

Welcome to Our August 2014 Newsletter

Note from the Editor Maxine: Welcome to this months newsletter: What a month for me as both my laptop and our main PC broke. Thanks to my son, we have a news letter for fixing my laptop. Don't forget, no meeting at Longsight, Harwood in August. The meeting in September there will be EGM. Please if you can't attend, could you either use the cut off slip off, or email your votes.



On a bad day she simply wants to be left alone.

with thanks to Invest in ME (www.investinme.org) for their kind permission to reprint this cartoon from the calendar available to download from their website.

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DISCLAIMER: Anything expressed within this newsletter may not necessarily represent the views of the editor, the Committee, nor the Bury/Bolton ME/CFS Support Group. Any products, treatments, or therapies featured are for information only and their inclusion should not be considered an endorsement.

Dates For Your Diary

Longsight, Harwood Meetings: Our main meetings, often with guest speakers, are held at Longsight Methodist Church (the big stone building with an elongated wheelchair ramp outside, not the smaller church hall opposite), Longsight Lane. Harwood, Bolton, BL2 3HX, on the third Thursday of each month from 7.30pm until 9pm (except in April, August and December). There is a car park and blue badge parking on the street and the building is wheelchair accessible. Entrance is £1, carers are free. Tea, decaf coffee, water, biscuits, etc provided. Gluten/dairy free also catered for. Any questions, please call Caroline on 01204 525955, or email caroline@mesupportgroup.co.uk.

NO MEETING IN AUGUST

Thursday 18th September 7:30pm- E.G.M & Book-Swap Social. We need to call an Extraordinary General Meeting, which should take no more than 5-10 minutes (simply a show of hands to vote in our new group documents).

After that boring stuff, we can have a Book-Swap Social, which was very popular last time. Just bring any books or magazines you no longer want, to donate, and you can buy some new books for 50p each, magazines for 10p each, raising some funds for the group. Please bring a maximum of 6 books, that you think other members would enjoy.

Thursday 16th October- Oliver, DWP Relations Officer, will be coming to talk to us about Personal Independence Allowance (PIP), formerly Disability Living Allowance, and about the changes surrounding it. If you have any questions, please send them to us in advance. He was recommended to us by another support group, who said he was very nice and informative.

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. **Our yoga classes are currently being funded by Comic Relief and The Co-operative Membership Community Fund.**

Radcliffe Socials: From September, our Radcliffe social will move a couple of miles down the road to Bolton. So we will no longer be meeting at either the Sparking Clog or the garden centre, but instead we will be at Pizza Me (www.wannapizzame.com), which is on Brightmet Fold Lane, BL2 6PP, just next to Brightmet health centre. We will continue with the first **Wednesday of the month at 2pm, so the next will be on 3rd September.** Pizza Me has ample parking, with a very short distance to walk to the front door, where there is level access with no steps. The toilets are located to the left of the door as you go in, or there is a disabled toilet in the entrance way. Although this is a restaurant, they are happy for us just to have drinks, but there is a range of food available for anyone who is hungry, including small snacks. We will be sat to the right of the bar (in the comfier seating) and will put a newsletter on the table so that you can recognise us.

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.

Septembers meeting is provisionally set for the usual second Wednesday of the month- **Wednesday 10th September 2014 at 2pm**. **Please check on Facebook first to check it is still going ahead, as that's the quickest and easiest way, or call Maria on 07867 862 341 if you are not on Facebook**. Apologies to those not online, but it is either this, or stop them altogether.

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.



Supported by

**Bolton
Council**



Reminders:

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.

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/bbmeecsopen>

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.

Mercure Bolton Health Club Discount: The Bolton Mercure branch has kindly agreed that our members can use 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 the group, please get in touch!

Hydrotherapy sessions: Preston and Chorley Fibromyalgia and Chronic Pain Support Group have kindly offered to let our group attend their private hire hydrotherapy sessions. There is no instructor, you can do your own exercises, or swim a few lengths. **Please note that the Saturday sessions have been cancelled.**

The sessions are 12pm - 1pm on the first Friday of the month. They are at the Jubilee Pool, Tennyson St, Bolton, BL1 3HW. It is £3 per person and carers are free. The sessions will be on:

Friday 5th September 12-1pm

Friday 3rd October 12-1pm

Friday 7th November 12-1pm

The pool is 34.9 degrees and air temp is 38.9 degrees so it is lovely and warm. They supply pool noodles, hoists and they have a stair case to get into the pool. I have been a couple of time now, and thought everyone was really friendly and welcoming.

Please text or phone Natalie on 07855 777636 if you are planning to attend, so they know how many people might be going. Thank you to group leader Natalie for the generous offer to our members. If you have any questions or are interested and want more information, please contact Caroline on 01204 525 955.

Bury/Bolton ME/CFS Support Group Meeting -July Meeting: Summer buffet.

Our July meeting was a lovely bring and share Summer buffet. Thanks to everyone who came along and it was nice to welcome some new members. I think we all went home stuffed, and with leftovers. There was plenty for gluten free and dairy free diets too, with enough for everyone to sample. Many thanks to everyone who helped out on the night, especially our admin lady extraordinaire and her friend Gillian, who spent most of the time in the kitchen refreshing drinks and washing up! Caroline.

Dianne had been asked for this recipe at the supper so here it is:

Crispy Chocolate Fridge Cake

300g/11oz dark chocolate, broken into chunks

100g/4oz butter, diced

140g/5oz golden syrup

1 tsp vanilla extract

200g/7oz biscuits, roughly chopped

100g/4oz sultanas

85g/3oz Rice Krispies

100-140g/4-5oz mini eggs/Smarties

50g/2oz white chocolate, melted

1 Line a 20 x 30cm tin with baking parchment. Melt the chocolate, butter and golden syrup in a bowl set over a pan of simmering water, stirring occasionally, until smooth and glossy. Add the vanilla, biscuits, sultanas and Rice Krispies, and mix well until everything is coated.

2 Tip the mixture into the tin, then flatten it with the back of a spoon. Press in some mini eggs and put in the fridge until set. When hard, drizzle all over with the melted white chocolate and set again before cutting into chunks.

Warm Home Discount Scheme Reminder:

Yes, I know we've just had a heat-wave, but I've been ordered to tell you about the Warm Home Discount scheme by one of our members. She's just applied successfully, and thinks it's fantastic because she can turn some lights on now! She'll get the money off in February next year.

The scheme entitles you to a discount of £140 a year toward your heating bills. The money isn't paid to you, it's a one-off discount on your electricity bill, usually between October and March. You can also qualify for the discount if you use a pre-pay or pay as you go electricity meters.

It's been in the newsletter before, but some may have missed it, or be newly eligible. Most main suppliers are with the scheme. It is mostly income based, and you also need something like Disability Living Allowance or child tax credit to qualify (may differ between suppliers though).

If you are eligible, you will get a letter saying you qualify automatically, or that you must apply by the deadline given. If you believe you qualify, but don't get a letter, please write to the team at: Warm Home Discount Team, Pink Zone, 1st Floor, Peel Park, Brunel Way, Blackpool, FY4 5ES.

Caroline.

Age UK Bolton Drop-In Desk

AgeUK now have a drop in desk at The Hub (where Bolton C.V.S is based), in Bolton town Centre. They can offer advice and information Monday to Friday from 10am-3pm, about anything from their handyman service (for gardening, decorating and small repairs), to their activities and courses.

On Wednesday mornings, (by prior appointment only), they offer a will-writing service, which is completely confidential. It is £30 plus VAT for a single will, and £50 plus VAT for partner wills. People must be aged 50+, be resident in Bolton and need a straightforward will to take advantage of this service.

To find out more, contact Age UK Bolton on 01204 382 411 or <http://www.ageuk.org.uk/bolton/>

For members in Bury, AgeUK Bury can be contacted at: 0161 763 9030

They have a Health Trainer to visit on Wednesdays, a café, activities at the Jubilee Centre in Bury, and coffee mornings for new members. They can also help older people and their carers fill in Attendance Allowance forms at their Jubilee Centre.

Their Insurance, Information & Advice shop is located at 19 Broad Street, Bury, BL9 0DA. It is open Monday to Friday from 9.30am to 4pm.

<http://www.ageuk.org.uk/bury/>

Find your nearest Age UK: <http://www.ageuk.org.uk/about-us/local-partners/>

A Bedside Diagnostic Tool?:

Reprinted with kind permission from ME Research UK. Originally appeared in Breakthrough, Spring 2014

At present, testing for autonomic nervous system dysfunction is done in a clinical setting – usually in a state-of-the-art assessment laboratory – so there is a need for a simple assessment method that can be used at the bedside or in the patient's home. In fact, a wide range of bedside techniques will have to be developed if severely affected patients are to get the scientific attention they deserve.

Prof. Julia Newton, Prof. David Jones and colleagues at Newcastle University are leaders in the assessment of autonomic nervous system dysfunction in a number of diseases. Since 2006, the group has developed one of the few research programmes in the world on ME/CFS, with the support of organisations like the MRC and ME Research UK (which has awarded it five grants).

In an impressive series of scientific papers, the researchers have shown that autonomic dysfunction, in all its aspects, contributes significantly to the symptom burden and quality of life of ME/CFS patients. It affects standing, blood pressure regulation, muscle activity and cognitive functions, such as the memory and attention problems which are frequent and disabling symptoms.

Prof. Newton has amassed a multi-disciplinary team of clinical collaborators, and one of them, Dr James Frith of the UK NIHR Biomedical Research Centre in Newcastle, has been assessing the role of measures of blood pressure variability, which is controlled by the nervous system, in the assessment and diagnosis of ME/CFS.

In a scientific paper in the Quarterly Journal of Medicine, Dr Frith has described his attempts to derive simple markers of autonomic dysfunction using a Task Force Monitor, a device which gives beat-to-beat data for heart rate, blood pressure and other key areas of the vascular system using non-invasive, easy-to-use technology. The researchers found striking differences between ME/CFS patients and the matched controls in diastolic blood pressure variability in the resting state.

Importantly, they observed that a combination of three particular aspects – resting low frequency, high frequency and total power spectral density variability – differentiated between ME/CFS and controls with a sensitivity of 77%, though specificity was lower (53%). The fact that these measures can be made at rest (unlike many autonomic assessment techniques) raises the possibility of assessing autonomic nervous system dysfunction at the bedside, using appropriate portable technology. The researchers' next step is to validate their findings in other groups, and to explore their diagnostic usefulness, in combination with other potential diagnostic markers.

Brain blood flow and autonomic symptoms:

As many ME/CFS patients have autonomic nervous system problems, particularly problems with standing (orthostatic intolerance) and with memory or concentration, there has been speculation that blood flow to the brain might be impaired, at least in some people.

With our support, Dr Jiabao He and colleagues at the Newcastle Magnetic Resonance Centre have been exploring whether the autonomic abnormalities in ME/CFS patients seen at the unit (particularly abnormal acid accumulation in leg muscles during exercise) are mirrored by changes in blood flow to the brain.

They did this by using magnetic resonance imaging to measure brain blood flow, and magnetic resonance spectroscopy to probe skeletal muscle during two challenges: an exercise of the foot and a standard autonomic function challenge called the Valsalva manoeuvre, in which the patient takes a deep breath and holds it for 16 seconds.

They found a correlation between brain blood flow and the accumulation of acid in the skeletal muscles: lower blood flow to the brain was associated with a reduced accumulation, while higher flow was associated with higher acidity.

Given this relationship between brain vascular control and skeletal muscle acid regulation, both at rest and when responding to challenges, the researchers speculate that autonomic nervous system dysfunction might underlie changes to brain blood flow.

As they point out, it is possible that ME/CFS itself is driven by a primary abnormality at the periphery of the body (e.g. skeletal muscles) which has secondary effects on the brain or other organs.

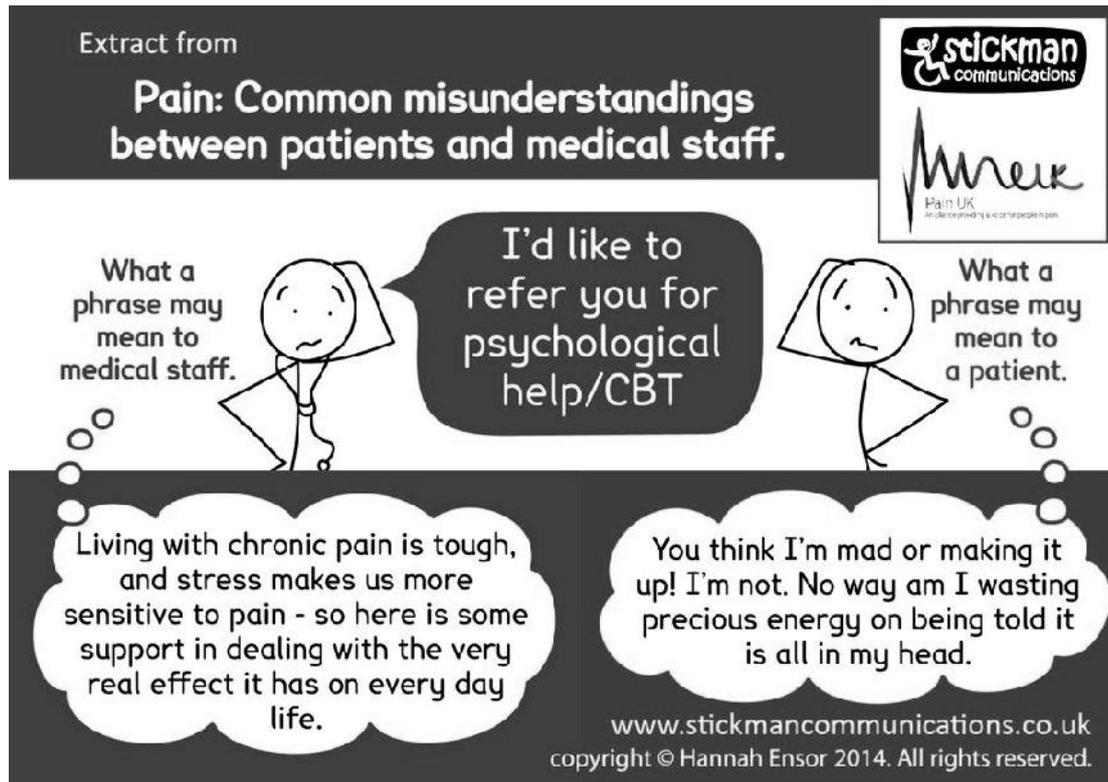
Pain: Common Misunderstandings Leaflet:

You may remember that we have featured a couple of Hannah Ensor's blogs/cartoons in the newsletter before. She has now created a fabulous double-sided leaflet about the miscommunications that can arise when talking about pain to health professionals.

This has been made, in association with PainUK, as a result of her own experiences in dealing with doctors and physiotherapists, and hearing it happening to others too. The A4 double sided leaflet puts opposing meanings of commonly used phrases together, so that everyone who sees it may be able to communicate more effectively about pain. Also, £0.10 pence per leaflet sold through www.stickmancommunications.co.uk will be donated to Pain UK.

We thought they were excellent and certainly recognised a lot of phrases in the leaflet! We thought they were so effective, it was worth sending a couple of copies to each GP surgery in Bolton and Bury, for the doctors to look at and to display in their waiting rooms for patients to see. We've also sent them to the ME/CFS clinic, the Fibromyalgia Clinic at Bolton One, and we will be sending them to the pain management clinics and PALS soon. We hope these improve patient/doctor communication. Please look out for them in your GP surgery waiting room (they are a nice pink colour, so will stand out).

