

September 2017 Newsletter



www.mesupportgroup.co.uk
Registered Charity No. 1161356

Thank you to everyone who attended our July talk with Ann, about benefits applications, some information and her contact details are in this newsletter.

Hope to see you in our last few meetings of the year, but if you can't attend, we are re-launching the former "Link-Up" group, so members can be in contact each other via phone, text, email or letter. Please return the necessary information to Emma, the information is on the last page.

Meeting Dates:

Please be aware that our main meetings in Bolton are now going to be on the **FOURTH** Thursday of the month (except April, August and December), a week later than previously. Same time and place still— The Friend's Meeting House, Silverwell Street, Bolton, BL1 1PP. This will mean a bigger, nearer room, it's quieter and there'll be more car parking spaces available.

Entry is £1, free for carers and under 16's. Refreshments provided. We are in the nearest room and there are disabled toilet facilities opposite. There is a small car park for the building, some on street parking bays and an NHS car park next door to the right of the building that we are permitted to use (the gate will be opened for us).

Thursday September 28th 7:30pm Bolton Carers' Support Group. Barry Glasspell will be talking to us about their work and how they can help carers.

Thursday October 26th 7:30pm Bury Citizens Advice Bureau. Dave Bevitt, chief officer, will tell us about the work they do.

Thursday Nov 23rd 7:30pm Pre-Xmas Bring and Share Buffet Social. Bring food to share and enjoy a social evening.

Thursday December – no meeting



Free weekly yoga sessions:

Enjoy nourishing yoga postures, breathing practices & deep relaxation to energise the body, release tension, and calm the mind. Sessions are gentle for people with ME and Fibromyalgia. Mats and equipment provided. You are welcome to bring a carer who can also participate. These classes are FREE for members, thanks to funding from The BIG Bolton Fund, administered by Bolton CVS.

New time: Every Tuesday, **4:15pm-5:15pm**, Jubilee Centre, Tennyson St, Halliwell, Bolton, BL1 3DX.

Please contact Lisa our yoga tutor with any questions.

Mobile: 07708 036636 or email: lisayogatori1@gmail.com.

New Contact Numbers:

A new landline contact for the group is Maria (meetings secretary) on 01204 575 613. Please leave a message if there's no answer, and she will get back to you. You can also email Maria113@talktalk.net. We welcome any speaker suggestions.

Caroline (chair) can be reached on 07837 077 491 (new number) or caroline@mesupportgroup.co.uk

Carole (librarian) can be reached on 01942810320 or caroles4@virginmedia.com

Lynda (treasurer) can be reached at: Lynda@mesupportgroup.co.uk

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. Think of us when Christmas shopping please! We raise a significant amount each year which helps us run the group.

Mercure Bolton Health Club Discount: The Bolton Mercure branch has a long-standing arrangement with our group and kindly offers our members use of the swimming pool and sauna for only £3.50 per visit, and accompanying carers will pay the same (no charge if they don't use the facilities). The usual price is £8. Just say that you are a member of our group! The best times to use the club are before 4pm weekdays, Saturdays 1-5pm, and all day Sunday (but is busier if it is raining).

Their address is: Mercure Bolton Georgian House Hotel, Manchester Road, Blackrod, BL6 5RU. Tel: 0844 8159029. **If you would like help in approaching your local club for a possible discount for our group, please get in touch!**

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. We also have SmartCrutches to borrow (ergonomic elbow crutches), please contact Caroline for those.

Volunteers: We are looking for volunteers who can help with all activities of running the group, if you think you can contribute, even if in a small way. Please contact Caroline on caroline@mesupportgroup.co.uk or 07837 077 491 for more

information. **Several other local groups in Lancashire have had to close over the last couple of years, due to lack of volunteers. Please do not let this happen to us.**

July Meeting - Welfare Rights with Ann Innes

We were delighted to welcome Anne to speak to us, as applying for benefits can be a very stressful and confusing. The meeting was well attended, showing how much advocacy and advice is needed.

Ann previously ran a welfare rights service for Stockport M.E. Group and still works privately with people with M.E. and Fibromyalgia to provide welfare benefits advice, help with form completion, mandatory reconsiderations and appeals on a chargeable basis.

Ann has a wealth of knowledge and a high success rate in gaining people with M.E. the rate of benefit and duration of award that they are eligible for. Many people are scared of the process, unaware of what they may be entitled to or think that they are not "bad enough" to claim benefits such as PIP because they are sometimes able to do things

Ann supports people with a range of physical and mental health conditions to complete claim forms, ask for mandatory reconsiderations, ask for supersessions (where someone's condition has worsened) and prepare people for medicals and tribunals, attending in person where required. She also represents people at first and second tier tribunals, both in writing and in person.

Stockport M.E. Group say feedback for Ann's services were overwhelmingly positive. If you would like to contact Ann for an appointment or to enquire about her charges, please call her on 07748 473263 or email her at wrafme@gmail.com.

"Nutritional, Naturopathic and Reiki Healing.

Addressing health issues through food choices, supplementation, natural detoxification techniques and energetics. Contact Ann Innes at beeabuddha@gmail.com or on 07748 473263 for further information."

A member recently posted on our Facebook group: "Thanks very much to Ann Innes for all your help so far, she helped me complete my form and was enormous help. If you can't remember who she is she came to the group in July and gave the talk about PIP and ESA assessments. I would definitely recommend her to help reduce some of the stress the form creates."

Ann paid particular attention in her talk to the eligibility criteria for Employment Support Allowance and Personal Independence Payments, explaining each descriptor in full and how scores are awarded for each descriptor.

She explained that there are 2 groups for Employment Support Allowance and how important it is to ensure that you are placed in the correct one. The work related activity group, she explained, was less money for new claimants and that one of the rules of the benefit in this group was the obligation to attend "work related activity", which could take the form of anything from weekly phone calls to having to attend government initiatives such as the "Work Programme" they may require regular daily attendance at set times. She explained how she had had a number of

clients come to her who had been sanctioned as they couldn't make appointments because of the fluctuating nature of their condition and were consequently forced to live on a reduced income until Ann intervened to get the sanctions lifted and her clients placed in the right group. You can appeal with medical evidence and get help from your M.P if this happens.

As regards Personal Independence Payments Ann explained that there are 2 components, the daily living component which replaces the care component of DLA, the difference being that the lowest rate of DLA care has now been shelved, and that claimants need to score at least 8 points to get the "standard" rate of PIP daily living and at least 12 points to get the "enhanced" rate. She explained that the mobility component distance had been reduced to 20 metres for the "enhanced rate" of PIP mobility (replacing the previous 50metres for DLA higher rate mobility) and that the "standard rate" was now 50 metres (previously 100 metres for DLA).

She also explained how planning and following a route should look both at familiar and unfamiliar routes but is not about someone's physical ability but rather their cognitive ability or any psychological problems they may have such as anxiety or depression preventing them from doing so.

Probably the two most important points of her talk to note were:

1. The importance of getting medical evidence to submit with the claim form that is immediately relevant to the descriptors being assessed. Ann mentioned that a lot of her clients had previously collected general letters about their conditions and symptoms from their medical professionals but that this would not aid their case. Ann has a proforma that she gives to clients to take to their medical professionals so that they can supply relevant information to the descriptors being assessed and mentioned how important it is to make their medical professionals aware of the degree of difficulty they have with each one, as this is not normally something that is discussed in a 10 minute GP appointment, for example.

2. The use of the words, "reliably", "repeatedly", "to an acceptable standard" and "safely" in giving evidence, both on claims forms and at the medical. In terms of reliably, if someone can carry out a descriptor at one point in a day but could not carry it out at another point, or repeat it, then they should be assessed as being unable to do it for the whole day. Claims are assessed on how someone is for over half the time, so it is important to quantify how often and how "reliably" you can do something. Assessors are also supposed to look at how often someone can repeat an activity, what the after effects are for them from that activity, whether they can do it effectively and whether they can do it safely.

So in terms of M.E., if someone pushes themselves to do a descriptor such as showering that leaves them in bed afterwards, this is neither safely, nor repeatedly.

Finally, Ann talked about how to prepare for a medical assessment, time limits with regard to asking for decisions to be looked at again (usually 1 calendar month for most decisions), the importance of sending things special delivery, requesting for medicals to be recorded and what constitutes a change in circumstances that requires reporting to the DWP.

Remember, for benefit form applications/appeals/tribunals, we have excellent guides available for members via post or email (saves us funds). Phone Ruth on 0161 766 4559 or email ruth@mesupportgroup.co.uk to request them.

Yoga for Wellbeing – other classes run by Lisa

In addition to the free Tuesday classes the group runs (thanks to Bolton CVS/BIG Bolton Fund), Lisa our tutor also runs other sessions. Gentle/moderately paced yoga classes suitable for beginners as options are given to suit all abilities.

Wednesday 10-11.30 am Deepdale Community Centre, Deepdale Rd, BL2 6PQ £2.50

Thursdays 10-11.15am Sevenacres Wildlife Trust Centre, Bury Road £20 for 4 week block or £6 Drop In

Please feel free to contact Lisa on 0770 803 6636 for an informal chat.

Triathlon for M.E Research

Some of you may know Gail Sumner, osteopath and Perrin practitioner. She's given a couple of talks to our group and I know a fair few people see her. She is doing a triathlon for the charity M.E Research U.K, a very good and active organisation whose findings we've covered in the newsletter. She would love to get more donations, however big or small, to further the research into this condition, so she would be grateful if you have £1 or £2 to spare. You can also use gift aid if eligible, to up the donation. They can also be anonymous if you wish, just tick the relevant box.

If you wish to donate but can't use the website, Caroline could possibly donate on your behalf, or pass donations to Gail in person. Thank you

She says: 17 years ago my life changed forever. I was diagnosed with ME/CFS..... having been fit and active, loving life, and my job, suddenly I needed to rest all of the time, there were days I could barely stand, or leave my home, and unable to work....I would do something then crash, spending days recovering to a level that was barely functioning. I turned to the NHS for help, had tests done, which were all clear, and was told there was nothing that could be done!

After 7 years of private tests, research and hard work, I was finally able to get back to work, working with others affected by this devastating illness.... a further 3 years on I was able to get back to exercise... since then I have slowly built up my fitness, and was able to do my first 10k run for ME research UK 2 years ago. Having done a practice run last year I am hoping to finish this one smoothly!

<https://www.justgiving.com/fundraising/gail-sumner1>

ME/CFS Clinic Steering Group Meeting

We are having our annual meeting with the ME/CFS Clinic Team at the end of November. Here we discuss the Clinics feedbacks and performance over the last years, and any issues arising.

If you have any feedback about the clinic, positive or negative, or questions to ask the team, please pass them on to Caroline on 07837 07 491 / caroline@mesupportgroup.co.uk or Maria on 01204 575 613 / Maria113@talktalk.net.

Quality of Advocacy: When looking to get assistance with the benefit application process, please try and check for feedback and reviews about the service first, if possible. Not all organisations, publicly funded or private, are of the same quality and lately we have been hearing of consistently poor service and forms of poor

quality from several members. This adds even more stress and upset to an already stressful situation, and in some cases, a substantial amount of money has been spent.

Whoever helps you, please make sure you see and approve all forms before submission. If anything is incorrect, request that it be changed before you copy it and send it in. The Benefits and Work guides are very helpful supplements to advocacy, so they are important to read if you can. Poor quality or incorrectly completed forms can really affect the award decision, and are harder to defend at mandatory reconsideration appeal.

You can get someone from organisations, or friends and family to go with you to the medicals and take notes. In addition to this, it would be helpful to get permission to record it, in case of discrepancies in the report they produce. This needs to be done in advance, and you provide the tapes and recorders.

Return of Friendship Group

At the AGM it was suggested that we had a contact list for people to communicate with each other (when they need advice or just someone to talk to), especially if they aren't on Facebook. We used to have a "Link-Up" group to facilitate this, but it stopped due to lack of volunteers to run it, and the growing use of social media. Emma has kindly volunteered to put the new list together so members can communicate via phone, email, text or letter. Thank you Emma, we really appreciate it.

Please remember to be respectful of members at all times. As a group we will not tolerate bullying of any kind. Also keep in mind that the person you are contacting might be having a rough day and might not get back to you straight away or need to cut the chat short.

If you decide to meet someone in person, do be careful and try to arrange to meet in a public place and let someone know where you are going.

You can send Emma the below information by email at echatwood@ntlworld.com or at one of the meetings or by sending it to: 87 Birchfield Drive, Worsley, Manchester M28 1ND

Name:

Phone Numbers:

Email:

Address:

Preferences for contact: email/home phone/mobile phone/text/letter

Would you be willing to call back members if they are on PAYG mobile:
Yes/No

Would you like your address to be included in the contact list: Yes/No

Best times and days to contact you:

Personal Information (particular interests) age and gender are optional: