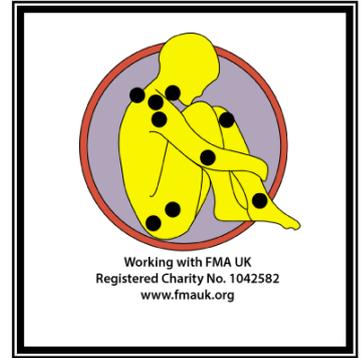




## **Welcome to Our April/ May 2015 Newsletter.**

Note from the Editor Maxine: Thank you to all that went to the AGM and Voted. Sorry this newsletter is a little later than normal. Between the editor and other helpers having ME and Printers that need memory we are not doing very well!



### **Monthly focus.**

We are a Registered Charity. Thank you to Caroline for all her hard work. Our charity number is 1161356.

Thank you Sara for all your hard work at the printing and posting end of the news letter. Maxine

### **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](mailto:caroline@mesupportgroup.co.uk).

**Thursday May 21st 7:30pm:** Unfortunately, Sandra from the Wildlife Trust will not be recovered enough from her recent operation to do our talk this month. We hope her recovery goes well, and that she is able to talk to us possibly in June, or a future date.

We do have a replacement. **Jennifer Calhoun Gilmour** will do a **craft demo** for us: she does all sorts of crafts, as well as running a weekly quilting club in Harwood and also facilitating a knitting club at Elderdale Community Centre. She also recently run a drop-in craft fun day at Red Lane church in Brightmet. She has stepped in at the last minute, so we really appreciate her help, and hopefully we'll have an enjoyable evening.

**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 Julia Silver-Wren 01204 394 768 or email [juliasilverwren@talktalk.net](mailto:juliasilverwren@talktalk.net) for details. **Our yoga classes are currently being funded by The Big Lottery Fund.**

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**April/ May 2015**

**Bolton Socials:** Unfortunately attendance at the Bolton socials has been quite poor the last several months and we now have **no alternative but to cancel them.**

**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 13<sup>th</sup> May and 10<sup>th</sup> June 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.

## **Bolton & Bury ME/CFS & FM Group AGM Minutes - 19<sup>th</sup> 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 17<sup>th</sup> March 2016 at 7:30pm.

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

## **COMMITTEE REPORT AGM, MARCH 2015**

In a year marked by change and upheaval for the group we have been even more indebted to our small army of volunteers for their help and support. Grateful thanks to all of them, without them the group would not exist.

Maxine now edits and distributes our monthly newsletter by email. She has some great ideas and has really settled into the role. Thanks Maxine.

Ruth sends out Benefit and Work Guides, by email and post. These are an invaluable resource for members, thank you Ruth.

Sara has continued to deal with many admin matters, though she hopes to stand down next month after heroic efforts. She has printed, assembled, stapled and sent out paper copies of the monthly newsletter, assembled and sent out welcome packs to new members and produced copies of leaflets and guides. Many thanks Sara.

Carole has continued on in her librarian role, which is a much valued service for the members. She also writes the minutes at our committee meetings and the reports for the AGM. Thank you so much Carole.

Susan has long been our main doorman at meetings, though she also is standing down. Thank you to Susan and to those who have covered the role when needed.

New volunteers, Angela Henry and Andy Simpson, have offered their help, manned the door at meetings and helped with refreshments. They have also offered to take on Sara's duties. Thanks to you both. Angela's mum, Sue Walker, manager of the One-Stop store in

Farnworth also deserves a big thanks as she held a bake sale for us and raised £167 for us. Well done Sue.

Thanks are due to Hilary, Joanne and Carol for their typing skills; also to Karen who has joined their ranks recently. Many thanks to Pam for taking notes at meetings.

Louise and her daughter Sophie have taken responsibility for our awareness merchandising, selling ME and FM badges etc and positive disability items. Thank you both.

Our yoga sessions are now run by Julia, who has continued to provide a much appreciated service. Thank you Julia.

Lynda, our Treasurer, still keeps a sharp eye on our finances. This is a huge and vital job, especially at this time of year with the extra work of processing membership renewals, so many thanks to Lynda for all her much appreciated work.

Our Meetings Secretary, Maria, is responsible for finding and booking interesting and varied speakers for our monthly meetings. She also plays an important role in supporting members on our facebook page and attends ETAG and other meetings on our behalf. Thank you for all you do Maria.

Jeff offers support and advice on practical matters, drawing on his knowledge and experience of benefits and support systems, both personal and professional. He has given talks to the group, supported members with applications and appeals advice, taken a fund-raising trip with his friend Chico and manned the door at meetings. Thanks for all of it Jeff.

Caroline fills many roles and is at the heart of much that happens in the group. She maintains the membership database, manages our website, applies for the majority of the grants that keep us functioning, writes newsletter articles, attends ME/CFS Clinic meetings and this year rewrote our constitution as she spearheaded our application for charitable status. Huge thanks, Caroline, for all you do.

Thanks to all those who donated raffle prizes for our socials and those who bought raffle tickets.

Kath Morgan gave us sterling service as tea lady and general support at Longsight Methodist Church, but was unable to join us at our new venue. Thanks to Kath for all her help.

Our new hosts for monthly meetings, Lancashire Wildlife Trust, generously set up the room for us and clear away afterwards. They also organise tea and coffee making facilities and have offered cupboard space for storage. Thank you to Sandra and colleagues.

We are honoured to have received donations in memory of loved ones – Mr Chris Hampson and Mr Frederick Gilmore. Grateful thanks to both families. We run on membership fees and grants, so any donation is greatly appreciated.

Thanks to SmartCrutchUK, who kindly donated a pair of their crutches as a raffle prize and for members to borrow.

Grateful thanks to all our sponsors, whose grants allow our group to function more efficiently: Festival Medical Services, The Co-Operative Members Community Fund, The Big Lottery Fund, Bolton Council/The Big Bolton Fund, administered by Bolton CVS who are always on hand with advice and support.

Special thanks to Helen of Bolton CVS for her invaluable help in guiding us through our application for charitable status, including an updated constitution. We really couldn't have done it without you.

Thanks finally to all our members, apologies if your help has not been acknowledged individually. Together we are stronger and can fight the frustration of isolation of ME and Fibromyalgia. Thank you all.

## **SECRETARY'S REPORT AGM, MARCH 2015**

The last year has been one of change and upheaval for the group; our monthly meetings have seen us change venue twice and we are well on the way to achieving charitable status (which was granted in April).

In May we moved from Longsight Methodist Church Hall to the Church itself, which had been newly refurbished to provide a meeting room. While we liked the facilities – and enjoyed the services of church member, Kath Morgan, who volunteered to be our tea lady, as well as helping to set out and clear away tables and chairs for our meetings – with building development in the offing, our future was unsure. There was a worry about future disruption when the proposed building work began and parking, already an issue for some because of the distance people had to walk, threatened to become an even bigger problem. As a consequence we moved in October to Lancashire Wildlife Trust on Bury Road; there is a car park, a lift to the first floor and some cupboard space, so that not everything has to be taken to and from every meeting. Sandra and her colleagues have made us most welcome; tables and chairs are set out for us, as are tea and coffee facilities and we are not required to clear away at the end of the meeting.

Our second leap into the unknown is the move to become a charity. We have applied for charitable status, which we were required to do as our income had grown and which should really have been done 2 years ago, and are eternally grateful for the advice and support of Helen at Bolton CVS. She met with Committee members, answered our questions and concerns and guided us through the process of developing a new constitution and the maze of the application procedure. Special thanks are due here to Caroline, who took on the task of producing the new constitution, using a combination of our old one and Helen's exemplar, resulting in a document of impressive and daunting length.

Committee members have had to become Trustees, for which there were the obligatory checks (again processed by Caroline) but since we were already covering all the requirements for attaining charitable status, once our application is approved there will be little or no change in our day to day functioning. The group has been in existence for a number of years now and the hard work of the past could not be wasted by allowing it to fold. If taking charitable status was the only way to keep the group alive, the Committee felt that any changes – and the work entailed – were worthwhile.

The Committee now has only 5 members (5 Trustees!) and the group could not function without the help of volunteers who give of their time and energy to help and support us. Our grateful thanks go to all of them.

We have held our usual 9 meetings, though we have convened at three different venues this year, with a mix of guest speakers and socials.

- In May our old friend, Dr Raymond Perrin, told us about his participation in the Stanford University Symposium, which was the 11<sup>th</sup> International Association of ME/CFS Conference, held in San Francisco in March 2014. As ever, Dr Perrin spoke at length and with great enthusiasm in a talk packed with fascinating information.
- Holistic Therapist, Tracey Hughes, spoke to us in June. She gave us a guide to Reiki, focusing on stress relief and positive energy.
- July was a social evening, with a gorgeous array of food.
- September's meeting was an EGM, where the projected bid for charitable status was discussed, voted on and approved.
- The expected speaker for the DWP, who was to have spoken to us about PIP's, cancelled at very short notice in October. Attending members held an informal discussion, where people were able to share their own experiences and offer and receive advice and practical tips.
- We held our traditional bring-and-share supper in November, where people could enjoy a wide variety of delicious food and a chat.
- Michelle Cardno of Fightback was our speaker in January, giving us lots of useful advice and information on completing application forms for PIP's and any subsequent appeals.
- February brought us Rebecca Richmond, who told us of her personal battles with Fibromyalgia and ME. She had fought this successfully and described the ways in which she had dealt with the stress at its root.

Yoga sessions continue at the Jubilee Centre, though with a new teacher in Julia Silver-Wren. We retain our grants to fund these sessions and they remain free for members.

Prestwich socials have seen an improved attendance but the Bolton socials, formerly held at Radcliffe's Sparkling Clog, have been forced into a series of changes of venue and attendance has fallen away to the point where they have been cancelled.

The group's library has had a number of new titles, including an extra copy of 'The Perrin Technique' donated by Dr Perrin and a copy of Rebecca Richmond's book. We have further extended our supply of recipe books, many focusing on wheat/gluten/dairy free recipes which are always in demand. Some of our new stock was bought with a grant for £100 in 2014 and we now have a new grant to be spent by May – suggestions are welcomed for possible additions, either specific titles or subject areas you feel could be extended.

We have maintained our connection with the ME/CFS Clinic in Brighton, with Caroline and Joanne attending the joint meeting. There have been a number of personnel changes at the Clinic but discussions continue about concerns raised by our members.

Caroline hit the media recently, featuring in the Bolton News and being interviewed on radio, along with Maria. We welcome any opportunity to raise the profile of our group and awareness of ME generally and the Bolton News feature garnered some positive comments and resulted in several enquiries about the group.

We have also registered as a group to work with Fibromyalgia UK, a registered charity. This means we can benefit from their literature and information and they can direct any local enquiries to us. We estimate that a quarter to a third of our members have ME as well as Fibromyalgia, and the Bolton Fibromyalgia group closed down a couple of years ago, so this seemed a logical step to take.

We hope that the year ahead continues to be successful for the group, with fewer changes than the last one.

## **We Are Now A Registered Charity!**

We are very excited to announce that as of Tuesday April 21<sup>st</sup> 2015, we successfully completed the process to become a charity! This was a necessary step we had to take in order to continue operating and supporting people with these debilitating illnesses, so hopefully it will all be worth it and we will be around for many more years. Our registered charity number is 1161356.

This means the 5 committee members are now Trustees. We already operate as a charity, in that we have an AGM and audit our accounts, so we won't have to do much more; just now there is a deadline for these to submit them to the charity commission, with penalties if we don't meet them.

Hopefully this will enable us to apply for more grants to fund our activities, and also give us more status in the community when asking for sponsorship or coverage in the media.

We would also now be eligible for Gift Aid, which means if you pay tax, we get an 25% extra added onto your donations, so your £8 annual subs becomes £10, at no extra cost to you, if you are eligible. We could also claim back on the last 4 years of donations. At present, we're not sure how much work is involved in setting this up and administering this, and we're not sure if enough people in the group pay tax to make it worth the paperwork. It's hard enough to run the group already and we don't want to add more for Lynda to do. People may pay tax either through work, or their pension, or if using a joint or tax-paying partner's account to pay their membership, so it might be worth it. We may look into this further down the line.

This is a great end-result after Caroline had to do a lot of background reading, email writing, telephone calls and hoop-jumping! Many thanks to **Bolton CVS** for funding our insurance, which is needed again now we are an independent charity. Huge thanks also to **Helen, the Group Development Co-Ordinator**. She met with the committee (now Trustees), after we had started the process and had rather a lot of questions and concerns. She was very helpful, knowledgeable, checked our application before submission and offered advice on it.

**Please think of us if you see any grants or opportunities for charities.** Caroline is an insurance policy holder of Liverpool Victoria and with their AGM voting papers you can nominate a charity to receive funds, and the winner will be selected at random. Small things like this are easy to do and would mean a great deal to us! Thank you for your continued support. Caroline

### **Volunteers Needed:**

- Writing up anything of interest for the newsletter, e.g. day trips out, recipes, an interesting article about ME or FM research you have found, etc.
- Can you help? Please contact [caroline@mesupportgroup.co.uk](mailto:caroline@mesupportgroup.co.uk) / 01204 525 955 if you can help.

### **Audio versions of The Bolton News**

Bolton Newstalk are a registered charity who provide a free, weekly digest of The Bolton News, delivered free to the visually impaired, and disabled. They also provide an Audio Conversion Service, with printed CDs if required, at very reasonable rates. Every Sunday, they record the previous week's articles from the Bolton News and send them to over 240 people a week, in Bolton and surrounding areas. Enquiries to 07547914637 / [newstalk@icloud.com](mailto:newstalk@icloud.com). <http://www.boltonnewstalk.org.uk/>

### **British Red Cross**

Some of our members who have been with us for a while, may remember a talk by the Red Cross a few years ago. It was very informative and we learned that they had a volunteer driver scheme and equipment loan service, which are just two of things which may be of benefit to our members. For new members, or just to refresh you memory, here's the information again:

**They provide short-term loans of wheelchairs and other equipment at almost 1,000 outlets in the UK.**

If you are recovering from an injury or operation, then the NHS or your local authority will provide you with crutches or a walking frame, etc.

If complete recovery is not possible, or if you have an illness or disability that permanently affects your mobility, then the NHS will provide you with a wheelchair for long-term use. However, if you need a wheelchair for less than six months – for any reason other than terminal illness, the NHS nor your local authority will provide you with one.

Where we work > HealthandSupport

The screenshot shows a search interface for 'Health & support services' in Bolton. The search area includes a location field set to 'Bolton', a radius dropdown set to 'within 5 miles', and a 'Search' button. Below the search bar, there is a 'Find Your Nearest' section with the text 'Find your nearest health and support services.' The search results area is currently empty.

Health & support services		Fundraising event		Charity shop		First aid course		Red Cross office		
<input checked="" type="checkbox"/> Hire a wheelchair	<input type="checkbox"/> Refugee support	<input type="checkbox"/> Support in emergencies	<input checked="" type="checkbox"/> Mobility aids	<input type="checkbox"/> Event first aid	<input type="checkbox"/> Fire and emergency support	<input checked="" type="checkbox"/> Transport support	<input type="checkbox"/> Hand, arm and shoulder massage	<input type="checkbox"/> Humanitarian education	<input type="checkbox"/> Support at home	<input type="checkbox"/> International family tracing

The types of mobility aids they provide include:

- Wheelchairs
- Backrests
- Bath seats
- Walking sticks and frames
- Commodes
- Bedpans
- Urinals

You can visit their offices to pick up, or they can deliver the items directly to you. The nearest branches to most of us are: Bolton (01204 369620), Swinton (0161 794 9022) Manchester (0161 888 8900).

They ask for a returnable £20 deposit, which you will get back when you bring back the item. Usually you can keep the items for 6 weeks (but perhaps longer if you ask, or if there is enough stock). This service runs entirely on donations.

Age UK also loan wheelchairs to over 55's.

They also have a **volunteer driver scheme** to offer transport support. This would be helpful if you need help getting to appointments, and have no transport, or can't afford a large taxi fare. The volunteers are DBS checked and the service depends on their availability. You are only asked to contribute to petrol costs, but will not be refused if you can't. (tel: 01204 369620). Some Councils also offer volunteer driver schemes, and there is Ring & Ride, and taxi vouchers, that we have previously covered.

The Red Cross volunteers offer **hand, arm and shoulder massage**, done through clothing. This relaxes, reduces pain and stress and improves well being. These can be given at hospitals, GP surgeries, community halls or at home. Referrals normally through health professionals, but you can self-refer. Contact your local branch for information.

Their volunteers will offer **support at home**, for those who have come home from hospital. They can help with getting prescriptions or shopping, offering companionship, and rebuilding lost confidence. They are trained in first aid and social care. Referrals can come from GPs, hospitals, CCGs, social workers and individuals. This help is only for a limited time, but would be of a great help to many dealing with readjusting to a routine, taking new medicine, etc. Call your local Red Cross office for info ...Caroline

### **“Voices From The Shadows” DVD**

We have obtained two copies of the DVD “Voices From The Shadows” for our group library. The film shows several case studies of people with severe ME, and the appalling “treatment” they received.

It is distressing, and probably not going to provide much useful information to someone with the disease: indeed it could cause some, especially someone newly diagnosed or who also has depression, to feel more pessimistic about their prognosis.

It could be valuable to lend to friends or family who have difficulty understanding or accepting the condition, but not young people, under-16s or anyone vulnerable. Please let me know if your opinion is different -Maria Sale

Their website is <http://voicesfromtheshadowsfilm.co.uk/>

## Laugh For ME on Sun 17th May 2015

On May 17th The Frog & Bucket will host a truly spectacular line up of comedians from all manner of places and every conceivable background. They will all have two things in common.

One is that they're joining forces to raise money for Walk For ME, a week of activities aimed at helping support the sufferers of this chronic illness and strive towards a cure. Supporting ME Research UK and Invest in ME via Walk for ME.

Caimh McDonnell - BAFTA award winning Irish wit & anecdotes.

Bethany Black - Cult comedian turned actress

Sully O'Sullivan - Gruff, deadpan brilliance from this New Zealander.

Ben Schofield - Larger than life, infinitely funnier.

Penella Mellor - As heard on BBC Radio 2

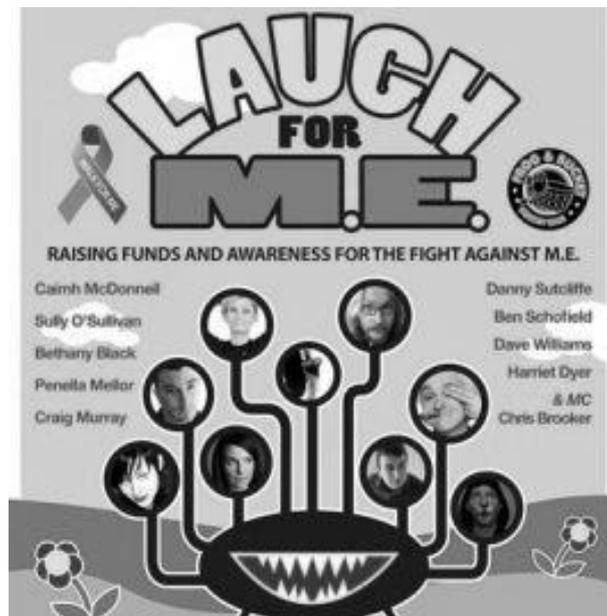
Dave Williams - Comedy Store regular

Danny Sutcliffe - Rock Radio comedy award winner, a local gem.

Craig Murray - A familiar face from TV

Harriet Dyer - One cannot be told what Harriet Dyer is... One can only experience her whirlwind for oneself.

MC - Chris Brooker - Organiser books himself as compere to the surprise of no-one.



Please note that the line-up is subject to change. Strictly 18+ with adult themes and language throughout. Please bring identification if you appear to be under 25 as you may be denied entry if you cannot verify your age.

Buy tickets: <http://www.skiddle.com/whats-on/Manchester/Frog-And-Bucket/Laugh-For-ME/12337625/> Venue: 0161 2369805

## Motability Big Event:

EventCity, Manchester on Friday 8 & Saturday 9 May 2015.

The Big Event is the biggest event of the year and is the perfect way to find out about worry-free motoring with the Motability Scheme. Everyone will be able to relax and enjoy the event while taking a look at the wide range of cars, adaptations, Wheelchair Accessible Vehicles, scooters and powered wheelchairs available through the Motability Scheme.

It's totally free and a great day out for all the family.

Here are just some of the reasons why you should join us at The Big Event:

- It's the UK's largest display of vehicles available on the Motability Scheme
- Motability advisors and adaptation specialists on hand to answer questions
- FREE entry and FREE parking, kids entertainment, refreshment and entry to prize draw to win an iPad mini.
- Test drives available in a range of automatic cars fitted with popular driving adaptations

For more information about the event visit [www.motability.co.uk/thebigevent](http://www.motability.co.uk/thebigevent)

## Comparative Pain Scales

How often have you been asked to rate your pain on a number from 1-10? Or make a mark on a line how bad your pain is? What about the cartoon faces with different expressions and you have to pick the one that's closest to you? This way, the doctors we meet can get an idea of how much our pain is affecting us on a daily basis, and how bad it is. You can't prove you've got chronic pain. They can't see it on test and it's invisible.

However, how bad is an 8? Is my 8, as bad as your 8? When I say a 6 this week, is this the same pain that I would class as a 6 last year? Do I have a lower threshold for pain than you?

It's a very subjective scale and varies very much by person, but will help you identify your pain levels over a period of days/weeks/months. People will often over-rate or even under-rate their pain, as they have no idea what an "8" on the pain scale really means.

The text below is a "Comparative Pain Scale", developed by Health Organization for Pudendal Education (HOPE). This is a very useful guide to what the numbers 1-10 really mean. So when a doctor asks us to rate the pain, and we say "11", you can now see that have to be a quite unimaginable level of pain.

Learn how to communicate the pain clearly:

Describe the sensations/feelings of the pain (shooting, burning, tingling, stabbing, etc).

How does this affect you physically and mentally?

Have you had to change the way you do certain things because of the pain, or rely on other people for help?

Have you had to give up work or any hobbies because of the pain?

Is it the same level of the pain throughout the day, or does it progressively get worse?

What helps the pain? What makes it worsen?

Keep a pain diary, writing down your activity and then rating your pain using the scale. This may help identify why you get pain flare ups and what helps them subside.

Arthritis Research UK have a very helpful booklet called "[Living with Long-term pain: a guide to self-management.](#)" It can apply to any musculoskeletal condition, or anything that causes long term pain and I found the advice in it really helpful. The booklet is very thick, with pages for you to write down notes in, but is the sort you can just pick up and flick through. We have several copies and usually have some at the main meetings (or call me to bring some).

<http://www.arthritisresearchuk.org/arthritis-information/arthritis-and-daily-life/pain-and-arthritis/pain-report.aspx>

Caroline

## Comparative Pain Scale

	<b>0</b>	No pain. Feeling perfectly normal.
<b>Minor</b>  Does not interfere with most activities. Able to adapt to pain psychologically and with medication or devices such as cushions.	<b>1 Very Mild</b>	Very light barely noticeable pain, like a mosquito bite or a poison ivy itch. Most of the time you never think about the pain.
	<b>2 Discomforting</b>	Minor pain, like lightly pinching the fold of skin between the thumb and first finger with the other hand, using the fingernails. Note that people react differently to this self-test.
	<b>3 Tolerable</b>	Very noticeable pain, like an accidental cut, a blow to the nose causing a bloody nose, or a doctor giving you an injection. The pain is not so strong that you cannot get used to it. Eventually, most of the time you don't notice the pain. You have <i>adapted</i> to it.
<b>Moderate</b>  Interferes with many activities. Requires lifestyle changes but patient remains independent. Unable to adapt to pain.	<b>4 Distressing</b>	Strong, deep pain, like an average toothache, the initial pain from a bee sting, or minor trauma to part of the body, such as stubbing your toe real hard. So strong you notice the pain all the time and <i>cannot completely adapt</i> . This pain level can be simulated by pinching the fold of skin between the thumb and first finger with the other hand, using the fingernails, and squeezing real hard. Note how the simulated pain is initially piercing but becomes dull after that.
	<b>5 Very Distressing</b>	Strong, deep, piercing pain, such as a sprained ankle when you stand on it wrong or mild back pain. Not only do you notice the pain all the time, you are now so preoccupied with managing it that your normal lifestyle is curtailed. Temporary personality disorders are frequent.
	<b>6 Intense</b>	Strong, deep, piercing pain so strong it seems to partially dominate your senses, causing you to think somewhat unclearly. At this point you begin to have trouble holding a job or maintaining normal social relationships. Comparable to a bad non-migraine headache combined with several bee stings, or a bad back pain.
<b>Severe</b>  Unable to engage in normal activities. Patient is disabled and unable to function independently.	<b>7 Very Intense</b>	Same as 6 except the pain completely dominates your senses, causing you to think unclearly about half the time. At this point you are effectively disabled and frequently cannot live alone. Comparable to an average migraine headache.
	<b>8 Utterly Horrible</b>	Pain so intense you can no longer think clearly at all, and have often undergone severe personality change if the pain has been present for a long time. Suicide is frequently contemplated and sometimes tried. Comparable to childbirth or a real bad migraine headache.
	<b>9 Excruciating Unbearable</b>	Pain so intense you cannot tolerate it and demand pain killers or surgery, no matter what the side effects or risk. If this doesn't work, suicide is frequent since there is no more joy in life whatsoever. Comparable to throat cancer.
	<b>10 Unimaginable Unspeakable</b>	Pain so intense you will go unconscious shortly. Most people have never experienced this level of pain. Those who have suffered a severe accident, such as a crushed hand, and lost consciousness as a result of the pain and not blood loss, have experienced level 10.

## **Healthwatch ME/CFS Survey:**

Created by Healthwatch Trafford following concerns raised to them about the treatment of people with ME/CFS by health and care services, the survey has been put together to collect real experiences of the system by those that have ME/CFS. It is intended to find out how people are finding their treatment and see where there are areas where more investigation will be required. It has been created with the help of several people (most notably Karen Morris, Dr Nigel Speight, 25% ME Group).

A number of local Healthwatch in England have been engaging with ME/CFS patients. If you have any experiences, positive, negative or otherwise that you would like to share, your local Healthwatch will always want to hear them so they can make a difference.

If you have any problems completing the survey, please contact **adam@healthwatchtrafford.co.uk** and he will help put you in contact.

Any Trafford residents who wants to provide ME/CFS feedback to Healthwatch Trafford (CCG) please complete the following survey  
<https://manchestersalfordmegroup.wordpress.com/healthwatch/>

Those outside of Trafford will be able to complete a survey on the relevant Healthwatch websites soon. To contact your local Healthwatch, find them at 03000 68 3000 or <http://www.healthwatch.co.uk>.

Bolton: <http://healthwatchbolton.co.uk/>,

Bury: <http://www.healthwatchbury.co.uk/>

Manchester: <http://www.healthwatchmanchester.co.uk/>,

Salford: <http://www.healthwatchesalford.co.uk/>

## **Devolution in Greater Manchester (DevoManc)**

On 21st April, Jeff Glasser and I represented the group at a meeting arranged by Action for ME with the overriding question: "How can we engage effectively with the evolving agenda for integrated health and social care commissioning in Greater Manchester, to ensure that the needs of people with ME/CFS are best met?" There were reps from Stockport ME group, Salford and Central Manchester ME group, and Manchester ME society. There were clinicians from the Stockport and East Manchester ME clinic and the Greater Manchester children's ME service and reps from Healthwatch Salford, Stockport and Bolton.

There was discussion around the patchy provision of services in Greater Manchester, the efforts (by groups and individuals) to raise awareness among GPs, and provision for out-of-area patients. The two clinics represented (I understand others were invited) described their concerns, including that ME services could be merged with other services, thereby losing expertise, and the difficulty of reaching GPs for training. We also exchanged information on the other local clinics, including our own.

People affected by ME would like to see:

\*proper integration of health and social care (no-one from social care attended) as this is a stated aim of DevoManc.

\*long-term follow-up

\*consistent data being collected, including outcomes

Moving forward we need to:

\* move ME up the agenda

\*show the need for an integrated approach

\*work together

\*contact social care personnel, form the statutory and voluntary sector

\*collaborate with other groups involved in ME, and other long-term and neurological conditions

\*reach out to power-brokers

\*try to attend council and CCG board meetings

\*engage with politicians

\*share personal connections

\*find and share best practice

\*approach recognised and respected medics

\*make early contact with decision-makers

\*involve MPs after the election, even hold a fringe meeting at party conferences.

It was also agreed to share Trafford Healthwatch's survey on ME/CFS widely to collect information (information also included in this newsletter). Indeed, two people at the meeting have decided not to continue with this initiative, and will be working direct with Healthwatch and others.

Your committee, after much discussion and consultation, have decided it is in our members' interests to continue, though we will monitor the situation. Stockport support group and, at the time of writing, Salford and Central Manchester group, are also in.

There is a lot of work to be done, and LOTS of meetings, so as usual we would be grateful for any members who would be willing to help. Anyone who has any contacts they think would be useful, please let us know. If you wish to discuss anything to do with this initiative, then please do so: my email is [maria113@talktalk.net](mailto:maria113@talktalk.net). Maria Sale

## **ME Awareness Day 2015**

May 12<sup>th</sup> is ME Awareness Day. This date is Florence Nightingale's birthday, and she was rumoured to have had ME. Thomas Michael Hennessy, Jr, was the man who founded the idea of May 12<sup>th</sup> as International ME Awareness Day. He died aged 59 in 2013, and did a lot to raise awareness of the condition in the 25 years he had it. Fibromyalgia organisations have also adopted this day as their awareness day.

What can you do to raise awareness of ME or Fibromyalgia on May 12<sup>th</sup> (that doesn't require too much energy!?)

Join the Light Up the Night Challenge on May 12<sup>th</sup>! Light your house blue, purple or green and send your photo to [info@may12th.org](mailto:info@may12th.org) or to their Facebook or Twitter pages.

Post a "status" on your Facebook page, about how ME or FM affects you, how isolating it can be and anything else you feel that might just make someone feel differently about these conditions which have so much stigma.

Have a conversation (in person/on the phone/by email) with a friend or relative who doesn't know much about the condition, or doesn't really understand it. If you've hid the condition from some of your friends, maybe now is a good time to explain it, due to the increased media coverage expected on the day (but only if you are comfortable with it). We can provide you with some awareness leaflets for your friends, family, GP surgery, etc.

Write to your MP to tell them about ME/CFS and/or FM, what it is, how it affects your daily life and how the governments cuts (on welfare, NHS, or other services), are making life difficult for you, and what changes you would like to see. Be polite, even though you may feel angry and let down.

You can also write to the Clinical Commissioning Groups who are in charge of commissioning NHS services, telling them what the problems are relating to ME or FM (having to phone at 8:30am to get a GP appointment, lack of parking at hospitals, your GP is dismissive of the condition, etc).

Write to, or call, a local newspaper or radio station, asking if they would talk to you (or get in touch with one of the charities to see if they will if you're shy!) about ME or FM. Many people still don't even know the Bury and Bolton group exists, despite our local efforts, and length of service.

## **Late edition - March 2015**

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

Theodore Henderson a psychiatrist in Denver, Colorado, has treated many of his CFS/ME patients with the antiviral, valacyclovir (Valtrex). After treating a small group of 15 patients, only one experienced nausea and had to stop. Improvement amongst the others occurred in the first 3-5 months, with 86% of patients responding by 3 months and 92% by 5 months. Dr Henderson claimed the symptoms of fatigue, exertion induced malaise, excessive sleep, napping, unrefreshing sleep, headaches, cognitive symptoms, and emotional symptoms were all resolved. - The Role of Antiviral Therapy in Chronic Fatigue Treatment – Psychiatry Advisor - March 25

Dr Richard Podell recently wrote about a probiotic called Bifidobacterium infantis 35624. In a well-designed double blind study this probiotic had anti-inflammatory effects for patients with CFS/ME, ulcerative colitis and psoriasis. Whilst he didn't clearly describe how it would change a person's life he did point out that taking it is relatively safe. However, like most studies it needs more testing before it's considered as a treatment by national health authorities. - A Commercially Available Probiotic Reduces Chronic Fatigue Syndrome's Inflammation—Should we offer this as a Treatment? – Prohealth - March 21

Here's an example of some of the complexities involved in CFS/ME research. This team found that analysing the fluid in the brain/spine area showed patients' immune systems were distinctly different from healthy people. This is just the summary: A group of researchers analysed cerebrospinal fluid from 32 CFS/ME cases, 40 people with multiple sclerosis and 19 normal subjects frequency-matched for age and sex using a 51-plex cytokine assay. Group-specific differences were found for the majority of subjects with an increase in cases of CCL11 (eotaxin), a chemokine involved in eosinophil recruitment. Network analysis revealed an inverse relationship between interleukin 1 receptor antagonist and colony-stimulating factor 1, colony-stimulating factor 2 and interleukin 17F, without effects on interleukin 1 $\alpha$  or interleukin 1 $\beta$ , suggesting a disturbance in interleukin 1 signaling. Our results indicate a markedly disturbed immune signature in the cerebrospinal fluid of cases that is consistent with immune activation in the central nervous system, and a shift toward an allergic or T helper type-2 pattern associated with autoimmunity. - Cytokine network analysis of cerebrospinal fluid in myalgic encephalomyelitis/chronic fatigue syndrome - Molecular Psychiatry - March 31

The mechanism that causes athletes to "feel the burn" makes people with CFS/ME feel exhausted by the most common daily activities, new University of Florida Health research shows. The study shows that the neural pathways that transmit feelings of fatigue to the brain "might" be to blame. In those with CFS/ME, the pathways do their job too well. The findings also provide evidence for the first time that peripheral tissues such as muscles contribute to feelings of fatigue. They also found that pathways seem to be much more sensitive in patients with CFS/ME than in patients without the disease, something that hasn't been studied before. - Study shows why exercise magnifies exhaustion for chronic fatigue syndrome patients – Prohealth - March 12

Norwegian cancer specialists Dr Øystein Fluge and Professor Olav Mella talk about their work on Rituximab and CFS/ME. After their initial studies they are now performing a larger phase three study with 152 patients. Fluge and Mella hope this will "either verify or refute if Rituximab will benefit CFS/ME patients in a significant proportion." - BBC Radio Cambridgeshire, Naked Scientists - March 22

For over 25 years the charity Canine Partners has been helping disabled people live independently. They train dogs to perform everyday tasks that disabled people find difficult, painful or impossible to do. Kerenza Holzman is from Bognor Regis and has M.E. She relies on her canine partner, Whisky, who "gives me confidence and makes me get outside and feel part of society again." - Burnley Express – March 17