



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

## July 2017 Newsletter

Maxine is taking a break from editing the newsletter for a while so she can rest and recover from a bad patch. Hope you feel better soon Maxine!

We hope to welcome her back again in the near future when she feels better, until then, we hope to find a volunteer to temporarily take on the role.

Please get in touch if you can help.

### 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 that we are permitted to use (the gate will be opened for us).

### Thursday July 27th 7:30pm:

#### Welfare & Benefits Information with Ann Innes

Ann previously ran a welfare rights service for Stockport ME Group and still works privately with people with ME and Fibromyalgia to provide welfare benefits advice, help with form completion, mandatory reconsiderations and appeals. Her talk will focus mainly on:

- \* Eligibility criteria for PIP and ESA.
- \* Details of the assessment and appeals processes.
- \* An exploration of what constitutes a "change in circumstances" that requires reporting.
- \* An exploration of the rules around voluntary work and permitted work whilst claiming.

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 entitled to. Ann will share her knowledge of the assessment process for people with fluctuating conditions and explain how the forms should be completed to provide a full picture of someone's condition and will be available for questions at the end.

### August – no meeting

Thursday October 26<sup>th</sup> 7:30pm

Thursday December – no meeting

Thursday September 28<sup>th</sup> 7:30pm

Thursday Nov 23<sup>rd</sup> 7:30pm

## **Changes to yoga class times (again!)**

Due to circumstances beyond our control, our weekly yoga classes are moving to a different time yet again, for hopefully the last time! It's only 15 minutes later, which will give the previous users time to exit and Lisa time to set up the mats and equipment. This should make parking easier and it will be quieter too.

Sessions include mindfulness and relaxation, and are very 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](mailto: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](mailto:Maria113@talktalk.net). We welcome any speaker suggestions.

Caroline (chair) can still be reached on 07851 647 550 or [caroline@mesupportgroup.co.uk](mailto:caroline@mesupportgroup.co.uk)

Carole (librarian) can be reached on 01942810320 or [caroles4@virginmedia.com](mailto:caroles4@virginmedia.com)

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

## **New M.E.N Arena Free Carer / Personal Assistant Tickets** from June 1st

Free tickets for Personal Assistants - New Scheme from 1st June 2016

Manchester Arena is working to ensure that the allocation of personal assistant tickets is a fair process and that all tickets are only available for those individuals who would be unable to attend an event without the support of another person. In order to do this we are implementing a new policy whereby individuals booking tickets through our accessible ticket line will now be required to submit a completed access form and supporting evidence before any ticket can be processed. This will be strictly enforced for new bookings made on or after 1st June 2016.

Automatic qualification for those in receipt of PIP, DLA, AA (any level), those registered blind, with assistance dogs. Proof is required.

To register for your personal assistant ticket for an event please fill out and return our Access Scheme Form with your supporting evidence by post to Manchester Arena, Victoria Station, Hunts Bank, Manchester, M3 1AR or via email to [accessibility@manchester-arena.com](mailto:accessibility@manchester-arena.com). Call the Accessibility Team on 0161 950 5229 (10.00am – 5.00pm Mon - Fri, 10.00am - 4.00pm on Saturdays, excluding Bank Holidays).

**ME and My M.E** A member has anonymously written about their experience of M.E/CFS. We invite you to write about yours for our newsletter, as everyone has different triggers, symptoms and experiences. Please email your story to [caroline@mesupportgroup.co.uk](mailto:caroline@mesupportgroup.co.uk).

“Roughly 11 years ago ME got me good and proper although I had been fighting it unbeknown for a couple of years before.

It felt like I had really really bad flu, my skin hurt I had a sore throat, brain fog, headaches and the fatigue, that’s what I remember and I have never really been the same again. I am sure others will recognise this but many will have different experiences, hence the title.

I had pretty muddled thinking at the time (still do if I am honest) but it felt like a bereavement and it took some time to start to accept the situation. Helped by my friends in the Bury Bolton group, by counselling from our clinic and a little from the lifestyle course although a lot of that was common sense for me, but ultimately you have to make your own path.

I have tried to maintain as part of everything I do some exercise, my muddled head said that if I had muscles yesterday then I still had them so I needed to try and keep some of that going. It has taken a long time and a lot pf practice to get a lifestyle that kind of works for me, it’s not how it used to be, but it is still way way better than it was 11 years ago.

Fundamentally I recognise when to stop and rest and what to avoid like the plague.

Any type of stress or anxiety should be avoided, total waste of energy, nothing gained, lots lost. People with viruses, they should all be shot or at the very least have the consideration to keep away from me. I need someone to design a protective suit. Winter is a nightmare for catching cold after cold and watching life go by from the sofa.

Find out what gives you a boost, it still works to an extent for me, appreciate the good things, the sunshine, a green light, flowers, birds. Whatever floats your boat. The important thing is to let it sink in and lift your spirits. The Breathworks course was also really useful as is our yoga although I don’t manage to get there, the meditation part always relieved the stress I habitually carry around which is another waste.

I hate having ME but I have learned a lot from the process, I was told by a very wise person that all I seemed to talk about was ME (they were nicely telling me to stop being so self-absorbed and illness absorbed) and they were right, if you make your world bigger somehow then ME has less of a hold. Also I feel better and still of some use to people by helping in small ways. The committee being one. It was something I noticed and realised was important to me, the need to feel as if I had a purpose still.

I was off work initially for about 6 weeks and then had a phased return to about 20 hours, it was carefully managed by my boss but I felt better just getting some interaction from others. I now do 25 hours a week but I work from home one day and my work are very flexible and accommodating.

I do so much more now by steadily but incrementally progressing but always knowing when to stop and rest. If I am tired I sleep, if it isn’t going to result in

imminent death it doesn't get done. I can eat later and it is easier to clean more dust than an odd speck. It's all about what is important and getting your balance right.

I know I am fortunate but I don't know why. One of the big frustrations I have is the lack of any recording of the rate of change in my health. How will it change anything if they don't damn well look."

**CDC removes CBT and GET as recommended treatments for ME/CFS in the U.S.A, but NICE Guidelines unchanged.**

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**In America, the Centers for Disease Control and Prevention (CDC) has updated its website information for ME/CFS, improving diagnostic criteria and removing previous recommended treatments – CBT and GET.**

While it seems that we must wait to see if this new information is reflected in updated guidance for medical professionals, it is nonetheless being heralded as an important development.

In the UK, NICE published its consultation document which confirmed the recommendation to take no action with regards to the current ten years old guideline, published in 2007. The ME Association is protesting this decision and is currently considering its written response as a stakeholder in the consultation process.

We feel there are many aspects of the current guideline that warrant review including the continued recommendation of CBT and GET. David Tuller in his latest blog, *Trial By Error: The CDC Drops CBT/GET*, explains in more detail what has happened at the CDC and why this may herald an important and fundamental change for ME/CFS.

We have selected pertinent extracts from his blog, and reproduced them below:

"Just as *The Lancet* has published more "evidence" for graded exercise, the CDC has moved decisively in the opposite direction. In revamping the information on the part of its website geared toward the general public, the agency has "disappeared" all mention of CBT and GET as treatment or management strategies. Patients and advocates have long pushed for this step, as did Julie Rehmeyer and I in a *New York Times* opinion piece in March. Although the revised text is dated as having been reviewed on May 30th, it apparently went live sometime during the first week of July. (The CDC has still not revised the pages designed for health care providers, although old information has been removed. The agency calls the illness ME/CFS.)"

"For advocates, the CDC's removal of the CBT/GET recommendations represents a major victory. "I think it's huge," said Mary Dimmock, an advocate who has long pressured the CDC to revise its website. Given the agency's stature, she added, the decision could have widespread impact, not just in the U.S. but internationally as well. Many health care providers and institutions here and abroad look to the CDC for guidance in public health matters."

“So many patients have been made worse by the treatments,” said Dimmock, who became an advocate after her son became seriously ill several years ago. “While there is more to be done, removing these recommendations is a significant step forward in protecting ME patients from harm.”

“In the revision, the CDC website has dropped the agency’s 1994 definition of the illness. The new definition, based on the one proposed in a 2015 report from the Institute of Medicine (now the Academy of Medicine), requires the presence of “post-exertional malaise.” In the 1994 definition, that was only one of eight optional symptoms. The immediate implication of the shift is that GET should likely be considered contraindicated, given the premium this intervention places on steadily boosting activity levels. The form of CBT prescribed in PACE could also be contraindicated, since the ultimate goal of that intervention is likewise to increase activity. (The CDC has not adopted the name proposed by the IOM report, “systemic exertion intolerance disease.”)”

“In addition to symptomatic relief, the revised CDC website suggests such management strategies as a balanced diet, nutritional supplements and complementary medicine.”

“Of course, avoiding “push-and-crash” is what patients already do when they practice pacing. The “push-and-crash” language itself appears to be closely aligned with the arguments provided by the PACE investigators and their colleagues; many patients might describe their experiences differently. Nevertheless, removing the CBT/GET recommendations is a welcome step, if overdue. For years, patients and advocates pointed out the problems with PACE and related research, and also cited the evidence that too much exertion caused harm because of physiological abnormalities, not the deconditioning presumed by CBT and GET. But until now, the agency refused to make the necessary changes.”

“The CDC has another urgent obligation: To communicate with the U.K.’s National Institute for Health and Care Excellence, which develops clinical guidelines for various medical conditions. NICE is currently debating whether or not its recommendations for the illness—which it calls CFS/ME—need to be reviewed; of course, these recommendations include CBT and GET as indicated treatments. NICE is soliciting input this month from stakeholders, but the expert panel assessing the situation has apparently made a provisional decision that no review is required.”

“The CDC has a long history of collaborating with key members of the PACE team and others in the U.K. medical and public health establishments; it is not surprising that prescribing CBT and/or GET should have become standards of care in both countries. It is now incumbent on U.S. public health officials to alert their British colleagues, including those at NICE, that they have just abandoned these longstanding recommendations. They should also explain why they have taken that major step, and why NICE should consider doing the same. (More on the NICE guidelines later this week.)”

David’s latest blog can be read in full here:

<http://www.virology.ws/2017/07/10/trial-by-error-the-cdc-drops-cbtget/>

Petition: <https://www.change.org/p/petition-the-nice-guideline-for-cfs-me-is-unfit-for-purpose-and-needs-a-complete-revision?recruiter=744708136>

## **Bolton Care Record – May talk by Hannah Carrington, Bolton CCG engagement officer**

Hannah came to talk to us in May about The Bolton Care Record and what this means for us as patients. This was the same week the NHS networks were held to ransom by hackers, so it was a very topical and sensitive subject – and the end of a very busy week for Hannah. She talked about what Bolton CCG had planned, but this is being rolled out across the country, and each county will have their own plans which will link up to others.

The Bolton Care Record is a new confidential computer record that will allow health and social care professionals directly involved in your care to access the most up to date information about you. These records are currently held separately and aren't available across different health and social care services when they are needed.

It does this by sharing appropriate information from your medical and care records between health and social care services in Bolton. This means your GP, a specialist at the hospital, a district nurse, or a social care professional will have access to the information they need.

Information is already shared by phone and paper records across health and social care organisations. The Bolton Care Record will enable your information to be shared more accurately and more efficiently with those professionals directly involved in your care. This should improve the care you receive. The NHS in England has been working with patients and clinicians to try and identify ways of ensuring that patients and clinicians are able to gain maximum benefit from their consultations. To enable this to happen, there is a target that the NHS should be paper free at the point of care by 2020.

To provide the best treatment, care and support to you as a patient or service user it is essential that health and social care professionals have access to the most up-to-date information. Information is already shared between health and social care organisations by phone and through paper records. The Bolton Care Record allows this sharing process to happen more efficiently, enabling better care for you.

What information will be shared?

- Your address and telephone number
- Diagnosis list – to make sure your health or social care professional has an accurate and complete record of your care.
- Medications – so everyone treating you can see what medicines you've currently been prescribed.
- Allergies – to make sure you aren't prescribed or given any medicines you could have an adverse reaction to.
- Test results – to speed up your treatment and care.
- Referrals, clinic letters and discharge information – to make sure the people caring for you have all the information they need about other treatment you're having elsewhere.

The benefits for patients:

- Joined up care is safer care
- More time spent on you and your care, instead of going over the same information over and over again
- More effective record sharing helps services work better together, potentially reducing hospital stays so you can get home sooner.

Common questions:

- Can anybody access my records?

No. Only health and care professionals directly involved in your care will see your Bolton Care Record and only with your consent. Your details won't be made public or passed on to third parties not directly involved in your care.

Hannah addressed repeated concerns that friends or relatives would be able to access their records. There are several safeguards in place to prevent this from happening, including needing consent, passwords and audits of access. By law, everyone working for the NHS and social care must respect your privacy and keep your information safe.

- If I receive treatment or care outside the Bolton area can health and social care professionals see my Bolton Care Record?

No. The Bolton Care Record is only available to the NHS and social care organisations in Bolton that have signed up to the system

- Do I have to share my records?

You can choose not to have a Bolton Care Record, but sharing your medical and social care information through a Bolton Care Record will make it easier to provide the best care and support for you.

- Can I access my Bolton Care Record?

Yes. Under the 1988 Data Protection Act you can request all information that an organisation holds about you. You can change or update the details on it, that can be viewed next time they are accessed.

- How do I opt out?

Your information will only be viewed with your consent. You can say no to any health or care professional who asks permission to view your information. You can also completely opt out and not have a Bolton Care Record. Contact your GP if you wish to opt out.

Visit <http://www.boltoncarerecord.org/> for more information, including news, videos, case studies and FAQ's. Thank you to Hannah for visiting us.

## **June Summer Social**

A small turnout for this meeting, the first one in the better room in the new venue, which we had originally wanted. It's nearer to the entrance and toilets, has a hatch to the kitchen, large windows and French doors to the courtyard outside, so if the weather's nice you can go and sit on the benches close outside.

The weather had been very changeable in the week before the meeting, so a lot of people were struggling with it, but we welcomed two new members and had a nice chat and buffet. Roll on November for the next one!

**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](mailto:ruth@mesupportgroup.co.uk).

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

**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](mailto:caroline@mesupportgroup.co.uk) or 07851 647 550 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.**

**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.

