighted her preparations for the 2012 Olympics. Stanford's aim is to make it round the course in one piece, as she's preparing to qualify for the 2016 Olympics.-Triathlete's Olympics bid following CFS- The Times- May 12

Writer Stuart Allison from Lydbrook had M.E. for 10 years and was housebound at times. He is now writing a book about his experience to raise awareness and help others living with the condition. Called, *M.E. and me. Chronic Fatigue: My Recovery After 10 Years* it's both a memoir and a guide for patients and their carers. "My intention is to educate those who don't understand the condition, help carers, and give sufferers some hope," says Stuart. - Writer aims to educate people about M.E. - Forest of Dean and Wye Valley Review - May 20