

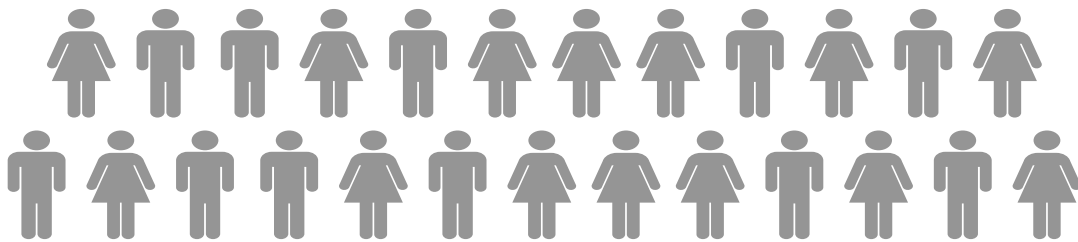
Sheffield ME Group  
Helping You with ME

# Sheffield ME and Fibromyalgia Group

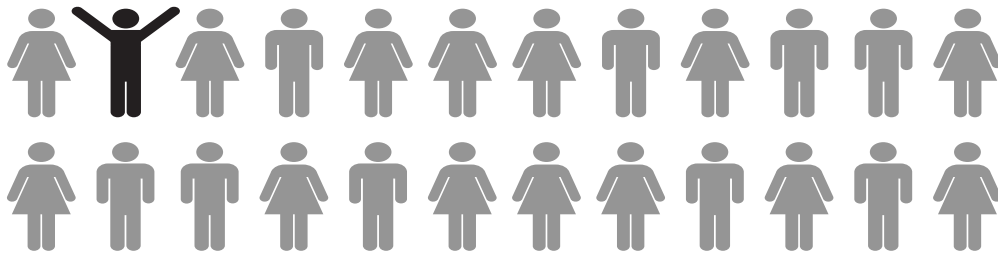
## Spring 2018 Magazine



**ME/CFS  
&  
Fibromyalgia**  
**12 May**  
International  
Awareness Day



**MYALGIC ENCEPHALOMYELITIS**



# #MILLIONSMISSING

Friday 11th May 10am-6pm  
Outside Marks & Spencer on Fargate

**JOIN US!**



*PACE Trial Westminster Debate*



*Our Christmas Social*

Sheffield ME Group is a Registered Charity: Number 1095416

# Sheffield ME and Fibromyalgia Group

The Circle  
33 Rockingham Lane  
Sheffield S1 4FW

0114 253 6700  
info@sheffieldmegroup.co.uk  
www.sheffieldmegroup.co.uk

## Patrons

Berlie Doherty  
The Very Reverend Peter Bradley

## Medical Advisor

Dr. R. A. Grunewald MA Dphil FRCP,  
Consultant Neurologist

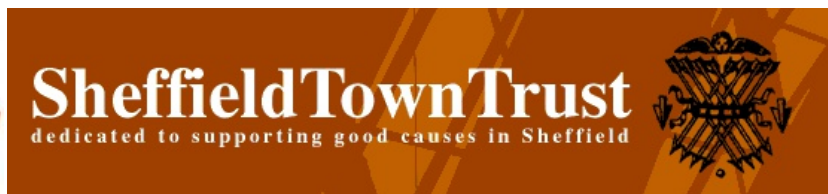
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## Sponsors



The People's Health Trust is 51 Community Interest Companies raising money to address health inequalities across Great Britain through the Health Lottery.



**MAY HEARNshaw  
CHARITABLE TRUST**



## Donations

We have received wonderful donations, firstly from Mark Wagstaffe, who not only had a collection at his 50th Birthday Party last year which raised over £150 but also very generously gave us money from his late mother's estate, for which we are so very grateful. Other wonderful donations have been made by David and Diana Shapiro, Marie Vintin and June Jennings. Marie and June continually work hard producing goods for sale on our behalf. Thank you so much to you all.

We greatly appreciate all donations to help us with our work. Please send cheques payable to "Sheffield ME Group" to the office address, or pass on a cheque to a trustee or put money in a collection tin at one of our events.

If you would like to donate by Bacs Direct Credit ("bank transfer") or set up a Direct Debit, please contact the office and we can provide you with reference details, account codes, etc.

# Dates for your Diary

## Sheffield

Wednesday 4th April, 2:00 - 3:30pm: Drop-In  
Pret a Manger, 2 Fargate, Sheffield S1 2GJ

Monday 9th - Friday 13th April, 10:00am - 4:00pm: **Information/Awareness Event**  
Winter Garden, 90 Surrey Street S1 2LH

Monday 16th April, 10:15 - 11:45am: Drop-In  
Waterstones Cafe, 24-26 Orchard Square S1 2FB

Tuesday 17th April, 12:00 - 2:00pm: Drop-In  
The Ball, 171-173 Crookes S10 1UD

Thursday 19th April, 2:00 - 3:30pm: Drop-In  
Costa Coffee, Fox Valley Retail Park, Stocksbridge S36 2AD

Wednesday 2nd May, 2:00 - 3:30pm: Drop-In  
Pret a Manger, 2 Fargate, Sheffield S1 2GJ

Thursday 10th May, 2:00 - 4:00pm: **AGM and Social**  
The Circle, 33 Rockingham Lane S1 4FW  
Speaker: Simon Duffy from the Centre for Welfare Reform

Friday 11th May, 10:00am - 6:00pm: **Millions Missing Event**  
Fargate S1 2HD

Tuesday 15th May, 10:00am - 12:00pm: Drop-In  
The Ball, 171-173 Crookes S10 1UD

Thursday 17th May, 2:00 - 3:30pm: Drop-In  
Costa Coffee, Fox Valley Retail Park, Stocksbridge S36 2AD

Monday 21st May, 10:15 - 11:45am: Drop-In  
Waterstones Cafe, 24-26 Orchard Square S1 2FB

Monday 11th June, 10:15 - 11:45am: Drop-In  
Waterstones Cafe, 24-26 Orchard Square S1 2FB

Wednesday 13th June, 2:00 - 3:30pm: Drop-In  
Pret a Manger, 2 Fargate, Sheffield S1 2GJ

Tuesday 19th June, 10:00am - 12:00pm: Drop-In  
The Ball, 171-173 Crookes S10 1UD

Thursday 21st June, 2:00 - 3:30pm: Drop-In  
Costa Coffee, Fox Valley Retail Park, Stocksbridge S36 2AD

# Chesterfield

Thursday 12th April, 2:00 - 4:00pm: Drop-In  
Stephensons Tea and Coffee House, 11-19 Stephenson Place S40 1XL

Tuesday 22nd May, 12:00 - 2:00pm: Drop-In  
Miss Poppy's Coffee Shop, 1st Floor, Eyres Furniture Store, 19 Holywell Street  
S41 7SA (There is a lift.)

Wednesday 27th June, 1:00 - 3:00pm: **Summer Social**  
Frederick's Cafe, Queen's Park, Park Road S40 2LP

Thursday 12th July, 1:00 - 3:00pm: Drop-In  
The Spire by Stephensons, 3 St Mary's Gate S41 7TJ

## Seated Tai Chi Classes:

Wednesday 4th April, 2:30 - 3:30pm  
Wednesday 18th April, 2:30 - 3:30pm  
Wednesday 2nd May, 2:30 - 3:30pm  
Wednesday 16th May, 2:30 - 3:30pm  
Wednesday 6th June, 2:30 - 3:30pm  
Wednesday 20th June, 2:30 - 3:30pm  
Wednesday 4th July, 2:30 - 3:30pm  
Wednesday 18th July, 2:30 - 3:30pm



All at Central Methodist Church, Saltergate S40 1UH

Chesterfield Seated Tai Chi classes are held twice a month. We subsidise these classes so that only a £3 donation is requested from members (£4, non-members).

Please just come along and give it a go: try something new and make new friends!

We need a volunteer to take over coordinating our Chesterfield Seated Tai Chi Classes. This involves booking and publicising classes, handling payments and keeping a register, and keeping attendees informed of all dates and any changes. For further details please ring Tina on 07759 145753. Thank you!

***Details of all our events can be found on our website:  
[sheffieldmegroup.co.uk/events.htm](http://sheffieldmegroup.co.uk/events.htm)***

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Drop-Ins are social meetings held at various venues. Why not come along and meet some new people or catch-up with those you know?

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In the interests of others, please don't attend our events if you have a cold or infection, and please don't wear strong-smelling perfumes. Thank you.





# Letter from the Chair

Dear All,

At last, dark days and freezing weather with the accompanying flu, coughs, colds and other nasty bugs are hopefully behind us and Spring is here! Buds are budding, birds are singing and signs of new beginnings of life surround us.



New beginnings for us too at the Group!

I'm delighted to let you know that The Very Reverend Peter Bradley, Dean of Sheffield Cathedral has kindly agreed to become a Patron of the Group. Peter is hoping to come to some of our events and I'm sure he'll be pleased to help us to raise the profile of the Group in Sheffield and the surrounding area.

Our "Reaching Out to the Community Project" funded by the People's Health Trust is now in its second year. We're pleased to announce that Lee Marsh is our new Project Co-ordinator and we wish him the best of luck in making the project a success. You can read more about Lee and the Project on p9-10.

It's been great to receive your enthusiastic responses to the different courses and sessions which have been organised through People's Health Trust funding. It's obvious that those of you who went to the different classes and therapies have really enjoyed getting out, socialising and "doing"... so much so, we'd like to continue them in the future. Sadly, money doesn't grow on trees so I find myself looking for yet more ways of raising funds. Any ideas you have for helping to organise this type of event, fundraising, etc., will always be welcome, especially from those of you who have benefited from the groups and want to see them continued.

Speaking of funds, many thanks to all of you who have paid your Annual Subscriptions and especially to those who have included a donation. We've also had wonderful donations from Mark Wagstaffe, David & Diana Shapiro, Marie Vintin and June Jennings. Thank you all so much. Your money will be put to good use in helping our members in different ways.

We are holding our Winter Gardens Awareness Week in the week commencing 9th April. Chris will be telling you all about this in his article.

Our "Millions Missing" event is now taking place on Friday May 11th, which is in ME Awareness Week. There are going to be a lot of small, coordinated events nationally, so our very own day, along with all the others, is obviously going to make the News! Thanks to all of you who have already offered to donate footwear. We do need more, and to find out how YOU can help please see p14-15.

Our AGM this year will also take place in ME Awareness Week and I'm pleased to let you know that Dr Simon Duffy, Founder and Director of the Centre for Welfare Reform has agreed to come to speak at this event. He is well known for speaking

out about the problems of the Welfare State and has called for the retraction of the PACE trial, writing in his Huffington Post blog that "the therapies recommended by the PACE trial are so harmful that, if they were medicines, they would be withdrawn from the market". I hope many of you will come along to hear what Dr Duffy has to say and how WE can push for Welfare Reform in our own small way.

Many thanks to the volunteers who have continued to offer support at our events and to those who have come forward with offers of help. Your efforts are much appreciated.

We'd also love to have more Trustees on the Board to help us to work on our future strategy to enable the Group to go forward with confidence. We're looking for people from all backgrounds who have life experience, people skills and common sense. We'd especially welcome people with experience in book keeping, management and fundraising, but this is by no means essential. We're hoping that our meetings will soon take place via "Zoom" so that coming into the office for meetings will be a thing of the past!

Please get in contact via the office if you'd like to know how you can help!

I would like to promote the idea that we organise a WhatsApp group for our younger adults with ME. We have two young people who would like to know the level of interest in this type of support for those aged 18 to 30. Please see p15.

I'm hoping to meet some of you at the various Events and Drop-Ins which will be happening soon, but until then....

Best wishes,

Hilary

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## **Our New Patron, The Very Reverend Peter Bradley**

We would like to warmly welcome and thank The Very Reverend Peter Bradley, DL, Dean of Sheffield, who has kindly agreed to become our Patron.

Peter is the senior priest of the Diocese of Sheffield, working closely with the Bishops within the Diocese to support them in their ministries. Peter spends much of his time developing new relationships with business and community leaders, in pastoral care and evangelism. Peter is also senior priest at the Cathedral, where he leads the team of clergy and lay people who share in its mission, and is involved in the Archer Project.

He is hoping to meet some of you at our future events and to hear your personal stories.



# Outreach Worker's Report

Hello everyone.....

At last spring is on its way!

Whilst Christmas seems a fair time away it was lovely to meet up with friends old and new at the Christmas Social.

Who can forget the Christmas quiz and a certain Mr Stone's answer to one of the questions? I cannot repeat the answer here, suffice to say it was not the cleanest answer I have ever heard to the question. However, what WAS wonderful was the sound of 40 people laughing all at once.

I am no comedian (some might say I am!) in the stand up sense but it gave me a flavour of what it must be like to stand at the front of a big hall and hear the sound of laughter from everyone in the room. It must give those who do comedy for a living one hell of a lift.

As I have always said the day I lose my sense of humour is the day I pack it all in.

If anyone who has been to see Ken Dodd over the last 20 years you will know what an uplifting (and very long!!!) evening this can be. The last time I saw him was in Torquay and we came out of the theatre at 12.45am. I couldn't remember any of the jokes but I just knew that my ribs hurt with laughing

What is all this leading to I hear you say???

Well, we are seriously thinking of having a laughter afternoon or morning which will entail us all laughing hopefully at a few one liners or longer jokes

Even if they have to be read out (which in my case they definitely will!!!) then we would like to think we have amused and cheered people up for a couple of hours so please let me know if you think you would like this type of event to be arranged. There may have to be a small admission fee to go towards the hire of the room but we will make sure it is worth it!!

One thing is certain it will get those chuckle muscles working!!!

On to a more serious note that I wanted to make members aware of.

As many of you know my own personal health has not been too good over the last 6 months so over the last couple of months I went to see another GP in my local practice and told her that I thought I was experiencing a severe flare up of my symptoms, particularly as I had had horrendous back pain which was leaving me very very fatigued.

I was therefore sent for blood tests and X-ray and MRI scans, all of which came back clear. The GP said that the MRI scan was clear so I would be sent to a physio (I am sure you have all been through this process!!).

However, in speaking to the physio my partner Marian just happened to make the comment, "Well, at least the MRI scan was clear", to which the physio replied, "Well, actually, it's not, it is showing that you have a prolapsed disc in your back which is impacting on the nerves".

Whilst the most obvious question is why wasn't it picked up earlier, I wanted to remind members that not every pain, strain or other symptoms can be attributed to ME as most of us think.

Anything out of the ordinary should be checked out properly with a GP. I was so convinced that my back problem was part of my ME and in this case it was certainly something very different.

By the way, this is not a plea for sympathy(!), but just hopefully an example of making sure you get to the root of a problem.

Do let me know your views on a couple of laughter workshops (for want of a better word!) and I leave you with a couple of one-liners:

Teacher "Name a bird with wings that can't fly"

Student "A dead bird Sir"

I went to the zoo this morning only to find out that some aquatic mammals had escaped. It was otter chaos.

I can hear you saying, "Don't give up the day job".

I won't!!

Till next time.....

Chris

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## Subscriptions for 2018

If you haven't yet renewed your subscription, please can we remind you to do so?

Your membership is vital to the Group's ability to help local people with ME and Fibromyalgia. Annual membership is £12. Compared to other groups around the country, and the national charities, we feel we are good value.

As you know we offer many services: the information line, quarterly magazine, Conference and AGM with speakers, Christmas Social, regular drop-ins, tai chi and other classes, facebook pages, website, lending library, information packs for new members, and more. Please see the back page for details of how to subscribe, and don't forget to let us know if you are eligible for us to claim Gift Aid.

We hope you'll feel that by being a member you are helping yourself and others. Thank you!



# Our New Project Coordinator

Hello there. For those who don't know me, my name is Lee Marsh and I am the group's new Project Coordinator. For those that do know me, well... you've either just fallen off your chair or are just in shock!!! So it's probably best to give you a little time to either clamber back up or pick your jaw off the floor

.....  
There you go.... I hope that was long enough!



First, a little bit about myself. I was brought up in Goldthorpe and consider myself a proper 'Barnsley Lad', so I was a bit dismayed when my partner asked me to move to Killamarsh. Moving out of Barnsley! Shocking!!! But I suppose being near the big city of Sheffield would be ok. At least I would still be in my beloved Yorkshire. Imagine my surprise then when I found out Killamarsh is classed nowadays as Derbyshire! Noooooo!!!!!!!!!!!!!! I've got to admit though, it's a beautiful place and my lovely partner is worth it... but only just.

Like a lot of you out there, I too have ME. I was diagnosed in 2003 but I believe, like many, that I'd had it for many years beforehand. I consider my illness mild compared to some but even that level is enough to devastate a life. For years I just found myself in the boom and bust cycle, getting so down and frustrated that all my positive action was seemingly making things worse. When I was finally diagnosed the relief at the recognition that it wasn't all in my head reduced me to tears, only to find that there was little or no help from the medical profession, bringing tears of despair. I carried on much the same for a number of years with no help, save for a few support groups, some negative, others limited.

It wasn't until I discovered Sheffield ME group that things really started to change... and for the better.

From being a member initially, the support I received encouraged me to start volunteering, helping to give the same support I'd had to others. This gave me so much pride and confidence back, that I eventually joined the Board of Trustees too.

Everything I've learned from the group has made a real impact on my health and well-being. I'm still far from recovered but the steps I've taken have made a massive difference. So much so, that over recent years I have managed to return to work, albeit on a part time basis.

Next, I'd like to tell you a little about the project and my role. The Peoples Health Trust (Health Lottery) have provided funding for us to engage with people with ME and Fibromyalgia from specific areas in Sheffield, namely Firth Park, Fir Vale, Burngreave, Shiregreen, Ecclesfield, Hillsborough and Tinsley. The main aim is to provide events and support that will ultimately enable members to set up and continue with their own small, local groups beyond the life of this project. Although

you may not live in these areas, the project also seeks to limit the levels of social isolation and financial hardship in and around Sheffield.

I'm sure you will all agree that there can't be many members out there who do not fall into at least one if not both of these categories, so the main goal of the group is unchanged. We are here to help and support as many as we possibly can....

Recent events we have provided have included a craft group, a Mindfulness course, Reiki and Massage taster sessions and regular Tai Chi classes. They have all gone down a storm with everyone who has attended thus far, so, if you would like to take part in any similar forthcoming events please register your interest by getting in touch by the usual means. You may even have ideas for new events and, if so, we would love to hear them.

I'm looking forward to seeing as many of you as possible in the near future.

Take care.

Lee

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## **Winter Garden Awareness Week**

### **Monday 9th - Friday 13th April**

We shall be holding an Information and Awareness Event in The Sheffield Winter Garden again this year. This takes place from 10:00am to 4:00pm each day.

This is a great opportunity to explain ME and Fibromyalgia to members of the public and to reach out to those in the city who have the conditions. As always, we need volunteers, please contact us if you would like to join in.

Please note that Michelle Cardno, benefits lawyer and founder of fightback4justice, will be joining us in the Winter Garden on Friday to answer your questions on benefits.

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## **AGM and Social, 10th May**

We are pleased to announce that Dr Simon Duffy is our speaker at the AGM, to be held 2:00 - 4:00pm on Thursday 10th May at The Circle in Sheffield.

Simon is the founder and Director of the Centre for Welfare Reform, based in Sheffield. He speaks regularly on television and radio about the welfare state and social policy. He works as a consultant and researcher with local social innovators and national governments.

Tea and biscuits will be provided.



# Would you like to become a Trustee?

## And what is a Trustee, anyway?!

It's that time of year, as the Annual General Meeting approaches, when we ask if you might like to become a trustee. But what is a trustee and what is involved in being one?

The trustees are the volunteers who together oversee the running of Sheffield ME and Fibromyalgia Group, which is a registered charity. They are elected by members at the AGM. They receive no payment at all.

The Board of Trustees meets once a month to discuss and make decisions on matters relating to the running of the Group, and on plans for the future: it is all about doing the best the Group can do to meet the needs of members. This strategic role is the core role of the trustee.

The trustees also undertake the business planning for the charity. This includes making sure the Group is financially viable and able to carry out its day to day business. This can mean submitting bids to trusts or Lottery funders, for example.

The charity is guided by people who have and understand ME and/or Fibromyalgia. All the trustees have a passion for the Group and for helping people with ME and/or Fibromyalgia, and find there is a lot of satisfaction in doing so.

If you have or care for someone with ME and/or Fibromyalgia, or if you have some knowledge of these illnesses, then you are eminently qualified to be a trustee.

Of course, all trustees understand if you aren't well enough to attend a meeting or do a task you said you would do, in time. We currently have a trustee who is housebound, but they still make a valuable contribution and we are glad to have them involved. The trustees never put pressure on each other to attend meetings or do work.

If you choose to, there is the opportunity to get involved in the day-to-day running of the Group. This can be very enjoyable, developing skills, being part of a team, and achieving something that is hopefully worthwhile and helps people.

If you would like to help by becoming a trustee, you will be made very welcome. We do need more trustees. Just speak to one of the trustees at the AGM, which is on Thursday 10th May at The Circle in Sheffield, or, if you cannot attend, get in touch via the office. You will need another member to nominate you, but don't worry about the election, we have never yet exceeded our maximum quota of trustees so there should be space for you.

Thank you.

Simon



# Our Christmas Social

The fun and games of our annual Christmas Social took place at The Circle in Sheffield on December 1st.

There was lots of Christmas party food, thanks to a very generous donation from our Patron, Berlie Doherty, one of Chris's quizzes, a tombola and a game of bingo.

It was great to see so many of you. Thank you to all who donated prizes for the tombola, and to the People's Health Trust, who funded the event.

Our regular drop-ins around Sheffield and Chesterfield are always social events where members can meet old friends and make new ones (see Diary Dates, p3-4). Our next big social event is as part of our AGM on Thursday 10th May at The Circle. We hope we might see many of you there.







## A message from Marie, who raises funds for the Group

Hi All,

I am a member and ex-Trustee and I wish to explain the photograph below for the members who couldn't make the Christmas Social. I have been fundraising all of 2017 to try to raise much needed funds for the Group by making and selling greetings cards, and cakes, pies, jams and pickles, all from home grown produce from my husband's allotment. I managed to raise £225 which as you can see from the extra large cheque I handed over to Sheffield ME and Fibromyalgia Group at the Christmas Social.

I would never have managed this without the help of a small group of friends who bought these items from me, so I would like to take this opportunity to thank Richard, Dave, Phil, Anne, Kim and Steve from the Ball Inn, you guys have been tremendous, not forgetting Darren Stone who eats me out of Piccalilli! A massive thank you for the continuing support you all give to the Group.

I am well on my way with raising more funds and hope that by Christmas Social 2018 (or before) I will have an even larger amount to donate, so if anyone would like to help me to raise funds, just let me know. If you would like to order any greetings cards, pies, cakes, etc., you can contact me via any one of the Trustees.

Thank you all once again for your kind support.

Marie (a volunteer)

(Marie is pictured on the far right.)



# Millions Missing

**Sheffield Day of Action, 11th May Fargate 10am-6pm**  
**Join us!**

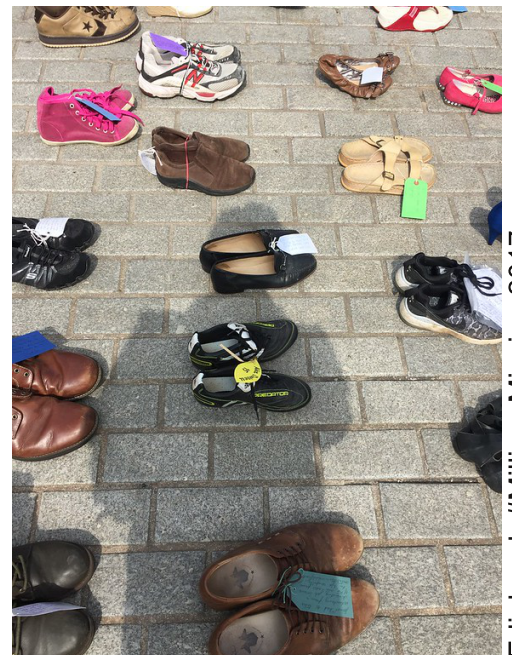
#MillionsMissing is a global campaign for ME health equality. The first #MillionsMissing took place in 2016; since then there have been protests and rallies around the globe. In May 2017, #MillionsMissing protests took place in 24 cities globally, and thousands participated online. Protests demanded adequate research funding and medical education from their governments. Now patients, caregivers and allies worldwide are preparing for an even bigger #MillionsMissing2018.

The three goals of the actions are:

**To Be Seen:** We will make ourselves visible and share our stories in order to grow our movement.

**To Build Community:** We will organize patients, caregivers, friends, doctors, scientists, and elected officials in order to build power.

**To Demand Concrete Action:** We will campaign to promote equality, treatment and research for ME.



Edinburgh #MillionsMissing 2017

In Sheffield we are holding our own day of action from on **Friday 11th May from 10:00am to 6:00pm outside Marks and Spencer on Fargate**, the day before the global #MillionsMissing actions on 12th May. 12th May is long-established as International ME Awareness Day.

This presence of volunteers, sufferers, friends and family, and of shoes laid out, is to raise public awareness in Sheffield. There will be a gazebo, places to sit and friendly welcoming faces, leafleting and donation collections.

We are hoping to have many pairs of labelled shoes laid out around our pitch to represent the many individuals who have had to stop something significant in their lives, be it running, climbing, dancing, walking (the list is endless).



Would you lend us a pair of shoes to represent yourself? Each pair of shoes needs to be labelled with a note of, for example, your name (or pseudonym), your age, how long you've been ill, what you are missing doing, and maybe how that feels.

Please bring shoes, photos, messages or anything else in advance to either:

- The Circle, Rockingham Lane Sheffield S1 4FW on Wednesdays 11th, 18th, 25th April, and Wednesday 9th May, between 10.00am and 4.00pm
- The Winter Gardens Awareness Event - Monday 9th April to Friday 13th April each day between 10.00 and 4.00pm.
- Or 6 Shirle Hill, Nether Edge, Sheffield S11 9AA. There will be a box provided in the porch at all times, you can drive up the drive, or you can post items here.

There will be luggage tags available at all locations for you to write your message.

If you would like your shoes back, please could you let us have your name and address with a note that you would like them returned. Otherwise, the shoes will be kept for future actions or donated to charity.

If you can join us on the day please:

- Bring friends and family along.
- Wear an item of red clothing.



This action is about everyone affected by ME, but is especially looking to enable those who are most isolated by this illness to have a voice, so if you have another idea about how to participate then do get in touch.

Together we can make this the biggest #MillionsMissing ever!

And remember to take to social media on Saturday 12th of May, add your own micro-events, however small, to join the global day of action, using the hashtags #MillionsMissing and #CanYouSeeME to share your story and photos, to let your MPs, councillors and all those in power know that we demand better research, treatment and care, and to ensure that although ME may be invisible, we will not be forgotten.

Join the #MillionsMissing2018 and be a part of the Global Day of Action on 12th May, as well as supporting the Sheffield group on 11th May; be heard and make a difference.

Sian and Carolyn



Our member Beatrice says "Here are my boots together with my trowel. I'm no longer able to do my PhD in Archaeology due to ME."

**16 - 30 years old?**

**Want to join a WhatsApp group of Sheffield's young people with ME/CFS and/or Fibromyalgia?**

**Send a message to Sam: 07508 847 955**



# **The PACE Trial and ME**

## **A report on the recent debate in Parliament**

On February 20th, Carol Monaghan MP led a debate at Westminster Hall called 'PACE Trial And Its Effect On People With ME'.

During the debate, Carol Monaghan said, "I think that when the full details of the trial become known, it will be considered one of the biggest medical scandals of the 21st century."

The Parliamentary Action was initiated by a supporter of Invest in ME Research.

After the debate Invest in ME said: "It was refreshing to see an MP actually speaking plain English and being genuinely passionate about the awful policies which Westminster governments and establishment organisations had brought to bear on sick and vulnerable ME patients for the last decades.... Carol Monaghan did a truly excellent job in bringing to the fore the scandal of the PACE Trial and deserves great credit for this undertaking. If only there were more MPs willing to stand up to the injustices of the establishment which have so disastrously affected people with ME and their families for the last decades."

Sheffield ME and Fibromyalgia Group are delighted that, after his visit to our Group last November to hear our concerns, Sheffield Central MP, Paul Blomfield, agreed to attend the Westminster Hall debate and spoke out during the debate, to ask Minister Caroline Dinenage about the potentially harmful CBT (Cognitive Behavioural Therapy) and GET (Graded Exercise Therapy) saying: "The Minister makes the point that final guidance is expected in October 2020, but given the significant doubt over CBT and GET and their impact now, does she recognise the strong case for NICE to suspend the current guidance, which points people towards those potentially damaging treatments?"

The Minister responded: "As an independent organisation, that will of course be a matter for NICE, taking into consideration the evidence."

Paul has also submitted a written question: "To ask the Secretary of State for Health and Social Care, what assessment has been made of the potential merits of removing cognitive behavioural therapy and graded exercise therapy as treatments for ME from the current NICE guidelines."

We are very grateful to Paul for his support. The difficulties that people with ME face are being recognised by politicians from all Parties and the Leader of the LibDems, Sir Vince Cable has recently signed up to Dr. Sarah Myhill's MAIMES (Medical Abuse in ME Sufferers) Campaign, saying that he also hopes to raise the issue in Parliament.

A full written record of the Westminster Hall Debate can be found online at [hansard.parliament.uk](http://hansard.parliament.uk)

Carol



# Making and Doing

## Our member Heather reports on our Craft Classes

Sheffield ME and Fibromyalgia Group organised craft classes for members in January and February, thanks to funding from the People's Health Trust. The classes were designed to be relaxed and informal, they were all about creativity and meeting old friends and new people. Everyone reported really enjoying the classes and felt enthused to carry on being creative. Heather reports below:

I was lucky enough to have been able to attend the 6 weeks course run by Charlotte Hutton of Making and Doing on behalf of the Group – six weeks covering six crafts. All the necessary items were provided so we didn't need to go out and buy anything extra.

Week one was glass painting. Two different sizes of glasses were available and a few colours of paint plus a special paint that creates the thick lines to make it look like stained glass/leaded light work. The following week we did paper quilling and iris folding, and created cards. Then it was screen printing. Most of us only thought this could be done with a large screen print machine, but Charlotte had worked out what we could do on a much smaller scale and we all thoroughly enjoyed this. We printed on tea towels and t-shirts.

Over the following weeks we learned how to make four pom-poms in one go and created a small rug from them, stitched felt animals – although, this was quite funny in that as it was Valentine's week, four of us created felt decorated hearts for our partners. For the last session we did lino cuts, using special thick lino especially for this sort of craft. We printed from the images we cut in the lino.

We also had a few discussions about continuing with some classes, and how maybe we members could help create our own craft group, helping each other out with a variety of crafts.

Heather



# New Year, New Ideas

It's a brand new year... well, newish... not as brand new as a few months ago but it's still pretty fresh, and this is the first newsletter of the year. That's my excuse and I'm sticking with it!

So, what about some new ideas and maybe a few revamped ones, ones where you can get involved? Of course, we'll still have our much-loved Drop-Ins, as well as the usual high quality guest speakers each year, but, **WE NEED MORE!!! WE DESERVE MORE!!! SO LET'S WORK TOGETHER TO HAVE MORE!!!**

Thanks to funding from the People's Health Trust, we have been able to provide a bunch of new events recently. These have included a 6 week Mindfulness class, a 6 week Craft Group and free, yes, your no doubt droopy, fatigued eyes are not deceiving you, **FREE** Massage and Reiki sessions!!! Our Tai Chi classes did return but have recently headed in for a pit stop and will resume shortly, better than ever.

Moving on to new ideas! How about heading to the cinema together? For those that are able, it can still end up being frustrating when you organise a trip but come the day you're just not well enough, and you end up feeling like you've let people down or, alternatively, you force yourself to go when you know you shouldn't and end up feeling so much worse. Grrrrrr! Why then can't we plan the odd cinema trip together. It's always good to be around people going through the same thing and where else would you get the same understanding if you can't make it.

Another idea is to form a gentle walking group. One where everyone is included. Where everyone can stick to their limits. Where anyone who uses walking sticks, mobility scooters or jet packs to get around are welcome, even people who wish to bring their pets along (within reason, of course, no lions or tigers!) We plan to call this the **ME and Fibro Rollers and Strollers!**

Last but by no means least, a possible volunteer craft group. Those that were lucky enough to attend the recent craft classes loved it so much they came to us asking if they could set up their own group, if we could fund a room and materials. This may well be doable and we know there are a lot of crafty folk out there (in the creative sense I mean, I'm not suggesting some are a bit shifty or sly!), so it all depends on your help and support to make it happen.

So, there you have it. Some fresh ideas for you to ponder. We plan to set up a few test runs for these events soon, but sadly we won't be able to give any dates in the newsletter. We will be posting them all on Facebook, the website and through the E-news, but we know some of you don't use any of these media so, and I can't stress this enough, if you are interested in any of these please, please get in touch by phoning the office or even writing to us. Once you register your interest we will make you aware of anything that's upcoming.

Lastly, you may have some fantastic ideas yourself for events so let us hear them. We can't act on them if we don't know what they are.

Lee

# Warming Drinks

Duraiya, a member of the Group, has written to tell us about the healthful drinks she makes during the Winter months.

I thought I would share my own homemade remedy; I make this drink at home during the winter months, when my immune system is low, predominantly when I have a cold or 'flu. This drink has become the “go to” for my whole family when they are run down or ill.

You will need:

One slice of ginger

Juice from half a lemon

Less than a quarter of teaspoon of turmeric

Pea-sized amount of butter

Teaspoon of honey (add more should it be required to your taste)

Method:

Chop the slice of ginger into very small pieces

Squeeze the juice of half a lemon

Add less than a quarter of a teaspoon of turmeric in a mug

Add the ginger and lemon juice to the mug

Boil water and pour in the mug

Add the pea-sized amount of butter.

Let the water cool down a bit then:

Add a teaspoon of honey (more if required)

Stir and enjoy

The other two drinks I am going to tell you about are traditional Indian drinks.

## **Turmeric latte**

Heat a mugful of milk

Add 1 teaspoon of turmeric and stir well

When the milk cools down a bit then add honey stir well.

## **Saffron latte**

Add a mugful of milk to a pan and gently warm

Then add a bit more than a pinch of saffron, stir it well, and bring to a higher heat

Add 2-3 chopped almonds and pistachio (optional) and stir

Add 1tsp sugar (unless you prefer honey) and stir till sugar dissolves

If you decide to have 1 tsp of honey (instead of sugar) then pour the milk in the mug and let it cool a bit then add honey and stir well.

I hope you get a chance to try these drinks and they benefit you as much as they have me. Other teas I would recommend are liquorice tea and tulsi (holy basil) tea, which is sold under the Pukka brand and is available in health food shops.

Duraiya



# Chesterfield Seated Tai Chi is 5 years old!

Hi everyone,

Well, I can't believe it's been 5 years since the start of our seated tai chi classes in Chesterfield! We celebrated the anniversary at our class, on 21st March. I think the group has me well sussed out by now - basically if there is any excuse for tea and cake, I will find it!

We had a really good turnout of 12 to the class, including newcomers and old friends. We were also delighted to see our former teacher, John, who joined us for tea and cake afterwards (very enjoyable it was too!)

John and I started this particular class after he was our guest speaker at a Chesterfield meeting in 2013. We had a mutual interest in adapting the practice to help people with ME, and the seated exercises have been of huge benefit to a number of us over the last few years. When John retired in 2015, his colleague Margaret stepped in, and she's done a great job.

I have to say that I am very proud that the class is still running. We had a few rocky periods where it looked like we would have to fold, due to low attendance and funding issues. But since opening up to those outside the ME group in January 2016, attendance has been consistently high, with a steady stream of local people coming to join in. With a bit of dedication and some free local publicity (not difficult when you know where to look), the class has gone from strength to strength. It is now well established, and with some background organising from me, it pretty much keeps itself ticking over.

Which brings me to my next point - sadly I will be moving onto other things this



The Tai Chi 5th Birthday Party.

Tina is pictured on the left (trying to keep all the cake to herself!) John is next to her, and Margaret is next to him.

Many people find the classes beneficial and enjoyable, if you would like to try a class, there is no need to book, just go along (the times and dates of classes are on page 4 of this magazine).



summer, so we are in need of a new co-ordinator! The new person would ideally need to start in June or July, before the summer break, so they are ready for classes to resume in September.

The role is voluntary, and can be adapted to suit any limitations in energy or time. Currently it involves a few things:

1. Keep an accurate register of attendees, take payment on class days and pay the teacher, organise room rent and invoices, and manage the class float.
2. Co-ordinate with the venue and SMEFG to book future dates, usually 3-6 months in advance.
3. Publicise future dates and information (including a contact number) through SMEFG and also through free local advertising. I print posters at home (modest costs can be reimbursed by SMEFG as expenses). I distribute the posters in selected places around Chesterfield, about 3 times a year. It is also helpful to make use of any other opportunities for free publicity, such as writing a short article for a local paper.
4. Keep in contact with all attendees (and teachers) by text or phone call (and sometimes email), to let them know new dates, and any other change of plans (e.g. a class being cancelled). I also currently send out a reminder text a couple of days before each class.
5. Keep a folder of examples of exercises on paper, and distribute them to attendees if they wish to take them home. Currently the church very kindly copies these for us for a small charge (covered by expenses), so we do not have to charge attendees.
6. Be welcoming and understanding to anyone new, and try to keep in touch with them if they wish to attend regularly. We aim to be inclusive, and have a range of ages and abilities, and a variety of health conditions in the group (and some with no health conditions!)

I have absolutely loved being Tai Chi Co-ordinator. It's a fantastic way to meet new people and contribute something to the local community, whilst improving your own health through the regular practice of tai chi. It's really helped me feel less isolated while having ME, and it's done me so much good to have a purpose, and something to focus on other than being poorly. It's great for sharpening skills too, such as communication and organisation. It can be a very useful example of activity, both in a benefits assessment and a job interview (I should know - I have done both in recent years!)

I have been part of this class since helping to set it up in 2013, and I have seen it grow into something that genuinely benefits the local community, which is wonderful. I have met lots of lovely people too. Needless to say I am going to miss you all very much, when I move on to new things this summer! I promise I will come back and visit from time to time- and of course, I will take the tai chi I have learned with me, and continue to practise it and benefit from it.

All interest is very welcome - and you can be assured of a good introduction and a smooth transition! Please do contact me on 07759 145753 if you would like to know more.

Many thanks, Tina

# New Monthly Classes in Chesterfield & Sheffield

Hello everyone, my name is Kerry and I am a member of the Sheffield ME/Fibromyalgia Group.

I was diagnosed with M.E 18 years ago. Throughout this time I have been housebound, unable to walk, chronically fatigued and living with a variety of debilitating physical symptoms on a daily basis which I am sure will resonate with most of you. I have had many relapses trying to find a way through M.E. It's been quite a journey both conventionally and holistically. I should say at this point that I have not fully recovered from ME, I still have chronic fatigue issues, but I am in a position where I am able to work part time as an Accredited Chakra Dancing and Creative Meditation Facilitator and I believe this practice has been instrumental to my own recovery.

I am very passionate about helping people with ME and Fibromyalgia because I really do understand how debilitating, frustrating, terrifying and isolating these conditions can be. So I would welcome the opportunity to share my experiences, various tools, and skills that I have learnt that have helped me get my life back. Please note: I am not offering a cure for M.E or Fibromyalgia.

With this in mind I am looking to set up a monthly group in Chesterfield and/or Sheffield (depending on interest) for adults suffering with ME and Fibromyalgia. This monthly class will be fun, very gentle and nurturing. You will be guided on a journey of self discovery. Experience Mindfulness/Relaxation/Creative Meditation exercises to help calm the body and mind. You will learn about the Chakra (energy) System and will discover how imbalances in the Chakras can affect you both emotionally and physically on a daily basis. Through very gentle movement, music and sound you will learn how to relax and recharge whilst releasing stress, pain and emotions that have built up in the body.

You will find more details about the Chakra System & Chakra Dancing and Creative Meditation on my Facebook Page - Chakra Dancing With Rainbow Connections

At this stage I am wanting to see if this kind of group would be of interest to some of you.

To register your interest in this monthly class - If you are on Facebook:

- 1- Please search for Chakra Dancing With Rainbow Connections.
- 2- Like my FB page, so you can be kept up to date with monthly class details.
- 3- Send me a private message through my FB page with your name - email address - preferred location - Chesterfield or Sheffield.

Finally if you are not on Facebook please can you forward:

- 1- Your name.
- 2- Your preferred location.

To the email address [rainbowconnections@btinternet.com](mailto:rainbowconnections@btinternet.com)

Thank you for taking the time to read my article.

I look forward to hearing from you soon.

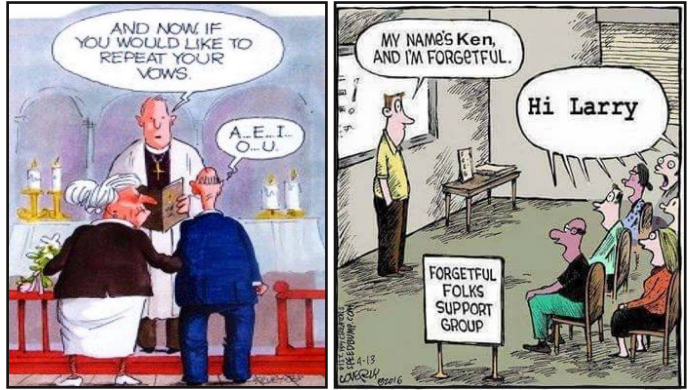
Best Wishes, Kerry



# Jokes!



It's getting beyond a joke here now, there's 2 feet of snow outside.



My **superpower** is holding onto junk for years and throwing it away a week before I need it.

Jokes courtesy of (i.e. please blame!) John

## Letter from the Editor

Hello everyone,

Welcome to the first magazine of 2018. I hope you all got through the cold and snow of Winter without too many problems.

Spring is a time of new things and while we don't have any lambs at ME Towers, we do have a new Patron, the Very Reverend Peter Bradley, and a new Project Co-ordinator, the almost irrelevant Lee Marsh (he's a mate, so I can say that!) Actually, he's a former trustee, he's knowledgeable and enthusiastic about helping people with ME and fibromyalgia, and he should do very well.

You will have seen that we have a few big events coming up, the AGM and Social, the Awareness Week in The Winter Garden, and the Millions Missing event on Fargate. We hope we might see you at these events, if you are able.

Can I remind any of you who haven't paid your annual subs for 2018 yet, to do so? Details are on the back page. The Group always needs funds (and practical assistance) to help the people in Sheffield and the surrounding area who have ME and/or Fibromyalgia.

Thank you to all who helped with this magazine: namely (in alphabetical order), Beatrice, Carol, Carolyn, Chris, Duraiya, Hilary, John, Joyce, Lee, Lu, Marie, Nupur, Shel, Sian and Tina. As always, more help is needed, and if you think you might like to help with the next magazine, either contributing or proofreading, it would be very much appreciated. Please get in touch with me through the office email or postal address. Thank you.

Roll on Summer!

Simon

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## Membership

You can pay your Annual Membership of £12.00 by a variety of means:

**By cheque or cash - either in person at events, or by post to the office:**

Please make cheques payable to "Sheffield ME Group", and fill in a membership form or write out your full name and contact details. A membership form can be printed from [sheffieldmegroup.co.uk/member.htm](http://sheffieldmegroup.co.uk/member.htm)

**Direct through your bank:**

You can pay for your Membership by Bacs Direct Credit ("bank transfer").

Bank: Lloyds Bank, 1 High Street, Sheffield S1 2GA  
Sort Code: 30-97-51  
Account No: 03571569  
Reference: Mem (then your name).

Please tell us if you are a taxpayer and so eligible for us to claim Gift Aid.

You could set up an annual Direct Debit if you wish. When people pay by Direct Debit we can forecast some income for the future.

Please email the office to advise if a payment has been made by Bacs, including your name and address, which bank was used and the date of the transaction, so we can record your payment.

Thank you!

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