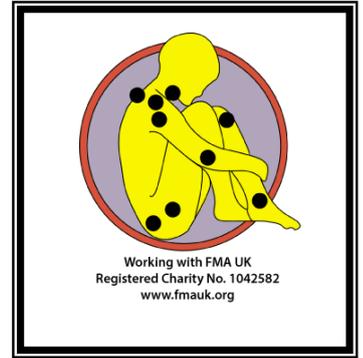




Welcome to Our November 2015 Newsletter.

Note from the Editor Maxine: Well done to Caroline for her charity head shave. Sorry about the late notice for last month's meeting being changed to a social, sometimes we cannot help cancellations. This month is the Social so please have a look on Facebook to add to the share supper or contact Caroline.



Monthly focus.

Registered Charity number is 1161356.

Samaritans

Now provide free calls to everyone who needs them
Their new number, 116 123, is free from landlines and mobiles in the UK.

Amazon

Sorry to say it so loud, but CHRISTMAS!! Yes, I can't believe it myself, but it's nearly here already. Seems like just yesterday I was buying Easter Eggs. Don't forget when you're panic-buying or splurging in the New Year sales, that the group gets a small commission on your Amazon.co.uk purchases.

To get the commission, you must first go to our website, www.mesupportgroup.co.uk and click on any of the Amazon links you see about, there's one on the left side all the time. You have to visit our site first each time you buy something for the purchase to be eligible. It's incredibly easy to do, takes seconds, but gets us about £150-£170 each year, which is fantastic. We really appreciate your support, thank you! Caroline

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 November 19th 7.30pm: Bring and Share Supper Our very popular pre-Xmas supper. Please bring a dish to share with fellow members. Don't worry, as there is always plenty of gluten, wheat and dairy free dishes and you won't go hungry!

No main meeting in December, but please join us at Prestwich!

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: Our Prestwich socials are now at **The Church Inn, 40 Church Lane, Prestwich, M25 1AJ.** This has level access and free parking outside. We meet on the **second Wednesday** of the month at 2pm, the next meeting is **Wednesday 11th November 2015** The attendance at Prestwich has been doing better lately, but do please try not to turn up too late in case numbers are low.

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 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.

Bury Bolton ME/CFS & FM October 2015 Group meeting

Unfortunately our speaker from Bolton CCG, had to cancel at the last minute, so we had a social instead. Sorry for any inconvenience to those who wanted to see her. If you have any issues you want to bring to their attention, please contact Maria Sale, who will be meeting with her (email: maria113@talktalk.net, or contact her via our Facebook group (the preferred choices), or phone 0786 7862341 if not online.

Caroline was on the door and ready to empty people's pockets for her sponsored head shave. Members have been extremely supportive, so thank you all.

We are pleased to see so many new members continue to attend, with the regulars on hand to welcome them.

Hope to see you all in November for our bring and share pre-Xmas supper.

ME/CFS Clinic Feedback

Representatives of the group will be meeting the ME/CFS Clinic team at Breighmet for the annual Steering Group Meeting at the end of November.

We would like any feedback, positive, negative, or otherwise, so we can see what members/patients experiences are of the service, and bring any issues to their attention, anonymously.

If you have any questions you would like us to ask the team, please let Caroline know: caroline@mesupportgroup.co.uk, 01204 525 955.

Caroline's Headshave



As mentioned in the last newsletter, group leader Caroline has undergone the chop in aid of the Bolton Destitute Animal Shelter. At the time of writing, £527 was raised! Can we reach £550? The hair was donated to The Princess Trust, who make wigs for children affected by cancer, so two charities have benefitted.

Caroline is unable to do most of the less energy zapping fundraising ideas (compared to marathons!) like skydives, bungee jumps, zip wires etc, because of her Ehlers Danlos and Osteoporosis, so getting her hair cut is something she can do! She did do the ice bucket challenge last year for the group though, just so that her Dad had to double his ice bucket donation for the group to £80. It was a lot easier than filling in loads of forms for grant applications.

Caroline got a lovely mobile hair dresser to do the honours (Terri Walker), and she looked quite traumatised by the end, having to take off all that hair! The hair needs to be washed and dried before it's sent off to be made into wigs. The hair is tied into pony tails, and tied at each end. You cut it before the ponytail, place in a sealed bag, and post off to the company that process the hair donations. Donators get a certificate via email later on. The rest of Caroline's hair was then shaved off (number 2 cut), and she now feels a distinct chill. She has been donated a small wig and a hat though, so it isn't all bad. She will dye it purple when it's long enough, but will keep it very short because it's so much easier to manage.

Caroline's two cats (Amber, 12 and daughter Jade, 11), were adopted from the Shelter in 2004. They were left in a cardboard box overnight. As most people with furry overlords will tell you, life wouldn't be the same with out them.



Hundreds of animals pass through the no-kill shelter every year, and they rely on donations. Founded in 1920, they take in stray/injured/lost cats and dogs and try to reunite them with owners. They neuter all animals which are rehomed to prevent a rise in the unwanted cat/dog population.

They will microchip dogs and cats for £7.00 (free for dogs if you are on benefits) Please ring the shelter to make an appointment on 01204 526 486.

There's still time to donate if you haven't yet! Go to:

<https://www.gofundme.com/carolineheadshave>

Or donate via PayPal to chigson47@gmail.com marked "head shave"

Or send a cheque payable to "Destitute Animal Shelter" to 53 Denstone Crescent, Bolton, BL2 5DE, or pass on at the November meetings please.

Many thanks for everyone's support, the group members have been so generous.

DevoManc.

I am still representing our group in discussions around the devolution and integration of health and social care in Greater Manchester, which are continuing in two parallel initiatives. I'll write about just one here, and the other at a later date when I have more concrete information.

A focus group was set up, initially for Salford and central Manchester CCGs, but we have been invited, as has Stockport support group. There has been a proposal for a new clinic, to be run by Dr. Patrick. The committee was concerned that there was a danger such a clinic could replace rather than complement our clinic and others, hence the discussion document below. Our clinic may not be perfect, but we don't want to lose it, and really want to enhance services under DevoManc.

Please feel free to send me your thoughts on these discussion points, which are a work in progress. I would prefer email, so I have it written and won't forget! My email is maria113@talktalk.net. Please let me know your opinions either way, or if you are happy and have no suggestions: we are now the largest group in Greater Manchester and we want to show our strength in numbers.

Maria Sale

Discussion document: ME/CFS

Second draft, following further consultation with the rest of the committee and members of the Bury and Bolton ME/CFS and Fibromyalgia group. The group has been in continuous existence for 25 years. It has an average of 170 subscribing members and is a charity with a committee of 5 trustees; regular formal and informal meetings; a private and public Facebook group, and a monthly newsletter.

- 1) DevoManc should be an opportunity to safeguard best practice and improve on it, while filling gaps in service. It should, by being more effective and meeting the needs of patients, save money in the long term.
- 2) Addition of a new clinic in or near central Manchester, run by Dr Patrick., who we understand is willing to take this on. This could work very well as part of a linking network. People could decide together with their GP to be referred to the nearest, or the one with the shortest waiting list, or the clinic run by the most appropriate consultant, eg., someone who has particularly difficult neurological symptoms may prefer to attend the Bury and Bolton and Wigan service, whereas another person may wish to see an endocrinologist. Under DevoManc, each clinic could be much

more flexible, and take patients from across Greater Manchester. Again, this could be cost-effective.

- 3) All clinics should have much improved links with workers in social /community care. The integration of health and social care is a fundamental part of DevoManc.
- 4) All clinics should have links to benefits advisers.
- 5) Any patient should be able to self-refer back to the clinic within 1 year of treatment, or through their GP if longer.
- 6) Every person with ME/CFS should have an annual review, as is the right of anyone with a long-term health condition. This could be done through GP surgeries with support from the clinics. Nothing of the sort is happening at the moment: people speak about being "abandoned": other conditions can develop unnoticed , with new symptoms being put down to the ME: it would also help to form a much more accurate picture of how many people have ME and what the recovery rate is. These data would be extremely useful for research. Ideally bloods should be done.
- 7) Rigorous diagnosis is vital, with good follow-up support.
- 8) A domiciliary service for the severely affected.
- 9) GP education is vital, particularly those practices which make no referrals at all to clinics.
- 10) ME/CFS services should be moved out of the mental health umbrella.

How to Cope with Side-Effects of Medications **Strategies for weathering the side-effects of prescription drugs**

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.

Many of us who suffer from chronic pain and illness are on medications with side-effects that, in some cases, are as difficult to cope with as our initial health problems. I've recently started a medication that I'm scheduled to be on for five years. I'm taking it because it significantly reduces the risk of a recurrence of my recent bout with breast cancer (if you want, you can read about that at <https://www.psychologytoday.com/blog/turning-straw-gold/201502/caught-guard-breast-cancer-first-impressions>).

And so, yes, I'm taking the medication... but I'm also struggling with its physical and mental side-effects. This article is not a substitute for talking to your doctor about any difficulties you're encountering with a prescription drug. That said, I want to share two strategies for coping with the side-effects of medications.

Start where you are

In my book, *How to Wake Up*, I write about Pema Chödrön's practice called *start where you are*. I describe how it's helped me make peace with living day-to-day with a number of unpleasant symptoms associated with a chronic illness I've suffered from since 2001.

With the help of this practice, instead of mounting a daily—but ultimately losing—battle against those symptoms by telling myself how much I hate them and how I must get rid of them, I say to myself: “Okay. These symptoms are my starting point today: I feel sick and I'm in pain. Now, how can I make the best of this day?” Pema Chödrön's *start where you are* enables me to be present for my life as it is and to try and enjoy it, instead of spending my time complaining about a life I can no longer lead.

This new medication has brought along with it a new *start where you are* challenge for me. In addition to coping with the flu-like symptoms from my longstanding illness, I'm now having to live with half a dozen side-effects of this new drug. Three examples: sleep is even less restorative than it used to be; my right thumb is so swollen and painful in the morning that I can barely bend it for a few hours until it loosens up. (“Joint pain or stiffness” and “Problems with your fingers while gripping” are included on the list of possible side-effects for this medication.)

And I've been feeling low mentally. (“Mood changes” is also on the list of possible side-effects.) Despite being chronically ill for many years, I've almost always looked forward to the day, no matter how sick I've felt. But on this medication, I can feel a change in my mental chemistry. I experience it as a low-grade dread of the day ahead and a lack of motivation, as if I can't be bothered to do anything. This is very unlike me.

At first, I felt tossed about by these physical and mental side-effects. I was irritable most of the day and complained a lot about the medication, even though I continued to believe that its benefits outweighed the negatives from its side-effects. No doubt about it: I was at a loss as to how to skillfully handle what was happening to me.

Then I remembered Pema Chödrön's *start where you are*. I thought about how complaining about side-effects did nothing to diminish them; in fact, it increased my mental suffering. I decided it would be better for me to stop fighting what was happening and to begin treating how I was feeling as my starting point.

I've been working on this, and it's turning out to be more helpful than I'd imagined. This change in perspective has even opened my mind to the fact that no medication's side-effects are set in stone. My body may adjust to some or all of them (the initial side-effect of shirt-drenching night sweats has already improved). I'd been so busy complaining about the medication that I hadn't considered the possibility that some of the side-effects might be temporary—despite the fact that the drug information sheet contains that very statement.

If you're on a medication that has unpleasant side-effects, I hope you'll try Pema Chödrön's practice. I'm confident it will feel better than being trapped in anger and resentment over something you don't control (just like you don't control having medical problems in the first place). To *start where you are*, acknowledge how you feel—side-effects included—and let that be your starting point for the day.

Okay, having started where you are, then what? That takes me to my second suggestion.

Find a work-around

As with *start where you are*, finding work-arounds is something I've been doing for years to cope with the symptoms of my chronic illness. If I have a task that has to get done, such as pruning some bushes, instead of doing it all at once, I make it a two- or three-day project. If I wake up feeling too sick to leave the bedroom, I try to come up with ways to enjoy myself on the bed that day.

Since I'd already been looking for work-arounds with my chronic illness, I decided I should try it with the side-effects of this medication.

I started with my right thumb. Because I'm right-handed, until my thumb loosens up, I'm limited in what I can do. I can't get the toothpaste cap open, let alone hold onto the cord I use to pull the blinds up in the bedroom. Some days, I can't hold a pen. When this first happened, I spent my mornings complaining to my husband and resenting the injustice of it all. He was sympathetic and supportive, but this was not pleasant for either of us.

Then one morning I said to myself: "Okay, first, *start where you are*: your right hand is of limited use for a few hours after you get up. That's the way it is." Then I looked for some work-arounds. I discovered I could use my left hand for simple tasks, such as unscrewing the toothpaste cap. I've learned to pull the blinds up without using my right thumb. I postpone other tasks until my thumb has loosened up. Life is much more pleasant for me and for my husband since I've started working around what I simply cannot do.

Finding a work-around for my low mood has proven to be more of a challenge. *How do you work around the feeling that you don't want to be bothered to work around a feeling?!* It took a while, but here's what I discovered works for me: gentle force. By gentle force, I mean compassionate force, which means I start by acknowledging how hard it is to feel down and motivationless...and how it isn't my fault. Having done that, I then force myself to start doing something.

Without that initial dose of self-compassion, I don't think force would work for me. Being kind to myself helps me muster the energy to get going, and once I'm "up and running," my mood improves. It reminds me of a lawn mower that's stubborn to start. You have to keep pulling on the starting cord. It may take a dozen times, but once the mower starts, it hums away.

How I came to write this very piece is an example. The idea for it came to me when I'd gotten up in the middle of the night to use the bathroom. Before I started on this medication, when I'd have one of those middle-of-the-night ideas, as soon as I'd get up in the morning, I'd *want* to get my thoughts down on paper. But not this time. When I woke up, I couldn't be bothered to write anything. I felt too down.

It was time for a work-around. First, I acknowledged with compassion how sad this lack of motivation is for me. Then I forced myself to open a document, label it "side-effects of medication," and type something—anything—about this topic. Having forced myself to do this, I was off and running like that lawn mower; I even enjoyed getting my initial thoughts

written down. When it came to editing (and I do a lot of it), I had to go through this same process again—a little self-compassion and a little force—but once I got going, I enjoyed it.

I recently had to use gentle force as a work-around with my friend Dawn. We had a date to meet at a nearby café for an hour. I came close to cancelling, even though I was feeling up for it physically. Mentally, however, I couldn't be bothered. I didn't want to see anyone or visit with anyone. Fortunately, I tried a "mental" work-around: I gently forced myself to leave the house and go meet her. I had a great time.

So that's my plan for coping with the side-effects of this medication. If they persist, it may turn out to be a five-year plan (although I will raise what's happening with my doctor at our next appointment).

If you're experiencing side-effects from one or more medications, I hope you'll *start where you are* and then look for some *work-arounds*. My heartfelt best to everyone.

Late edition - October 2015

This month, widespread coverage was given to the recent long term follow up of the 2011 PACE trial. The reporting caused a strong reaction against their findings. So to shed more light on the issue, we're copying an excerpt from the Lancet Psychiatry journal so you can see what was written by the research team.

Background

The 2011 PACE trial found that, when added to Specialist Medical Care (SMC), Cognitive Behavioural Therapy (CBT), or Graded Exercise Therapy (GET) were superior to Adaptive Pacing Therapy (APT) or SMC alone in improving fatigue and physical functioning in people with Chronic Fatigue Syndrome 1 year after randomisation. In this pre-specified follow-up study, the research team aimed to assess additional treatments received after the trial and investigate long-term outcomes (at least 2 years after randomisation) within and between original treatment groups in those originally included in the PACE trial.

Interpretation of their results

After the groups were asked a series of questions and the results calculated, the conclusion was as follows:

The beneficial effects of CBT and GET seen at 1 year were maintained at long-term follow-up a median of 2.5 years after randomisation. Outcomes with SMC alone or APT improved from the 1 year outcome and were similar to CBT and GET at long-term follow-up, but this data should be interpreted in the context of additional therapies having being given according to physician choice and patient preference after the 1 year trial final assessment. Future research should identify predictors of response to CBT and GET and also develop better treatments for those who respond to neither. - Rehabilitative treatments for chronic fatigue syndrome: long-term follow-up from the PACE trial – The Lancet Psychiatry - October 27

COMMENT: Despite the controversy amongst media and patients, it is important to recognise the following excerpts in this research which dilute the sensational headlines in the press. They are:

- *This study, “does not provide evidence that CBT and GET are better than SMC and APT in the longer term because patients allocated to these treatments had improved to a similar degree by the time of the follow-up”.*
- *At no stage in the report does it say that patients recovered. It only talks about “improvement” or “significant improvement”.*
- *They also said, “The observation that some patients remain unwell at long-term follow-up reminds us that more effective treatments are still needed for these patients.”*
- *The 481 patients were far from a uniform group, showing what a diverse sample size they looked at. For example, 46% also had a psychiatric disorder. The duration of ME/CFS people had was from 16 to 66 months. Only two thirds met the International CFS criteria for the disease, and just over half met the London CFS criteria.*
- *The researchers also identified 4 limitations that affected the validity of the results.*

The bottom line is that the researchers were dealing with an incredibly complex issue where the sample size, methods, measurement etc. are all impossible to clarify or standardise. Therefore, applying even the highest scientific rigour still opens projects like this to doubt and criticism.

Other articles published this month

In the USA, it has long been felt that researchers pay scant attention to ME/CFS. Therefore, U.S. National Institutes of Health (NIH) has announced that it is increasing efforts to figure out what causes the illness and to find treatments for it. NIH Director Francis Collins told Science magazine that some investigators have long shied away from studying ME/CFS because it has been a “tumultuous” research arena, with high-profile leads that imploded and a vocal advocacy community. Changes they are making including re-assigning the oversight of ME/CFS research from the Office of Research on Women’s Health to the National Institute of Neurological Disorders and Stroke (NINDS), as well as studying people shortly after they develop related symptoms from a probable but as yet unidentified infection. - NIH refocuses research into chronic fatigue syndrome - Science - October 29

A recent study into Pandemic influenza A (H1N1) infection has revealed it was associated with a more than two-fold increased risk of ME/CFS. However, researchers found no indication of an increased risk of ME/CFS after vaccination. Their findings were consistent with a model whereby an infection triggers ME/CFS, rather than medication to stimulate the body’s immune system. - Chronic fatigue syndrome/myalgic encephalomyelitis (ME/CFS) is associated with pandemic influenza infection, but not with an adjuvanted pandemic influenza vaccine - Prohealth - October 24