Hannah Ensor is an author, cartoonist, and wheelie. Image is copyright Hannah Ensor 2014. Please be sure to visit her website, www.stickmancommunications.co.uk, for her humour filled take on life with a disability. As her work is copyrighted, a cover note is sent with all leaflets explaining they cannot be altered or photocopied. Caroline



DWP Performance Measurement Reviews

The Department of Work and Pensions recently stated on their website (<https://www.gov.uk/dwp-visit>), that:

“You may get a visit from a Department for Work and Pensions (DWP) officer to check that your benefits payments are correct.

A Performance Measurement review officer may visit you if you're claiming:

- Employment and Support Allowance
- Housing Benefit
- Income Support
- Jobseeker's Allowance
- Pension Credit

Your name is selected at random to be checked.

You won't always get a letter in advance telling you about the visit."

The website www.benefitsandwork.co.uk (who do the great guides we have available for members), made a Freedom of Information request to the DWP.

They discovered that, the majority of people selected do not get a letter in advance. From the letter they obtained, you can also be assured that:

- You are not obliged to let them in.
- You can request to be given proper notice.
- You can request an interview at a DWP office instead.
- Doing any of the above will not affect your benefits (but refusing to participate in any interview at all, may lead them to suspect fraud and open an investigation).

These visits are only selected for a small percentage of claimants, but most of those who do, are not given notice.

If two un-notified visits are made on the same day, then another un-notified visit must be made on another day. After that, a letter has to be sent giving you at least 48 hours' notice of a visit, or 24 hours where the letter is hand delivered. There are also certain classes of claimant who should never receive an unannounced visit, including:

- customers aged 70 or over
- customers with an appointee
- customers in remunerative work (including self-employed) who are in receipt of Standard Housing
- customers suffering from depression or a medically defined mental illness
- customers with an alcohol or drug-related dependency
- disabled customers where there is evidence from the preview information that they may be distressed if an officer calls unannounced.

However, where the visiting officer suspects, from your files, that you may be committing fraud, they can visit you without notice, even if you are in the above categories.

The officers will look for discrepancies in what you wrote on your work capability assessment form, and what you are doing at home and in the interview. If you have a fluctuating condition, you must tell them if that day is a better day.

The DWP officer will have an I.D card. As explained above, you do not have to let them in. If you are doubtful as to their identity, you can call the JobCentre Plus and confirm their name is on the employee list. Whether you choose to have the interview at home or at a DWP office, it may be helpful to have a carer, relative, friend with you, for support.

Brain-Fog Competition Results.

A while ago, we asked you to send in your best "brain-fog" stories. We all have them as part of ME/CFS or Fibromyalgia, and we thought it would be a bit of fun to share our stories, and to show that we all do it! We received eight entries and Bury 3SDA kindly agreed to judge the entries, which were submitted anonymously (to make it fair, as some committee members submitted their stories as well).

Bury Third Sector Development Agency (B3SDA), are a charity which seeks to support and develop third sector organisations in Bury. ("third sector organisations" are community, voluntary and faith organisations, social enterprises, charities and cooperatives.) They offer support, advice and training to voluntary and community groups in Bury, such as ourselves. They work in partnership with public sector to represent our issues. Website: <http://www.b3sda.org.uk/>

The unanimous winner was declared as Maria, our Meetings Secretary, with these gems:

"I once reported my car stolen because I was convinced I'd parked it in one place when it was somewhere else. I had parked in Bury and had a couple of jobs to do. I returned to find the car gone. I couldn't believe anyone would steal such a scruffy old car displaying a disabled badge, so my first thought was that I must have parked it elsewhere. I phoned my Dad to drive round with me looking for it, but no luck, so I reported it to the police and insurance company, and had to phone my parents' building society to cancel their pass books, as they were in the car. Then, at about 8 that evening, 5 hours later, I suddenly had a picture of where I'd parked. I phoned my brother, and sure enough, there it was. Cue embarrassed call to the police.

I once had Trafford Centre security staff try to break into someone else's car. I thought my fob battery had gone flat, and it needed to be used to deactivate the alarm. There was nowhere to buy batteries, but one of the guys knew a way of "bumping" the car to override the alarm, so I could then use the key. As they were doing this (we had been at the car about 10 minutes by this time) I noticed the children's toys and clothes on the backseat.....and then noticed my car in the next row. Oops!"

Carol, our Librarian and Minutes Secretary was in second place; these were some of her stories:

I recall telling friends that I'd forgotten to iron the hanging baskets.

I've stuffed an armful of dirty towels in the oven, then stood puzzled, trying to decide what temperature to do them at.

I've lost count of the times I've gone out in the car and come home on foot or bus, only to have a momentary panic that my car has been stolen. I've even driven past my house and thought "Oh no. My car's gone!"

Well done Maria, and thank you everyone for your entries.

My entry was to explain how I had scooted all over the supermarket car park after shopping, looking for my husband for ages, totally confused as to why I could not find him, only to then realise that I had driven myself there!

The above three stories from committee members should indicate to you just what a funny/tragic event our Committee meetings are like! Half the time we forget what we're saying mid-sentence, the other half, we're interrupting each other so we don't forget what we we're about to say! **There are only 5 people on the committee (all sufferers of ME/CFS), we really, really need more people. A healthy person would be most welcome too, please! Please call Caroline on 01204 525 955 if you would like to help us.**

More stories:

In a brain fog moment, someone put their iPad in the microwave! Amazingly, it still works!

There was also a member, who cut up her new bank card when it arrived, not her old one! Whilst they were watching TV on Boxing Day, they became outraged when they saw an advert for Easter hot cross buns...they started to rant, and then realised they were watching a show they'd recorded many months before! Her daughter will not let her forget it.

She also said "I dragged myself out of bed for work, only to find I was not on the rota. It was April 1st. I have never April Fooled myself before."

Someone turned up for appointment a week early, but also forgot about an appointment they'd made the same day. She also says "I left my card in the machine at the same supermarket two weeks running and forgot where I was going, and then when I remembered, wasn't too sure where I was. The mysterious place I was going was David Lloyd Farnworth, where I had played badminton for donkey's years. I was lost on the A666."

A member and her husband got a parking fine after he dropped her off for an appointment at Bolton one, despite them both agreeing she had got a ticket from the machine. She says "after a spell of confusion and cursing, it dawned on me that I could of put the wrong car registration into the machine, oops. At the time I was rather fed up with my Fibro fog cock-up. Any how, he appealed and explained the error and they have refunded him, thank goodness."

After I wrote about our Brain-Fog competition, I noticed a Tweet from the M.E Association ([@MEAssociation](#)) in our Twitter feed:

"Apologies for any failures to reply to DMs (direct messages) in last few months. Been locked out of account coz I couldn't remember password. Doh!"

I replied that we were running a competition, which they re-tweeted to all their followers, and people replied with their funny moments!:

"searched all over the house for my car keys, getting really cross, only to find they were in my hand the whole time" [@Miz Pi3](#)

"Did that with my mobile phone! Even rang it and wondered where the sound was coming from!!" [@NanoGirl13](#)

"Nearly put milk in the iron" [@NanoGirl13](#)

"oops! I lost my glasses only to realise I could actually see" [#IWasAlreadyWearingThem](#)
sigh" [@samjmoore87](#)

Don't worry, you're not the only one with brain-fog! Hope these stories have made you smile. Caroline

Scooters on the Metrolink Reprinted with permission from TfGM

People can now take approved mobility scooters on Metrolink trams, under a new trial permit scheme that launched this month. Anyone who lives in Greater Manchester and holds an English National Concessionary Travel Scheme (ENCTS) Disabled Person's Pass or a TfGM Travel Voucher pass can apply for a permit to use their approved mobility scooter on Metrolink.

The Metrolink scheme was created and launched in direct response to national guidance, published in spring last year. That report found that, of over 300 types of scooter available, at least 22 models could be accommodated on public transport. TfGM and Metrolink have since assessed a wide variety of models, using the DfT guidance, and have worked with ShopMobility Manchester to manage their safe introduction on to the raised-platform network. The initial six-month trial will help us to finalise a permanent scheme.

The permit itself is an official sticker on the mobility scooter chassis that contains a part of the user's ID number from either their ENCTS Disabled Person's Pass or their TfGM Travel Voucher pass. The photo IDs give Metrolink staff a quick and easy way of making sure that both the user and their scooter have been assessed and accepted for the scheme. Mobility scooters have to meet set conditions, including size and turning circle, for safe use in and around the network in order to qualify. Customers are also assessed, in a process supported by ShopMobility Manchester, to ensure they are able to manoeuvre their approved scooter safely around and within a tram's wheelchair space and around the network's raised platforms. Before a permit is issued, customers will be asked to sign a declaration agreeing to abide by the terms of the scheme.

If you are interested in applying, call 0161 205 2000 for a form, or apply online:
<http://www.metrolink.co.uk/mobilityscooters/Documents/Mobility-Scooters-application.pdf>

For more information about the scheme, visit www.metrolink.co.uk/mobilityscooters.

E.G.M

We need to hold a short EGM to adopt a new Constitution (our Governing document, which tells us what our aims are, how to run the group and any rules). We already have a very thorough one, put in place in 1991. It has been very helpful when getting grants for projects like the yoga.

However, we now need to become a **registered charity** as our income has grown over the allowed threshold. The committee does not want to do this, as it means a lot of work to register and set it up, and more pressure on having to send in accounts, reports, etc in on time. However, after seeking advice, we do not have a choice, as it is a legal requirement. The 5 committee members must become trustees of the charity (who are all ill with ME/CFS themselves).

We have been advised that our existing Constitution is not thorough enough and would more than likely be rejected. We have to replace it with the new standard of Constitution released by the Charity Commission. All 18 pages of it! That's why we are not sending copies of the new version out with this newsletter. If you would like to see it, or are having problems getting off to sleep, please phone Caroline on 01204 525 955 or email caroline@mesupportgroup.co.uk for a copy. Several copies will be available at the September meeting to read through.

Most of the Constitution remains the same as the old one. We have added in that we also help people with Fibromyalgia, and that if we dissolve, our funds should be split between different charities (to be decided as yet, we will have this finalised by the EGM).

We also need to put in place a “Vulnerable Adults Policy”, which details what we should do if there is an incident with a member, or if a member is harmed, and the appointed persons contact details. Nothing has happened so far, and it should be noted at all the committee members/trustees themselves are also vulnerable adults. This is just something we need in place to tick a box. It’s a standard document from the Council, if you would like a copy, please contact Caroline.

Since we’re in a policy-adopting mood, we’re going to throw in a “Volunteer Policy” too! This explains how we recruit volunteers (basically, we say “Yes please! How soon can you start?”).

However, don’t worry, our day to day running will be the same! We already go above and beyond what’s needed of us, and we already run like a charity, in that we hold AGMs, have audited accounts and a Committee report.

We are now down to 5 Committee members (soon to be called “trustees”) and a small handful of helpers. We are all ill, just like you. It’s not a case of that we’re not as bad as we could be, therefore we help with the group. We help with the group because no one else will do it and otherwise a valuable resource for 150 poorly people will be lost! **We’re exhausted.** Please, if you think you can help us in any way by donating a skill to help with the running of the group, or fundraising, etc, please do!

If you cannot attend on the night to vote, please return you completed ballot papers (on the last page) to: Carole Senior, 182 Church Street, Westhoughton, Bolton, BL5 3SX by the 13th September 2014. 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 EGM Ballot in the heading and typing “Yes” and the underlined word for each of the things you want to vote for and sign your name. **It is important that you place your vote to make the EGM valid**, please do, it only takes a minute. Thank you for your support.

E.G.M Notice

Thursday 18th September 7:30pm at Harwood Methodist Church, Bolton, BL2 3HZ

Agenda:

1. Apologies.
2. Resolution to adopt a new Constitution.
3. Resolution to adopt a Vulnerable People’s Policy.
4. Resolution to adopt a Volunteer’s Policy.

✂

I vote in favour of changing the group’s Constitution

I vote in favour of adopting the Vulnerable People’s Policy

I vote in favour of adopting the Volunteer’s Policy

Name: Signed: