



Welcome to Our September 2016 Newsletter.



Monthly focus.

Volunteers: We are looking for volunteers who can help with all activities of running the group, if you think you can contribute, from home or at meetings, when your energy permits, 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. The group will unfortunately have to gradually cut services as we cannot continue like this.

Dates For Your Diary:

Bolton Main Meetings at Wildlife Trust Centre, Bury Rd:

Our main meetings, often with guest speakers, are 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-ish (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 September 15th 7:30pm Social Evening: Please join us for a light refreshments and a friendly chat.

Thursday October 20th 7:30pm Gail Sumner. She will be talking to us about her work with Dr Perrin's NHS research and the other interesting things she is involved in

Parking: Attendance may be higher for Gail's talk in October. Please remember that we have a small car park available, and you can also park on the main road on the same side as our venue after 6:30pm (with a blue badge, or not, Bolton Council confirmed this). It is a main road, so please take care.

Our meetings are kindly supported by **Sport Relief**, administered by **Forever Manchester**

****ROADWORKS NOTICE**** St Peter's Way (A666) will close from 7pm until 6pm every night, from 4th July for 13 weeks, so may affect some members travelling to the September meeting. However, there are alternative routes (as long as you remember!). Please join us if you can.

Parking: If you come to our Bolton main meets at the wildlife centre, you might have had to double park when the small car park is full.

The parking restrictions (going up towards the hill) on the main road end at 6:30pm, and our meeting is 7:30pm with people arriving from 7pm.

Obviously, this is a main road, so do be careful if you choose to park here, badge or no. This option may not obviously be suitable for some, but an option if the car park is full and you cannot walk the distance from other residential streets.

If you happen to be blocked by someone who has double parked due to lack of spaces, please ring the door buzzer for reception and ask the Wildlife Trust staff member on duty upstairs to pass on the message (with car description) to us, and the car owner can come down. This means you don't have to trek up and down again. Hope you can join us.

Yoga Classes: Are **3:15pm-4:15pm every Tuesday** at the Jubilee Centre, Darley Street (off Eskrick St), Bolton, BL1 3DX. Designed to cater for the average ME& FM sufferer, classes are free and yoga mats are provided. **Carers/friends etc welcome**, also free of charge. 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 Bolton Fund, administered by Bolton CVS and Forever Manchester.**

Prestwich Socials: **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 meetings are **Wednesday 14th September 2016 and Wednesday 12th October 2016.** Please try not to turn up too late, as 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, 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.

Road works on meeting nights

Notice: St Peter's Way (A666) will be close after 7pm every night for several weeks, and affects October meeting (perhaps October one too if work dates are delayed).

PLEASE bear in mind when travelling to and from our meeting. Sorry for the inconvenience.

Council notice: In order to safely carry out resurfacing works, there is a programme of planned overnight closures of the A666 St Peters Way.

Every night from 7pm to 6am, starts June 19th for 13 weeks

St Peters Way - entirely Closed

Please check the Bolton Council website, Roadworks section, for updates.

Dr Gaber talk, June 2016 BBME & FM meeting

Thank you to Joanne for taking notes and typing up the meeting talk.

We were fortunate enough to have Dr Gaber, a consultant neuro-rehab surgeon who heads our Bury and Bolton ME/CFS clinic come and talk to us. He has recently contributed to a paper about the overlap in symptoms between MS and ME/CFS and the challenges there are. The paper is titled: "Multiple Sclerosis/Chronic Fatigue Syndrome overlap: When two common disorders collide" by Gaber, Oo and Ringrose printed in the journal "Neuro Rehabilitation".

Dr Gaber explained that in MS common features are, brain and central nervous system problems, there are lots of interconnected "wires" and the nervous system increases conductivity of these wires and insulations start to be eroded.

Inflammation is also an issue. The body will think there is an attack when there isn't. As we live in an ultra clean environment the immune system is shocked by it. The immune system in MS patients start to attack the insulations surrounding the nerves. Patients can take drugs for a relapse but this does not reduce the severity of degeneration. Dr Gaber explained that people think the meds helps, however, this is not always the case. This confuses the MS to be tricked into feeling it will be helped by pills during relapses, but the degeneration will still continue.

MS usually presents with fatigue as the most common symptom in 92% of patients, and is the most disabling. No one has tried to investigate fatigue or relapses, as studies do not investigate this and it only plays a small role in existing studies. This is probably because fatigue is a very subjective symptom and hard to define and classify.

As the symptoms are so diverse it's difficult to get a definitive outcome for treatment.

Over the last 10-20 years studies are improving and ongoing.

Fatigue means something different to each individual. MS fatigue research are contradictory regarding drug trials as they objectively measure failure.

There are around 1000 MS patients in the Bolton area.

The first step in the diagnosis of CFS/ME according to the regularly used Fukuda criteria (1994), is to exclude other causes of fatigue. The assumption that a patient cannot be

diagnosed with two common causes of fatigue e.g. MS and CFS/ME is clearly flawed as you would expect a small number to have both.

If an MS patient went to the clinic and didn't say they had MS but stated what their symptoms were they would probably be diagnosed with ME/CFS instead.

Out of the 64 patients that were referred to the clinic in a 12 month period and retrospectively reviewed, 9 of those would also fit the Fukuda criteria for a ME/CF diagnosis. These 9 were all women with average age of 52. All had significant fatigue linked to post exertional malaise/flu-like symptoms after a bout of activity and all had non-refreshing sleep that was not related to any MS symptoms.

All patients admitted having perfectionist driven personalities (most of our members have said this!) and reported boom and bust behaviour (not pacing out activity and paying the price for days for over-expending energy).

Excluding the different known cause of fatigue, all MS patients in the study met the Fukuda criteria for a ME/CFS diagnosis. Boom and bust and perfectionist mindsets and are strongly associated with ME/CFS patients also.

The subjects in the study showed wide fluctuations in their day to day abilities, making it hard to monitor progress.

They propose some signs that ME/CFS may exist alongside MS, and express concern that there are some MS patients with an undiagnosed ME/CFS illness who may deteriorate with mismanagement.

- Large fluctuations in patient ability and symptom severity.
- Post exertional malaise – flu like symptoms following activity
- Generalised muscle/joint pain not matching any other origin like arthritis. Fluctuates in severity.
- Perfectionist behaviour, boom and bust activity patterns.
- Un-refreshing sleep pattern, not related to sleeping problems like night spasms.

An MS diagnosis needs be thoroughly investigated and confident, as the wrong drugs could be given. Many thanks to Dr Gaber for the enlightening talk.

Lisa's Evening Yoga classes

If you cannot get to our own free of charge adapted classes, kindly funded by a carers grant from The Big Bolton Fund and Bolton CVS, you could give this a go. Every Wednesday, at Bolton Arena, 8:05pm-9:05pm (evening!), Lisa our yoga instructor runs a yoga class in the Studio area.

This is for beginners/intermediates. New members are welcome. Moderate level. Bolton Arena offer a Arena Active card, offering the price of sessions at £5, instead of £5.50 Please contact Lisa on Mobile: 0770 803 66 36 / Email: lisayogatori1@gmail.com.

Edgar Stene Prize Competition 2016

Winner: Simon Stones, Bolton, UK

"Living with a rheumatic or musculoskeletal disease (RMD): How I take action to enjoy life to the full"

Via FMA UK: This is an annual international award for patients who live with rheumatic and musculoskeletal (RMDs) conditions, that includes fibromyalgia, arthritis, etc. The 2016 Prize has been awarded to Simon Stones, now trustee of FMA UK, who inspired the judges with his essay sharing how his life was affected by fibromyalgia and rheumatoid arthritis, and how he helps others living with the conditions. Well done Simon!

Ampligen now approved drug for CFS in Argentina

Ampligen is now the first drug approved anywhere in the world, for CFS/ME, by the Argentina's FDA, for use in those with severe ME/CFS. This approval was based on the people who participated in the studies.

The US FDA will proceed with a large trial once funding has been obtained, and if approved would be worth billions to the pharmaceutical industry.

It is in the very early stages yet, and it will be many years before it will be approved and then even more before it is available on the NHS (if at all), but all encouraging news

Release of PACE Trial Data

The Queen Mary University of London (QMUL) has to release data from the PACE Trial, which was until recently, withheld under the Freedom of Information Act. The trial had some controversial results and resulted in some contested recommendations for treatments. Hopefully analysing the raw data will lead to debunking of the trial.

The trial is the biggest study on ME/CFS treatments, and concluded with recommend cognitive behavioural therapy (CBT) and graded exercise therapy (GET) being the most successful. The results ignored and contrasted with evidence that ME/CFS is a organic, real illness and that GET widely worsens symptoms in patient surveys.

The definition of "recovered" was expanded, and participants could even deteriorate over the trial, yet still count as "recovered" by the finish, so the trial was flawed in this way. Yet since the raw data has been withheld until now, it has been impossible to analyse and interpret this data.

QMUL has spent upwards of £200,000 on legal fees to stop the release of this data to. Their team has also tried to get The Freedom of Information requests thrown out, as harassment towards the staff involved, but was thankfully dismissed.

We look forward to an independent review of the raw data in the study.



Permission received

Refuelling just got easier for disabled drivers

Posted in General News on Wednesday, June 15th, 2016

FuelService, a revolutionary phone App, has been launched to enable disabled drivers to re-fuel their vehicles more easily. FuelService is being trialled at Shell service stations in the North West of England with a national rollout later in the year based on success.

The idea was the brainchild of Niall El-Assaad who after becoming paralysed in a cycling accident was fed up with struggling to get help to put fuel in his car. The App helps the driver find a local petrol station and check that there will be an attendant able to help before they go.

Niall El-Assaad said, “Not only was I embarrassed by having to drawing attention to myself by honking my horn and waving my Blue Badge about, but also when a station is single manned the attendant was unable to leave their position to help. It meant I was waiting for ages wondering if they had seen me and if I would get help. When no one came I would need to drive to another petrol station and try again – just hoping I didn’t run out of petrol.”

FuelService has addressed all these issues. The App works by providing an easy way for a disabled driver to find a petrol station and then contact the petrol station to check that there will be an attendant able to help before they go. If they can help great, but if not there is no wasted journey and they can try another. Once at the petrol station the driver can use the App to tell the petrol station they have arrived and the details of their car making them easy to spot. The driver is told via the App how long the attendant will be before they come out to help, so they are not sat waiting in hope.

Sue Annis, Senior District Manager, Shell UK said, “I am pleased we are supporting this great App. fuelService will complement the other ways we are helping all drivers on our forecourts, such as Fill Up & Go, Shell’s mobile payment at pump service and our Attended Service offer. We see through our customer feedback programme, how frustrated some disabled drivers are on occasions when our Service Champions aren’t able help them. I hope the introduction of fuelService will help. “

It is hoped following the pilot in the North West the service will be rolled out nationwide and other fuels retailers will sign up. To help get this App off the ground please download the App from <http://fuelservice.org/getapp> or by searching for “fuelservice” on your devices app store.

FuelService is a not for profit organisation and all proceeds go to spinal research.

Travel Vouchers

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

Who qualifies for Travel Vouchers?

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

you are registered blind with your local authority, or

you are in receipt of DLA (Disability Living Allowance Higher Rate Mobility Component), or

you are in receipt of Higher Rate (formerly known as 24 hour) Attendance Allowance, or

you are in receipt of the War Pensioners Mobility Supplement, or

If you do not receive any of the above benefits, you may still be entitled to travel vouchers if you are not able to walk 100 metres (110 yards) or more, or climb steps of 300 millimetres (approximately 12 inches) or more, however, this must be certified by your doctor on your application form.

Where can I go using Travel Vouchers?

You can travel anywhere in Greater Manchester and the neighbouring counties using travel vouchers. However, you can only use travel vouchers with taxis, private hire vehicles, community transport schemes and accessible bus services, such as Ring and Ride, which are authorised. If you use transport that is not part of the scheme your vouchers will not be accepted.

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

How do Travel Vouchers work?

When you join the scheme you will be given a travel voucher user card that shows your name, your photograph and a user number; you must show this card when you pay for a trip using Travel Vouchers. Vouchers are not free but are substantially discounted. Travel Voucher Users can buy up to £120 worth of vouchers for £30, which is just one quarter of the full value.

Vouchers can be used instead of cash, which means that if your journey costs, say £6, then you will hand to the driver £6 in vouchers, but remember, as you have only paid a quarter of their full value, the journey has only cost you £1.50. Taxi drivers and private hire vehicles drivers must give change if your journey costs less than the value of your vouchers.

Vouchers change colour every year and you will not be able to use them after the date printed on the voucher. Each voucher has a number on it and we keep a record of which vouchers you have bought in case they are lost or stolen.

If you already have a Free Travel Pass or Concessionary Travel Permit, which provide free or cheap travel on buses, trains and Metrolink in Greater Manchester, you must hand it in when you join the Travel Voucher Scheme. You cannot have both a bus pass or permit and Travel Vouchers; however, the travel voucher user card provides free or cheap travel on trains and Metrolink in the same way as your pass or permit.

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

How much do Travel Vouchers cost?

Travel Vouchers are not free, you must buy them, but they are substantially discounted. You may buy up to £120 worth of vouchers at a cost to you of £30. The vouchers come in sheets - each sheet contains 2 x £5, 4 x £2 and 2 x £1 vouchers and will cost you £5.

The Travel Voucher year starts on 1st April in one year and runs until the 31st March the following year. It doesn't matter when in the year you join the Travel Vouchers scheme, you can still buy up to 6 booklets. However you can only purchase Travel Vouchers from April to the following February, as orders received during March will be processed for the following year.

You may buy a limited number of sheets each year. Currently you can buy up to a maximum of 6 sheets in a year. We are not able to make any exceptions to the maximum number of vouchers allowed per person per year, even if they do not cover all your travel costs. However, the yearly allowance is reviewed each year and may change in future years.

You don't need to buy them all at once, for example, if you buy three sheets you will pay £15 and get £60 worth of Vouchers. You can buy more if you need them, but only up to 6 sheets. But you must use all your Vouchers before 31st March so if you think you might not spend £120 on travel; it would be best not to buy them all at once. Please only purchase the amount you know you will use as there are no refunds or exchanges.

How do you apply for Travel Vouchers?

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

Concessionary Travel
Transport for Greater Manchester
2 Piccadilly Place
Manchester
M1 3BG

Phone: 0161 244 1050

Thanks to TGM

Warm Home Discount Scheme

Time to apply again for this year.

For winter 2016 to 2017, you could get £140 off your electricity bill through the Warm Home Discount Scheme.

The money isn't paid to you - it's a one-off discount on your electricity bill between October and April.

The discount won't affect your Cold Weather Payment or Winter Fuel Payment.

Not everyone gets the discount - check if you qualify. Those on pension credit, means tested benefits or on a low income may qualify. This doesn't affect any Cold Weather Payments or Winter Fuel Payments you may get.

Pre-pay or pay-as-you-go meters

You can also qualify for the discount if you use a pre-pay or pay-as-you-go electricity meter.

If you qualify, you will get a letter, by December 16th, telling you:

- you don't need to apply – the discount will be applied automatically **or**
- to apply before 28 February 2017 - the letter will tell you what to do

Contact the Warm Home Discount Team if you don't get a letter but believe you qualify.

Warm Home Discount Scheme Telephone: 0345 603 9439, M-F, 8:30am to 4:30pm
Warm Home Discount Team , Pink Zone, 1st Floor , Peel Park, Brunel Way, Blackpool
FY4 5ES

From our Facebook Group : Medic Alert Bracelets

A member writes: Sometimes the subject of medic alert bracelets comes up here, so I thought I would post a link to this that I just got from Etsy, in case anyone else wants to order one. What I really like about it is that it's prettier than most other stuff available (it's shinier than it looks in the photo), has room for so much more info (the standard ones just won't fit the words I need) and most importantly I can get it on/off easily on my own. The lady was so helpful in making it exactly how I wanted it and even changing the listing to add a smaller size option, because I like to be able to take it on and off without bending so it lasts longer. I should warn that annoyingly I got stung for £12 customs charges (£8 of which was the Royal Mail processing fee) but it was still worth it to me because it's the nicest one I've ever managed to find that can fit so many words on.

<https://www.etsy.com/listing/266880652/rheumatoid-arthritis-ra-rheumatoid>

Bracelet by QuietMindDesigns

