

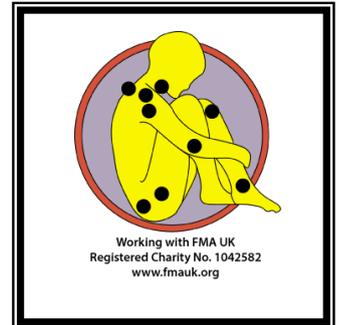
HAPPY HOLIDAYS



Welcome to Our December 2014 Newsletter.

Note from the Editor Maxine: Hope that you all have a Merry Christmas and Happy New Year from all the team behind your newsletter.

Do people realise we are working with FMA UK? Yes, we are. Check out their web page at <http://www.fmauk.org/> for all our Fibromyalgia sufferers.



Monthly focus.

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.

Please think about going paperless and having your newsletter sent by email.

Help required. We are looking for volunteers who can help with all activities of running the group, if you have a particular skill (or just a pair of hands!) you think you can contribute, or are up for a certain task, please contact Caroline. **We are really struggling to keep the group going;** we are just a small number of sufferers, so we need all the help we can get please. Please contact Caroline on caroline@mesupportgroup.co.uk or 01204 525 955 for more information.

Dates For Your Diary:

Bolton Main Meetings at Wildlife Trust Centre, Bury Rd:

Our main meetings, often with guest speakers, are now held at The Wildlife Trust Centre, 499/511 Bury Rd, Bolton, BL2 6DH.

They occur on the third Thursday of each month from 7.30pm until 9pm (except in April, August and December). It is not far from Brightmet Health Centre. The building is on Bury Rd, between Morrisons/Home Bargains and the junction to turn onto Crompton Way, on the way into Bolton town centre.

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.

No meeting in December.

Thursday January 15th, 7:30pm: Michelle Cardno, from Fightback4Justice. Non profit group offering welfare benefit advice/appeals and disability benefit applications completed. They have an office based in Bury and have given well received talks to other M.E groups. Michelle is a law graduate and has previously worked for the Citizens Advice Bureau.

Yoga Classes: There will be no yoga sessions on the 30th December.

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.**

Bolton Socials: Are now at Pizza Me (www.wannapizzame.com), which is on Brightmet Fold Lane, BL2 6PP, just next to Brightmet health centre. We meet the first Wednesday of the month at 2pm, so the next will be on 7th January 2015. There 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. Wednesday 14th January 2015 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.



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.

Bury/Bolton ME/CFS November 2014 Meeting

Our second meeting in our new surroundings was our bring and share pre-Xmas supper (as always in November). We had a lovely selection of food, to suit all tastes and dietary requirements. It was lovely to welcome some new members, as well as some faces we haven't seen for a while, and our trusty regulars. Our helpers really went above and beyond, which is very much appreciated as we were several people down on the night.

NB: The door to the building has a buzzer, but we will make sure there is a volunteer to let you in so you are not waiting. The tables in the meeting room have been moved back, so there is more room to manoeuvre/walk when you enter the room, going towards the adjacent room where tea/coffee is, so not as cramped for wheelchairs/scooters as our first meeting there (many thanks to the staff for noticing this).

Appeal to go paperless:

A large portion of outgoings is photocopying costs – awareness leaflets, welcome packs, monthly newsletters and several lengthy BenefitsAndWork.co.uk guides. It would help cut printing and postage costs (as well as our volunteer's energy, electricity and time) if you would get the email versions of the benefit guides and newsletters if you are able to please. (If you do not have access to email/a printer, does a friend or relative?) Could you also return the guides where possible so we can pass them onto other members to re-use, and also save some trees). Only around 40% of our newsletters go out by email. Of course we know not everyone has email, but if you can get the newsletter this way, please would you consider it to save us funds. A huge, unseen amount of work by people with ME/CFS/FM goes into them, producing these and getting them to you. Please contact caroline@mesupportgroup.co.uk / 01204 525 955 to switch to email newsletters. Thank you.

Jeff & Chico's Fundraising Trip



Chico and Jeff are now safely back in the U.K. From their updates and photos they seem to have had a lovely time. We will print some of the photo's in next months issue. Go to <http://www.gofundme.com/gulliver> if you wish to donate for their efforts. Thank you.

Thank you for your continued support

This has been an extremely busy year for our group, with *many* changes and challenges behind the scenes. I hope next year is a bit quieter! Our charity registration submission has now been submitted. We hope it will be a smooth process with no problems (we can dream, can't we?).

Just to say thank you for your continued support of our group, and to all who have contributed to the success of it. We are only a small (exhausted) core group, so we really appreciate the offers of help, from raffle prize donations to helping us at meetings. Thank you, and here's to a happy and healthy 2015!

We came second in the Asda Burden Park token collection and have a £50 cheque for the group. We have also been told we will receive £105 from the Waitrose community matters token scheme. Many thanks to both for their generosity. Caroline.

Mobility scooters on Metrolink Update!

People who live in Greater Manchester and hold an England National Concessionary Travel Scheme (ENCTS) Disabled Person's Pass or a TfGM Travel Voucher pass can apply for a permit to use their mobility scooter on Metrolink.

The permit 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 on these passes 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 our network in order to qualify for the scheme. You can find out more about the makes and models already assessed, along with several other criteria and considerations, at:

<http://www.metrolink.co.uk/mobilityscooters/Documents/Mobility-Scooters-application.pdf>

Customers themselves will also be assessed, in a process supported by ShopMobility Manchester, to ensure they are able to safely manoeuvre their approved scooter 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 having already read through the documents provided above, you can download an application form.

To submit your application, or talk it through with someone, please contact ShopMobility Manchester to make an appointment.

Tel: 0161 839 4060

Shopmobility Manchester, L18 New Arkwright Way, Arndale Centre, Manchester M4 3AJ

A Not-To-Do List For Caregivers of the Chronically Ill

Toni Bernhard is the author of the award-winning *How to Be Sick: A Buddhist-Inspired Guide for the Chronically Ill and Their Caregivers* and *How to Wake Up: A Buddhist-Inspired Guide to Navigating Joy and Sorrow*. Until forced to retire due to illness, Toni was a law professor and served as dean of students at the University of California—Davis. Her popular blog, “Turning Straw Into Gold” is hosted by Psychology Today online. She can be found online at www.tonibernhard.com.

She writes:

In August 2013, I posted “A Not-To-Do List for the Chronically Ill.” It led me to turn my attention to those who take care of us. In a study published in the *Journal of the Royal Society of Medicine*, “Quality of life: impact of chronic illness on the partner,” *JRSM*, v. 94 (11) Nov. 2001, the authors stated:...the most striking research finding is a tendency for the partner’s quality of life to be worse than that of the patient.

The people who are least likely to be surprised by this finding are not just caregivers, but those who are in their care. The study focused on partners and spouses, but I’m certain that the finding would be the same when the relationship of caregiver and “cared-for” is parent/child, child/parent, sibling/sibling... or a host of other relationships.

From my own personal experience, as well as from feedback from others, I’ve learned a lot about the life of a caregiver (called “carers” in most countries other than the U.S.). If you’re a caregiver, here is my Not-To-Do list for you.

1. DO NOT shy away from sharing with others that you’ve become a caregiver.

The reluctance to tell others about this life-changing, high stress event is particularly prevalent among men. They’re likely to hide it at work. They often hide it from their friends. It’s a sad commentary on our culture that we still haven’t found a way to make men feel comfortable sharing with others that, when they’re at home, they’re taking care of a partner, a sibling, a parent, or a grown child. They’re doing the cooking and the cleaning; they’re running all the errands; they may even be providing nursing-type assistance.

The consequence of caregivers hiding their role is that people who’d be willing to help don’t even know that help is needed. Not only can this lead to caregiver burn-out, it also helps account for why caregivers have a high incidence of clinical depression. The National Family Caregiving Association in the U.S found that over 60% of caregivers who provide at least 20 hours of caregiving a week suffer from depression.

If you’re a caregiver, I hope you’ll talk to others about your life. If you’re the one being cared for, encourage your caregiver to share with others the difficulties he or she is facing. No one benefits from a caregiver “going it alone.” It may take only one friend to make a significant difference in a caregiver’s life: one friend whom he or she can confide in and talk to about how stressful and difficult life has become; one friend whom he or she can ask for help and support. “Troubles shared are troubles halved” is one of those good clichés.

2. DO NOT pretend that everything is like it used to be; you need time to grieve the loss of your old life.

Many people (including myself) have written about the need for the chronically ill—including those in chronic pain—to go through the same type of grieving process that’s triggered by other life-disrupting events, such as the break-up of a relationship or the death of a loved one. If you’re a caregiver, you need time to grieve too.

The drastic change in your life can be a shock. One day you were free to go out whenever you wanted and hang out with whomever you wanted. The next day, you were tied to the house and expected to understand how to take care of someone who may need help with the most intimate of life functions. Our culture does a poor job of preparing people for this very real possibility. (An estimated 45 million people in the U.S. alone are caregivers for elderly relatives or the chronically ill.)

In addition to grieving the loss of freedom, you may be mourning the loss of the relationship you once had with the person you're caring for. In my life, except when we were at our respective jobs, my husband (also named Tony) and I used to do almost everything together. Now when he goes out, he almost always goes out alone.

This past Christmas, Tony went to a holiday party—by himself. He rarely goes to these events anymore, but the couple who were hosting it issued a special invitation to him, so he went. He saw people from our smallish town whom he hadn't seen for years. This is the type of event that would have been fun for us to “compare notes” about afterward. Instead, when he got home, he told me who was there and how they'd all asked how I was doing (a question that, once answered, tends to be a conversation killer, even though people ask with the best of intentions).

Pretending that everything is like it used to be doesn't work: caregivers need time to mourn the loss of their old life and to adjust to their new one.

3. DO NOT attempt to be Super Caregiver.

Let yourself have “bad” days when, even though you're doing what needs to be done for the person you care for, your heart isn't in it and you wish you were free of the obligation and the burden. Don't feel guilty if resentment arises now and then. Like everyone else in this life, you're going to have good days and bad days.

On the flip side, don't feel guilty when you have a good time. Be on the alert for that Super Caregiver mentality that has you thinking you're not an adequate caregiver unless you're giving the person in your care 100% of your attention and unless you're sure never to have more fun than he or she is having.

Speaking personally, I want Tony to have a good time. It makes me feel less bad about the drastic change in his life and about the responsibilities he's had to take on. As an added bonus, it makes me happy to know he's having fun. Buddhists call this *mudita*—feeling joy for other people who are happy. It's a practice to cultivate, and a wonderful side-effect of *mudita* is that feeling happy for Tony often boomerangs, meaning it comes back at me so that I begin to feel happy myself, as if I'm having a good time through him.

A few weeks ago, he took our granddaughter, Cam, to see the Harlem Globetrotters. When I was growing up, my dad took me to see the Globetrotters whenever they came to town, so it would have been a treat for me to take Cam. But I couldn't, so Tony did. My choice was to be envious and resentful—or to be happy for Tony. I chose the latter. And so, throughout the afternoon, I imagined the two of them in their seats—Tony pointing out a dribbling sleight-of-hand that Cam might have missed, both of them laughing at the Globetrotters' antics just as I had. The result was that I felt joy myself, especially knowing that my caregiver was having a good time.

4. DO NOT be reluctant to share your challenges and difficulties with the person in your care.

Of course, every relationship is different, but sharing your struggles with the person you're caring for can make the two of you closer, despite the many changes in your lives together.

Many caregivers are reluctant to share their difficulties for fear of making the person in their care feel worse. But sharing your struggles and even your sorrows can make the “cared for” person feel as if he or she is giving you emotional support. As a result, not only will you get that support, but the person you’re caring for will feel as if he or she is contributing to the well-being of the relationship. In addition, there may be important issues, such as financial constraints, that badly need to be talked about in order to avoid harder times down the road.

5. DO NOT become isolated yourself even if the person you care for is housebound.

Caregivers are often as isolated as the person they’re taking care of. If this is the case for you, consider asking someone to step in for part of a day so you can do something for yourself. Many communities have programs that provide this kind of support. Volunteers visit people’s houses for the specific purpose of allowing a caregiver to go out for a while. (see Crossroads--Caroline)

There are also online support groups for caregivers that can go a long way toward easing isolation. Connecting with others in this way benefits both you and the person you’re caring for, because it puts you in touch with others who understand the challenges you’re facing. Not only can this uplift your spirits and renew your commitment, it can also provide valuable information that will make it easier for you to carry out your responsibilities.

6. DO NOT neglect your own health.

You can’t be an effective a caregiver if you don’t care for yourself physically and emotionally. Ignoring your own physical and mental health can negatively impact both you and the person you’re caring for.

Caring for yourself is part of being a good caregiver for another.

Group Library Note: We have got a new book for carers in for our library; “The Selfish Pig's Guide To Caring: How to cope with the emotional and practical aspects of caring for someone” by Hugh Marriott, a high rated and funny book. We also have “Chronic Fatigue Syndrome/ME: Support for Family and Friends” by Elizabeth Turp, which is very popular.

Carer Organisations:

Bolton Carers Support: 01204 363056 www.boltoncarersupport.org.uk

Bury Carers Centre: The 1-stop-shop advice number for Bury covering issues such as Outreach/Advocacy support/ Carers Rights/ access to benefits advice and more <http://www.burycarerscentre.com/> Tel: 0161 763 4867 Gaddum Centre, Victoria Buildings, 9, Silver St. Bury

Bury Young Carers: 0161 253 5144 <https://www.facebook.com/buryyoung.carers>

Carers Direct: Tel: 0300 123 1053 (9am-8pm Mon-Fri, 11am-4pm Sat-Sun) www.nhs.uk/carersdirect

Carers Federation: www.carersfederation.co.uk Tel: 01159 629 310 Range of support for carers including specialist Information & support services.

Carers Trust: <http://www.carers.org/> Tel: 0844 800 4361

Carers UK: Adviceline is open Monday to Friday, 10am-4pm. Call 0808 808 7777. www.carersuk.org

Crossroads: Charity offering practical & emotional support for carers incl. personal care of patients & respite packages. www.gmcrossroads.co.uk/
Bolton Crossroads office 01204 365025
Bury Crossroads office 0161 763 4163
Manchester Crossroads office: 0161 445 9595

DWP "Carers Allowance" Unit: Tel 0345 608 4321 (for claiming the benefit).

Culinary Corner.

Please can people send me their recipes to maxine@mesupportgroup.co.uk

Thank you to Dianne for this month's recipe.

CHOCOLATE & GINGER REFRIGERATOR SQUARES

MAKES 32	300g/11oz ginger nut biscuits, roughly crushed
PREP 15 mins	300g/11oz plain chocolate
COOK 5 mins	100g/4oz butter, diced
	100g/4oz golden syrup

1 Line a 20 x 30cm tin with baking parchment. Mix the biscuits with most of the ginger, then set aside. Melt the chocolate, butter and golden syrup in a bowl set over a pan of simmering water, stirring occasionally, until smooth and glossy. Pour this over the biscuit and ginger mixture and mix together well.

2 Tip the mixture into the prepared tin and sprinkle over the reserved ginger, then flatten the top lightly – it doesn't need to be completely smooth. Chill for at least 2 hours, or overnight, before cutting into small squares.

MAKE AHEAD These squares will last in the fridge in an airtight container for a week, or freeze for up to a month.

Late edition - November 2014

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

Dr Unutmaz is new to CFS/ME research. He has specialised in HIV, heart disease and cancer and focusses on the role of the immune system in these illnesses. His theory puts CFS/ME in the same arena as the major disorders he's already looked at, suggesting that chronic inflammation is responsible for most CFS/ME symptoms. Patients' immune systems are out of sync. and need to be rebalanced for an effective recovery. At present he is using data from 50 patient samples and hopes to apply for a significant grant to develop his work. - HIV, Heart Disease, Diabetes ... and Chronic Fatigue Syndrome? The Unutmaz Project to Decode ME/CFS - Prohealth - November 5

A few years ago, Dr Judy Mikovits led an investigation that claimed XMRV was the cause of CFS/ME. However, her study results could not be repeated and the claims had to be withdrawn. Now Judy has co-authored a book called "PLAGUE: One Scientist's Intrepid Search for Human Retroviruses, Chronic Fatigue Syndrome (ME/CFS), Autism, and Other Diseases". This is her chance to tell her side of the story and features a range of positive reviews the book has already received. PLAGUE - The Reviews Are Coming In! – Age of Autism - November 18

Kate Young had a 12 year career in Human Resources before she was hit by CFS/ME. She tried a life coach as part of her recovery and found she started to get better as her beliefs, thoughts and values changed. Kate said, "I am not saying this is the right approach for everyone, but it was perfect for me and I made a full recovery." Kate believed the coaching experience was so effective she re-trained to become a professional Life Coach. Kate said, "I feel proud of myself every time I help a client make a difference to their lives, no matter how small. With my business I feel like I am making a difference and there's no better feeling". - Life coaching was a life-saver for Rugeley woman who battled back from ME to set up her own business – Staffordshire Newsletter – November 16

A new oral medication known as IMC-1 has proved to be highly effective at reducing pain and other symptoms of fibromyalgia after a recent clinical trial. The results were presented at the American College of Rheumatology annual meeting in Boston by William L. Pridgen, M.D., FACS. According to Daniel J. Clauw, M.D., director of the Chronic Pain & Fatigue Research Center at the University of Michigan (Ann Arbor), "IMC-1 shows promise as a potentially new treatment for the millions of people who suffer from this debilitating condition. - Novel Fibromyalgia Treatment Shows Promise in Study – ProHealth - November 20

The article poses the question can eating Turkey help Fobromyalgia? It's an effective seasonal hook to get the reader interested in a supplement called 5-HTP. Although some people benefit, there may be side effects such as memory problems, chronic pain, liver disease and high blood pressure. Therefore a doctor should be consulted before deciding to take it. - Could eating Turkey help treat fibromyalgia? – Med City News - November 27
Whatever the public holiday having CFS/ME is very difficult. The writer brings home the issue to coincide with the Thanksgiving holiday in America. She also highlights the lack of a celebrity sufferer who can lead fundraising, research and political efforts. - The Cruelty of the Holidays – Huffington Post - November 26

**Whatever celebrations you'll be participating in this December,
from everyone on
the Committee and from our volunteers too, we hope you enjoy
yourselves and keep well.
Have a happy and healthy 2015, and we hope to see you soon.**

