



Welcome to Our March 2016 Newsletter.

Note from the Editor Maxine: AGM date 17th March 2016, Caroline is collecting raffle prizes. Please complete the tear off slip or email to vote for your trustees and the resolution.



Monthly focus.

The doctors planned strike dates are 9-11th March, 6-8th April and 26th-28th April I just rang up as I have an outpatient appointment on 7th April and was told they contact you the day before to tell you if your appointment is cancelled.

Membership renewal will be due in April, have you thought about setting up a standing order? Or do you prefer to internet banking to pay your membership? Are you a cheque sender? The group would prefer the first two as it saves the group energy and time having to go to the bank to cash the cheques. It also saves you the hassle of posting them, and means you won't ever forget to renew your membership! The Standing Order form is enclosed with the renewal form this month, or can be obtained on our website.

Volunteers: We are looking for volunteers who can help with all activities of running the group, if 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). 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 March 17th 7:30pm. Our Annual General Meeting and raffle. Please consider us for any unwanted or duplicate gifts that we can use as raffle prizes. The essential stuff usually lasts less than 20 minutes, then we can chat to ourselves.

No Meeting in April

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. Please contact our instructor Lisa. Mobile: 0770 803 66 36 Email: lisayogatori1@gmail.com. **Our yoga classes are currently being funded by The Big Lottery Fund.**

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 meeting is **Wednesday 13th April 2016.**

Please try not to turn up too late, because if numbers are low and those attending are not feeling very well on the day, 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, AS SOME MEMBERS ARE VERY SENSITIVE TO THESE PRODUCTS, THANK-YOU.



LOTTERY FUNDED



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.

Hydrotherapy at Bolton One

The waiting list is now open for the next "taught" course, which will begin in November and run on Wednesdays for 5 weeks. The cost will be around £30, as our group is a member of Bolton Neuro Voices. Don't forget that if you have had hydro for a neurological condition, you may be able to go straight to the maintenance programme, which runs all year round, in blocks of around 8 weeks, with breaks for half terms and holidays.

If you are interested, please contact Marie (pronounced “marry”) Otxoby. Email is preferable: otxoby_929@btinternet.com, or phone 01204 594 004, giving a little information about your condition, and contact details. A physio will contact you in the autumn to assess which group is best for you. Marie talked to the group last September about the hydro project, so there is more information in the October newsletter., or check out the website of the physios: www.neurologicalphysio.co.uk/hydrotherapy-aquatic-therapy However, you are welcome to contact me if you have any questions. The easiest way is through the Facebook page, or email or phone: Maria Sale: maria113@talktalk.net, or 01204 575 613.

Should I or Shouldn't I?" The Dilemmas of Chronic Illness.

Seven recurring dilemmas faced by 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*. Her newest book is called *How to Live Well with Chronic Pain and Illness: A Mindful Guide* (Fall, 2015). Before becoming ill, she was a law professor at the University of California—Davis. Her blog, “Turning Straw Into Gold” is hosted by *Psychology Today* online. Visit her website at www.tonibernhard.com.

After almost 15 years of being mostly housebound by chronic illness (which includes chronic pain), here are a few of the dilemmas I've faced over and over. I'm confident that I'm not alone in my “should I/shouldn't I?” world.

Do I accept an invitation from a friend to get together or do I refuse it?

If I refuse the invitation, depending on who issued it, it may be the last one I'll receive from this person. In addition, if I refuse, I'll feel even more isolated from in-person contact than I already do.

If I accept the invitation, I might be too sick to visit when the day arrives. I don't want to disrupt my friend's plans in this way. Before I became chronically ill, I was so dependable; I wish I could be that way now. Not keeping a commitment tends to make me feel bad about myself, and that's not good for me, so sometimes it feels more self-protective to just turn down an invitation from the start.

Do I tell family and friends how I'm faring with my health or do I keep it to myself?

If I talk about my health, I worry that they're tired of hearing about it. Recently, a woman wrote to me about a chronically ill friend whom she loves and tries to support, but who does nothing but talk about her medical problems. The writer said that no matter how their conversation starts, it always turns to the subject of her friend's health. She told me that she has problems of her own that she'd like to talk about, but it never happens. She wants to be honest with her friend, but is afraid she'll offend her if she tells her how she feels.

If I don't talk about my health, I increase my sense of isolation because, let's face it, chronic illness is a major feature of my life. Not a day goes by without my having to think about it, and not a day goes by without it impacting me some way. Sharing my life with others brings me closer to them.

Do I keep a routine follow-up doctor's appointment or do I cancel it?

It's a strain on my health to make the trip to a doctor's office. That's why the question of whether go to a routine follow-up where I have nothing new to share can be a dilemma for me. (I currently have two routine follow-up appointments I'm supposed to make...but I haven't.)

If I go to the appointment, it may be a waste of my time. (A funny side-note: I recently kept just such a follow-up where I had absolutely nothing new to report to my primary care doctor. Two hours later, back at home, I came down with a bladder infection. I sure could have used that appointment then!)

If I cancel the appointment, I might miss some new information the doctor has. Since I've been treated for breast cancer, I've added three types of oncologists to my "routine follow-up" list. I'm always tempted to cancel, but I've learned one thing that I even joke about with my husband: never cancel a follow-up appointment with a cancer doctor! This may not be true for everyone but, afterward, I'm always glad I went because I never fail to learn something useful.

Do I try to look my best when I'm around other people or do I let my looks reflect how I'm really feeling?

If I try to look my best, I'm concerned that people will misinterpret the state of my health. Doctors may not realize how sick and in pain I am. Friends may not understand why I have to cut short a visit. Family may not understand why I'm not pitching in at gatherings.

If I let my looks reflect how I'm feeling, it can negatively affect my morale. It's good for my emotional well-being to spruce up a bit!

If a special opportunity arises, do I go beyond what I know my body can comfortably handle or do I play it safe?

If I participate, the payback may land me in bed for days.

If I play it safe, I could be missing out on something that will give me an emotional lift.

Recently, I was invited to give a short book talk at a place that's special to me. Unfortunately, it was a two-hour drive from where I live. Before I got sick, that would have been no big deal but now, even with my husband driving, it's well beyond what I can comfortably handle. I went, and I'm glad I did; but I'm also glad I don't have any commitments like this in the future. The payback has been very tough.

Do I try a new treatment someone is urging on me or do I take a pass?

If I try the treatment, not only is it likely to be expensive, but I might be setting myself up for disappointment if it doesn't work. In my book, *How to Be Sick*, I write about how important it is for our peace of mind to work on accepting, without bitterness, that some things work for us and some don't. And yet, I can't help but always get my hopes up at least a little bit.

If I don't try the treatment, I could be passing up something that might help me. Not a week goes by without someone suggesting a new treatment. Sure, I know immediately that some of them aren't for me. But what about those that sound reasonable? This "should I/shouldn't I?" dilemma is one of the most difficult I've faced since becoming chronically ill.

Do I pursue a new interest even though it exacerbates my symptoms or do I stick to my old routine?

If I pursue it, even though a whole new world might open up to me, I'll may feel more sick as a result of the mental and physical exertion.

If I don't pursue it, I'm limiting my already limited options even more. In addition, I'm passing up a chance to focus my attention on something other than my health. This is a "should I/shouldn't I?" dilemma I'm facing right now. Many years ago, I tried my hand at painting. In an effort return to a creative task that had brought me such joy, I recently got out my paints and brushes (I use water-soluble oils so I'm not exposed to turpentine fumes, etc.).

Unfortunately, I've found that working even for a short time uses up my energy stores and, worse, exacerbates my symptoms. The result: When I paint, I feel more sick. And so, I have a dilemma: should I continue to paint and feel more sick **or** should I stop doing something I'm feeling passionate about at the moment so that I'll feel less sick? I'm in the process of deciding.

What I want, of course, is to paint *and* to not feel more sick, but we know from the Buddha and The Stones that you can't always get what you want—a life-long dilemma that presents itself for my consideration every single day.

I'm aware that those of us who struggle with our health don't have a monopoly on being faced with dilemmas in life. We do, however, tend to share the same ones. I hope this piece was useful to everyone.

© 2016 Toni Bernhard. Thank you for reading my work. I'm the author of three books.

Late edition - February 2016

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

Vagus nerve stimulation is one of the most promising chronic pain interventions under development today. In a 2011 study, a vagus nerve stimulator (VNS) implant helped improve a woman's fibromyalgia symptoms. She was part of a small study which suggested that a VNS might be very effective in fibromyalgia. The study was small but the success rate was high. Dr. Natelson, a neurologist who's been treating and researching FM and ME/CFS for decades said: "The results blew me away. I have never seen an effect as powerful as this." Progress however, has been hampered by the high cost of the implants and the lack of funding for follow on research. – Vagus Nerve Stimulation, Fibromyalgia and Chronic Fatigue Syndrome (ME/CFS) – Prohealth – February 16

A pensioner claims she has been left "like a leper on a scrapheap" after being told to pay for a lifeline drug which she had been receiving on prescription. Carol Place says she has been left "trapped in a body that does not work and with zero quality of life" after being told vital monthly medication from her GP would now have to be paid for. The 69-year-old had gone to her GP surgery last month for her regular prescription for Ubidecarenone to treat

her ME only to be told she was no longer entitled to the drug. Now, Carol is facing handing over at least £30 per month on the medication. Husband Brian, 72, said: "We know this drug is not licensed by NICE but it has been available to Carol on prescription for some time now. "It's infuriating and unfair that doctors are being told what they can and can't prescribe. We are now in a position where we will have to find the money if we want the medication that best helps Carol." – Northumberland pensioner told to pay for lifeline medication she had been receiving for free – The Castles Express – February 27

A year ago, the Institute of Medicine proposed that a new name, Systemic Exercise Intolerance Disease (SEID), should replace the separate classifications of ME and CFS. Although it has not happened yet, the author says the new name will not resolve a number of methodological and diagnostic issues. Firstly, a new diagnostic entity cannot replace two distinct, partially overlapping, clinical entities such as ME and CFS. Secondly, the SEID criteria seem to select an even more varied patient population, causing additional diagnostic confusion. – Replacing Myalgic Encephalomyelitis and Chronic Fatigue Syndrome with Systemic Exercise Intolerance Disease Is Not the Way forward – Prohealth – February 22

Researchers wanted to look at the effect of swimming on pain, functional capacity, aerobic capacity and quality of life on patients with fibromyalgia (FM). They looked at 75 female patients, aged 18 to 60 years with FM, randomly assigned to a swimming group (SG; n = 39) or a walking group (WG; n = 36). After testing them, patients in both groups experienced improvement in pain after the 12-week program, however with no difference between groups. The same results were found regarding functional capacity and quality of life. Moreover, no statistical difference between groups was found regarding aerobic capacity over time. So they concluded that swimming, like walking, is an effective method for reducing pain, improving functional capacity and quality of life in patients with FM. – Swimming Improves Pain and Functional Capacity of Patients with Fibromyalgia: A Randomized Controlled Trial. – Prohealth – February 29 2016

In 2011, the Solve ME/CFS Initiative engaged Biovista to search their vast medical database find new drugs that might help ME/CFS. Although they came up with Low Dose Naltrexone and Trazodone, neither have gone forward for further research as they didn't have positive effects which would have led to more trials. The study wasn't entirely unsuccessful though. The results teamed together two drugs that may target a hot topic in ME/CFS, the glia cells in the central nervous system. – Low Dose Naltrexone Drug Combination Proposed for Chronic Fatigue Syndrome (ME/CFS) – Prohealth – February 24

Bolton & Bury ME/CFS & FM Group AGM Minutes - 19th March 2015

Present Angela Henry, Andrew Simpson, Andrew & Kieran Gillibrand, Margaret Barlow, Louise & Sophie Day, Pamela Turner, Jeff Glasser, Karen Scully, Mandy & Dave Gore, Lynda Marney, C Higson, J Coupe, Maria Sale, Julia and Emma Chatwood, Carole Senior, Sue Courtney

Apologies

Carol Hobson, Angela Cassidy, Andrew Levy and Ruth, Norman & Rachel Fryman.

1. Minutes of last AGM held on 20th March 2014 - Pamela Turner proposed that these be accepted as correct and Mandy Gore seconded the proposal. Members voted unanimously to accept.
2. Matters Arising. No matters arising.

3. Resolution to vote in new constitution. Caroline explained the changes in the new constitution. Maria Sale proposed it be accepted. Angela Henry seconded the proposal. All present voted in support.
4. Secretary's Report and Committee Report. Members were able to read copies available at the meeting. Amanda Gore proposed and Pamela Turner seconded that the reports be accepted. All present voted in support.
5. Treasurers Report - Lynda Marney gave a brief outline of her report, copies of which were available at the meeting. Carole Senior proposed and Andrew Gillibrand seconded that the accounts be accepted as correct. All present voted in favour.
6. Election of Committee. It was proposed by Emma Chatwood and seconded by Louise Day that the five candidates be accepted. The vote was passed unanimously. Elected members of the committee are: Jeff Glasser; Caroline Higson; Lynda Marney; Maria Sale; Carole Senior.
7. Appointment of Honorary Auditor - it was proposed by Jeff Glasser and seconded by Margaret Barlow that David Whittall should be adopted as auditor for the coming year. This was agreed unanimously.
8. Any Other Business. No other business.
9. Date and time of next AGM - to be held on the 17th March 2016 at 7:30pm.

The AGM closed at 7:52pm, followed by a raffle and social evening.

Agenda for A.G.M

7:30pm - Thursday 17th March 2016

At: Environmental Resource Centre (Lancashire Wildlife Trust),
499 - 511 Bury Road, Bolton, BL2 6DH.

Agenda

- Apologies
- Minutes of last AGM
- Matters Arising
- The Secretary's Report
- The Treasurer's Report
- The Committee Report
- Resolution to raise annual membership fee.
- Nominations for the Committee
- Appointment of honorary Auditor for next year
- Any other Business
- Date and Time of next AGM
- Raffle

If you are unable to attend but would still like to cast your vote for the trustees, please tick the names on the list below and return to Carole Senior, 182 Church Street, Westhoughton, BOLTON, BL5 3SX by the 12th March. 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 AGM Ballot in the heading and copying/typing all of the names that you want to vote for. PLEASE STATE YOUR NAME. It is important that you are able to place your vote, as we have to show that are members are getting a say in who represents them each year. Thank You.

Raffle prizes welcome please! You can bring to socials, main meetings, or on the night of the AGM. Thank you!



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Please tick next to which trustees you are voting for (you can vote for them all, or whichever ones you wish). Information about each trustee was in the last newsletter.

- Carole Senior Caroline Higson Jeff Glasser Lynda Marney
- Maria Sale

Resolution to increase the annual membership to £10 **from April 2017.**

I vote in favour of increasing the annual membership.

I vote against increasing the annual membership fee.

Your name: