



Welcome to Our February 2016 Newsletter.

Note from the Editor Maxine: AGM advanced warning date 17th March 2016, Caroline is collecting raffle prizes. Please complete the tear off slip or email to vote for your trustees and the resolution.



Monthly focus.

Membership renewal will be due in April, have you thought about setting up a standing order? Or do you prefer to internet banking to pay your membership? Are you a cheque sender? The group would prefer the first two as it saves the group energy and time having to go to the bank to cash the cheques. It also saves you the hassle of posting them, and means you won't ever forget to renew your membership! Contact Caroline, or visit the website for the form.

Volunteers: We are looking for volunteers who can help with all activities of running the group, if you think you can contribute, or are up for a certain task, please contact Caroline. **We are really struggling to keep the group going;** we are just a small number of 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.

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 February 18th 7:30pm. Maria talking about Devo Manc. Our very own meetings secretary will be talking to us about the DevoManc proposals, as she has been to many, (many, many) meetings on our behalf about it. These are plans to devolve responsibility for health and social care to statutory organisations in Greater Manchester.

Thursday March 17th 7:30pm. Our Annual General Meeting and raffle. Please consider us for any unwanted or duplicate gifts that we can use as raffle prizes.

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. Mobile: 0770 803 66 36 Email: lisayogatori1@gmail.com. **Our yoga classes are currently being funded by The Big Lottery Fund.**

Prestwich Socials: *****PLEASE NOTE CHANGE OF VENUE. *****Due to parking problems at The Church Inn, from January our Prestwich social will move to **The Woodthorpe, Bury Old Road, Prestwich, M25 0EG**. This is a very roomy pub, with ramp access, a disabled toilet, a variety of comfortable seating and free parking outside. It also serves a range of full meals and snacks if anyone is hungry. We meet on the **second Wednesday** of the month at 2pm, so the next meeting is **Wednesday 9th March 2016**.

Please try not to turn up too late, because if numbers are low and those attending are not feeling very well on the day, it would be a shame if you missed us.

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.

January Meeting

Luckily our January meeting night wasn't accompanied by howling gales or torrential rain, though it was a bit cold. It was my 30th birthday on January 1st (I wrote about my visit to Bleakholt in the last newsletter), and very kindly everyone had got together to throw me a surprise do at our meeting! I was very touched by the effort and thought that was put in to it all. I wasn't feeling very well at all on the night, but perked up a lot when I got there. There were banners, lots of (purple) balloons, vegan cake, a card and gift. I very kindly let a couple of people have a few small crumbs of the cake before I hid it away, it was my breakfast, lunch and tea for the next three days.

Thankfully for our public liability insurance, no peer reviewed research has proven a link between blowing up an entire pack of balloons and the development of emphysema, in either humans or Welsh Springer Spaniels.

It was very nice chatting between friends and much fun was had trying to wrangle all the balloons into the car afterwards. I forgot to take pictures of the cake, but here's a picture of Jade modelling the balloons. They are still up, bar a few casualties, a over a week later.



Many thanks to all those involved, it was so very appreciated. Caroline

*Update: We popped the balloons two weeks later and much fun was had with the helium one.

Community Care Assessment Successes

A member posted on Facebook a couple of weeks ago that they had finally asked for a Community Care Assessment off the council as their health had deteriorated, but were worried about what to expect. She asked for people's experiences, worried about what might happen. Members replied with suggestions and their experiences. After the assessment, the member posted this positive update. We are so pleased she is getting help.

"Hi everyone thought I would let you all know how I got on with my community care assessment. I want to thank everyone for their help and support from my last message it really helped. My social worker came on Monday and went through things with me. He was lovely and listened to everything. He is getting me moved from this house as it is not suitable for my needs yipppeeeee, he is getting independent living team out to me for any adaptations I need for new house and things to help now. Looking into me having a personal assistant to help with daily things and lots of thing I forgot. Good job mum was here lol. Anybody not had one of these and needs help please get one I was really concerned but I need not have worried they are there to help not to judge you and I feel so much better knowing things are going to move forward and get me out of this house I have been stuck in for weeks. I will keep you all informed as things go forward. Thanks again. A"

We post this with her permission, in the hope it encourages more of you to ask for these assessments from your council. We have had several members recently get in touch to say they have been successful, and it can make a real difference.

Caroline's Experience of Hiring a Support Worker

After many years of trying to get an assessment off social services, I was finally awarded some help. A friend was with us during it which helped a lot. I wanted to get a regular person in that I could hire myself, rather than rely on an agency. For your support worker, you can hire anyone, as long as they do not live in the same house as you. So it can be a friend, family member, neighbour, etc.

Before your assessment, make a list of all the things you need help with and the things you want to do. Someone to drive you to relatives house so you can visit them? Go to

hydrotherapy sessions? Get them to change the bed, walk the dog, prepare your clothes, sort out pills, etc. Layout your medical equipment for you, run a bath? They'll ask what help you need from morning through the night. You can hire someone in your family who is not living with you to help, they can advertise for you, or you can also ask around for possible candidates. Friends, their friends, or ask if you can put notices in your local GP surgery, pharmacy, church or community centre.

Make sure the social worker sees you as you are. If your house is a tip because you've been too tired to clean, keep it that way and tell them why it's that way. If it's a pyjama day, stay in them. Don't exert yourself to look the business if you really can't, as they tend to judge on looks I'm afraid and you'll pride yourself out of help. If possible, have someone with you to help you remember things, who is assertive and can vouch for your condition.

If you are awarded help, you can use it for whatever you want, but use the time wisely, it disappears quickly. Don't use up 3 hours of your 5 hours ironing when that would be much better spent shopping, hoovering and changing the bed. Remember, you are an employer and they the employee. Tell them how you want things done, and if something they are doing (probably unintentionally) is stressing you out, tell them, they can't read your mind. You need to be comfortable in your own home. They are there to help, not stress you out.

Hiring a support worker: The council call them "Personal Assistants", but they can also be called Support Worker if you choose. They put an add in a P.A agency to say what you are looking for. The Human Resource element of this has now been privatised by Bolton Council, so hiring, disputes, enquires, etc now go to a company called Salvere, not the Direct Payments team.

I contacted a candidate to arrange an interview at my house. You are provided with handy questions to ask, or you could also find helpful tips searching online. Someone from the HR company can be there with you at the interview. I offered her the job and we had to sign some Inland Revenue forms to arrange for her to be paid.

Payment: The council added on an extra amount to my Personal Budget to pay a payroll company to sort out tax, National Insurance, etc, because I would not stand a chance at that. I had to set up an empty bank account which is solely to be used for my Council's Personal Budget money and no other money is to be paid in/out. You could also use an existing account that is empty. You get audited annually, just requiring a statement to be sent in.

Employers Liability cover was arranged for me. I just had to pay for it out of the money they gave me. I would recommend going for medium/high cover that includes legal advice.

I get so many hours per week and I have to call them in every 4 weeks on a Friday to the payroll company, including any sick days and holidays. They send you a calendar with the days you should call so you don't forget. They generate a payslip which is posted to you, so you know how much to pay. The Council top up your bank account every month so you can pay your worker. You get extra money in your budget for holiday and sick cover to enable you to pay your worker and pay someone else to cover them. You can have more than one worker. The pay rate is set by the Council. At first I was very confused by the payroll process and had to call them and the Direct Payments team a few times to ask questions and to check I was doing it right!

To keep track of our hours, I have a little log book. We write down the date, and hours done on that day, and tally them up as we go along. Sometimes we go over, in which case we will carry them over to the next month, though you might work out a different system with your helper if you both agree to it.

I would strongly recommend anyone who has a disability or long term condition get a community care assessment off the Council, as is your right. It's made life easier. The concept of Direct Payments and hiring a support worker and all the paperwork and responsibility sounds very complicated, but it's not too bad once you get the hang of it. You can also use a broker to deal with all the employment and payroll, or use an agency instead.

Our Yoga teacher – A short interview with Lisa

How is the class progressing?

I feel That the group has really knitted together, in that the atmosphere is easy and comfortable, and in that the class provides a little safe haven where people can just relax, do a gentle yoga practice, and just be themselves. The atmosphere is friendly and accepting, and has a 'good feeling' about it, the energy from which I also benefit as a teacher.

How has yoga benefitted the students?

Yoga is not just about physical practice. It's about how we feel mentally and emotionally. So we practice relaxation to come down to the ground and become more stable. Tuning into our breathing also helps and students can also use these techniques outside the class if they experience stress or anxiety.

Yoga helps people to build these different techniques. As everyone has different limits though, they take it at their own pace and accept who they are. So it's important not struggle against yourself and not treat it as a competition. Otherwise a person can create tension instead of the objective of releasing tension. It's important let go to and allow yourself to relax.

In the class, we work slowly at a low level and it's about using movements to create an energy flow. Relaxing and helps improve that energy flow, with postures adjusted to all levels. There must be no struggle and ideally students should feel good when they leave the class.

The class is free to members. How does that help?

If people had to pay, it might not attract the number for a weekly class to fund itself. Yes there are regulars, but the class is always there for people who may need to take a break because of a relapse. It also helps people who might not be able to afford a regular yoga class.

For more details about the free weekly Yoga class each Tuesday see the website, or contact Lisa on 0770 803 66 36 or e-mail: lisayogatori1@gmail.com

Proposed increase in membership fees by £2 per year:

At the AGM, we will hold a vote on increasing our annual membership fee by £2, to £10. This will be implemented from next year, as our renewal month is April, giving people notice, and chance to alter any direct debits, etc if needed.

Quite a few members kindly send £10 as the membership donation anyway, and it has been £8 for a number of years now. Many groups charge more than this, and we think there's a lot on offer, such as our monthly newsletter, benefit information guides, free weekly yoga, a book library, equipment to borrow, socials, meetings and Facebook pages. Our trustees go above and beyond to keep the group running and give the best support possible, as do our small group of faithful volunteers. Please vote in person at the AGM, or return the voting slip.

£10 a year is less than 85p a month!

Late edition - January 2016

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

The BBC asked 3 CFS/ME sufferers to explain what people should not say to someone with the illness. They recommended people should not say, "We all get tired", or "It's laziness". Other examples they included were, "Why don't you just take a nap" and "Can't you just get on with it?" The article then goes onto explaining how they actually feel, with Charlotte saying it's, "like a bone-crushing tiredness. Like somebody sitting on you, or you're walking through treacle. Before I was diagnosed I was sleeping for 18 hours a day, I was finding it really difficult to walk. I got loads of headaches and I collapsed a couple of times." – What not to say to someone with chronic fatigue syndrome - or ME – BBC – January 26 2016

You'd imagine that walking and thinking at the same time was easy for a CFS/ME patient. Not so, say a group of researchers who looked at the issue amongst 72 sufferers. They found that compared to a "healthy" group more with CFS/ME opened their eyes when asked to walk with them closed, and more had to look down at their feet before setting off. Finally, over 10 times more CFS/ME patients had to stop walking when they had to do a simple maths problem. The researchers, wrote, "The present observations might explain in part why patients with CFS often report difficulties when walking for a prolonged time and are unable to reach the recommended 10,000 steps per day. " Walking and Thinking - Not a Good Combo in Chronic Fatigue Syndrome (ME/CFS) Walking and Thinking - Not a Good Combo in Chronic Fatigue Syndrome (ME/CFS) – Prohealth – January 30 2016

Recently researchers looked into the mitochondrial genes to see if there were links to people who had CFS/ME. They found that some (ancestrally related) groups of people are more likely to exhibit certain neurological, inflammatory, and/or gastrointestinal symptoms. However, they observed there was no increase in susceptibility to ME/CFS of individuals carrying particular mitochondrial genomes or SNPs (i.e. a variation in the DNA sequence). – Mitochondrial DNA variants correlate with symptoms in myalgic encephalomyelitis/chronic fatigue syndrome – Prohealth – January 27 2016

Innovative Med Concepts announced that the U.S. Food and Drug Administration (FDA) granted Fast Track Designation to the development of IMC-1 for the treatment of fibromyalgia. A previous trial showed that IMC-1 appears to have promise treating the pain and other symptoms of fibromyalgia. William Pridgen, M.D., Founder and CEO of Innovative Med Concepts, said, "We are pleased that the FDA has granted Fast Track status to IMC-1, as it demonstrates their recognition of this condition as a significant unmet medical need. IMC-1 has a novel mechanism of action designed to suppress chronic tissue-resident herpes virus, which may have a role in triggering or maintaining symptoms of fibromyalgia." – Innovative Med Concepts Announces Receipt of FDA Fast Track Designation for IMC-1, a Novel Treatment for Fibromyalgia – PR Newswire – January 28 2016

ME is much more common among teens than previously thought, affecting one in 50, a study has revealed. It is also more prevalent in poorer families, despite the condition's middle-class associations, experts say. Chronic Fatigue Syndrome, also known as ME, causes young sufferers to miss more than half a day of school per week. Girls were almost twice as likely as boys to have it and it was most common between the ages of 13 and 16, said Bristol University scientists. Dr Esther Crawley, senior report author and consultant paediatrician specialising in CFS/ME, said treatment for teenagers with the condition was

effective but few had access to treatment in the UK. "Children attending my specialist service only attend two days a week of school on average. This means that only the most severe cases are getting help. "As paediatricians, we need to get better at identifying CFS/ME, particularly in those children from disadvantaged backgrounds who may be less able to access specialist care." – New research reveals that ME hits one in 50 teenagers – The Sun – January 25 2016

Sonya Chowdhury, CEO of Action for ME, was one of 37 influential leaders who wrote an open letter to Iain Duncan-Smith about the proposed cut to Employment Support Allowance:

Dear Secretary of State for Work and Pensions

We believe the Government's proposed cut to Employment and Support Allowance (ESA) will undermine its commitment to halve the disability employment gap, and push sick and disabled people further away from work and closer to poverty.

The Government committed to protecting disability benefits, but instead is pushing through a cut of £30 a week to new claimants in the Work Related Activity Group of ESA. These are sick and disabled people who have been found currently unable to work. The Government says this £30 disincentivises sick and disabled people from finding work, but it has so far offered no evidence for this claim. In fact, a recent independent Review showed the opposite is true: that this cut will make it harder for disabled people to find work.

Almost 70% of sick and disabled people we surveyed say this cut to ESA would cause their health to suffer and just under half said they would not be able to return to work so quickly. We call on the Government to listen to the damaging effect this will have on the lives of sick and disabled people and immediately halt this cut.

– Open letter to Iain Duncan-Smith – Rochdale Online – January 26 2016

Meet Your Committee/Trustees.

As our AGM is coming up, we thought we'd include a bit about the people we are asking you to vote for, and their volunteer roles. We all have ME/CFS and some of us Fibromyalgia also, and other co-existing conditions. The work we do for the group is unpaid and is at great cost to us, physically and mentally.

Now we are a registered charity, the committee are trustees. We may get to do an article on our handful of helpers in a future issue.

Caroline (Group Leader): I'm 30 (only just!) and have been a member of the group since 2002 when I was diagnosed and a friend invited me to the meetings. At the first "18-25 Social" I attended at Starbucks in Middlebrook, I met my now husband of almost 13 years. Steve also has ME/CFS.

I started volunteering for the group by growing the website and being membership secretary. Over the years, I have performed varied roles in the group at some point, including newsletter production, fundraising, manning the Facebook groups, being group contact, etc, with a two year break when I attempted to do a degree, but was ultimately too ill. I'm vegan, obsessed with cats and purple, and continue to amaze the medical profession with my unusually large collection of conditions and broken body. I can't pace and hate to have unfinished things to do, but I am a fan of lying down in our Super King bed which can accommodate us and several cats. I can't use the computer every day, so please allow time for reply, or contact via phone/ Facebook for a quicker response. I have a scooter and the SmartCrutches at my house, along with a room full of things like literature, etc that I hope people find useful.

Maria (Meetings Secretary): I joined the support group in around 2002, and found myself on the committee fairly soon, and have been here ever since. I try to find speakers for the monthly meetings (any suggestions gratefully accepted!), which too often involves following up unanswered emails and phone calls, and apologising to members when a speaker cancels at short notice: again, too often.

I attend various things on behalf of the group, including the Bolton Equality Target Action Group and Health and Wellbeing forum, meetings with CCGs (and Primary Care Trusts before them), the clinic staff, and a few others I can't remember. Recently, I've been working on two initiatives for the devolution of health and social care in Greater Manchester (DevoManc). I have also worked with Bolton Neuro Voices to help our members take part in their hydrotherapy project I have had ME since 1991 and fibromyalgia since the end of the 90s.

Lynda (Treasurer): Prefers numbers to words, single has an adult daughter who lives in London and a cat called Scamp and is currently looking after a Yorkie. Likes reading, music, baking, walking, cycling and badminton but can't do a lot of it. Works part time, gets very cross about the neglect of ME/CFS sufferers and frustrated because of lack of interest shown by medical profession et al. Copes by pacing, ignoring people and being stubborn has found mindfulness and my on version of Graded Exercise with Pacing useful but not had any real change in last ten years. Brain Fog and fatigue probably worst symptoms.

Carole (Librarian): I'm Carole Senior and I've been a member of the group for about 10 years, joining soon after I was diagnosed. I'd been struggling with various mystery symptoms for some time [refusing to accept a diagnosis of depression] but finally reached the point where I could no longer function. Slow to recognise this, I carried on working - I was a special needs teacher - and pushing myself to 'cope' until my life imploded and I was forced to stop. I was eventually granted early retirement on medical grounds and life is now very different but better in many ways. I'm still hopeless at pacing though!

I am currently on a [very] long term project to declutter and live in chaos [for those old enough to remember Steptoe & Son, that's my house!] with an oversize feline delinquent named Barney - aka The Ginja Ninja - whose hobbies include shredding sofas and hiding small, important items. Need a pen? Mobile missing? Just look under the sofas or fridge!

I run the library for the group and take the minutes at committee meetings. The library contents are at home with me for the moment - I'm working on a stock review - but I'm happy to bring to meetings anything members ask for. Contact me by phone or email with requests or suggestions for additions.

Jeff: My name is Jeff Glasser I have had ME since the early 1990s, at the time it totally affected my life, over time though I have found a range of ways to help me cope with it.

I have been a member of the group for nearly the same time and have seen a whole range of changes with it. I personally was never actively involved in the group other than attending meetings, as I felt with my part time work and other interests in life there was little room for anything else without it affecting my health. About 2 years ago there seemed to be a shortage of committee members and some of my other activities ceased, so doing more to support the group was a good idea. I do not have a particular role but am happy to assist with any task or attend meetings as and when possible.

Regarding my background I worked as a hospital social worker for 17 years, assisting patients with a whole range of issues particularly those newly diagnosed with various ongoing health issues and assisting them to return to the community and have some quality of life. During this period I became interested in welfare rights and benefits issues, as for many the reduction in income after hospital admission or with a newly diagnosed

condition affected the level of income and quality of life. I have continued with this interest but find it much harder these days to keep up with the ever changing rules and regulations. I have also until recently been involved with Bury shopmobility as a volunteer assisting with practical tasks there as well as helping people learn of what resources were available to them.

From 2000 to 2009 I worked for a charity in Manchester, doing telephone advice work on the wide ranging subject of social and welfare issues and became quite knowledgeable on the subject of Community Care and provision of services to people from both the local authority and the NHS, an offshoot of this was explain people who were unhappy with services provided by these services, on how to make a formal complaint and achieve a positive outcome.

Bolton & Bury ME/CFS & FM Group AGM Minutes - 19th March 2015

Present Angela Henry, Andrew Simpson, Andrew & Kieran Gillibrand, Margaret Barlow, Louise & Sophie Day, Pamela Turner, Jeff Glasser, Karen Scully, Mandy & Dave Gore, Lynda Marney, C Higson, J Coupe, Maria Sale, Julia and Emma Chatwood, Carole Senior, Sue Courtney

Apologies

Carol Hobson, Angela Cassidy, Andrew Levy and Ruth, Norman & Rachel Fryman.

1. Minutes of last AGM held on 20th March 2014 - Pamela Turner proposed that these be accepted as correct and Mandy Gore seconded the proposal. Members voted unanimously to accept.
2. Matters Arising. No matters arising.
3. Resolution to vote in new constitution. Caroline explained the changes in the new constitution. Maria Sale proposed it be accepted. Angela Henry seconded the proposal. All present voted in support.
4. Secretary's Report and Committee Report. Members were able to read copies available at the meeting. Amanda Gore proposed and Pamela Turner seconded that the reports be accepted. All present voted in support.
5. Treasurers Report - Lynda Marney gave a brief outline of her report, copies of which were available at the meeting. Carole Senior proposed and Andrew Gillibrand seconded that the accounts be accepted as correct. All present voted in favour.
6. Election of Committee. It was proposed by Emma Chatwood and seconded by Louise Day that the five candidates be accepted. The vote was passed unanimously. Elected members of the committee are: Jeff Glasser; Caroline Higson; Lynda Marney; Maria Sale; Carole Senior.
7. Appointment of Honorary Auditor - it was proposed by Jeff Glasser and seconded by Margaret Barlow that David Whittall should be adopted as auditor for the coming year. This was agreed unanimously.
8. Any Other Business. No other business.
9. Date and time of next AGM - to be held on the 17th March 2016 at 7:30pm.

The AGM closed at 7:52pm, followed by a raffle and social evening.

Agenda for A.G.M

7:30pm - Thursday 17th March 2016

At: Environmental Resource Centre (Lancashire Wildlife Trust),
499 - 511 Bury Road, Bolton, BL2 6DH.

Agenda

- Apologies
- Minutes of last AGM
- Matters Arising
- The Secretary's Report
- The Treasurer's Report
- The Committee Report
- Resolution to raise annual membership fee.
- Nominations for the Committee
- Appointment of honorary Auditor for next year
- Any other Business
- Date and Time of next AGM
- Raffle

If you are unable to attend but would still like to cast your vote for the trustees, please tick the names on the list below and return to Carole Senior, 182 Church Street, Westhoughton, BOLTON, BL5 3SX by the 12th March. Please can you label the envelope with the words Ballot Paper on the left-hand side of the envelope?

Alternatively you can send an email to caroles4@virginmedia.com, stating AGM Ballot in the heading and copying/typing all of the names that you want to vote for. PLEASE STATE YOUR NAME. It is important that you are able to place your vote, as we have to show that are members are getting a say in who represents them each year. Thank You.

Raffle prizes welcome please! You can bring to socials, main meetings, or on the night of the AGM. Thank you!



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Please tick next to which trustees you are voting for:

Carole Senior Caroline Higson Jeff Glasser Lynda Marney
 Maria Sale

Resolution to increase the annual membership to £10 **from April 2017.**

I vote in favour of increasing the annual membership.

I vote against increasing the annual membership fee.

Your name: