

Sheffield ME Group  
Helping You with ME

# Sheffield ME and Fibromyalgia Group

## Summer 2018 Magazine



**Winter Garden**



**AGM and Social**

**Henry Boot**

*Thank you to  
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Sheffield ME Group is a Registered Charity: Number 1095416

# Sheffield ME and Fibromyalgia Group

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## Patrons

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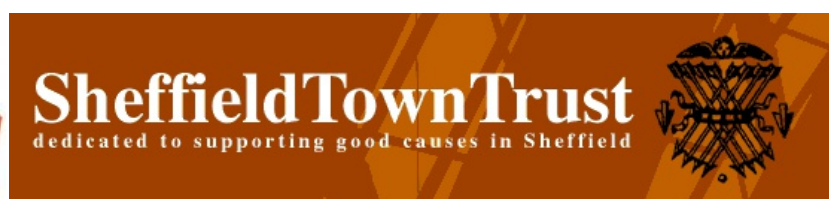
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## Sponsors

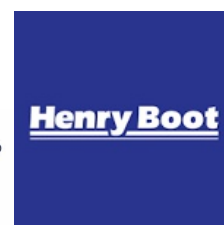


The People's Health Trust is 51 Community Interest Companies raising money to address health inequalities across Great Britain through the Health Lottery.



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## Donations

A big thank you to our Patron, the author Berlie Doherty, who kindly held a coffee morning and cake sale at Edale Village Hall, raising a fantastic £275.

Also, a big thank you to Henry Boot plc, who very kindly donated £250, and to our member, Mel Sanderson, who requested it on our behalf.

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 account codes, etc.

Cover photos: Millions Missing by Chris, Winter Garden by Ellie Colton, AGM by Michele

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# Dates for your Diary

## Sheffield Drop-In Meetings

Tuesday 3rd July, 11:15am - 12:45pm  
Costa Coffee, 872a Chesterfield Road, Woodseats S8 0SH

Wednesday 4th July, 2:00 - 3:30pm  
Blue Moon Cafe, 2 St James Row S1 2EW

Tuesday 10th July, 10:00am - 12:00pm  
The Ball, 171-173 Crookes S10 1UD

Wednesday 18th July, 5:00 - 6:30pm  
Cafe Rouge, St Paul's Place (The Peace Gardens) S1 2JL

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

Friday 20th July, 2:00 - 3:30pm  
Marks and Spencer Cafe, Crystal Peaks Shopping Centre S20 7PQ

Wednesday 8th August, 2:00 - 3:30pm  
Blue Moon Cafe, 2 St James Row S1 2EW

Monday 13th August, 2:00 - 3:30pm  
Angelica's Tea and Cake, Atkinson's (first floor), 78-82 The Moor S1 3LT

Tuesday 14th August, 11:15am - 12:45pm  
Morrisons Cafe, 84-130 Meadowhead S8 7UE

Thursday 16th August, 2:00 - 3:30pm  
Costa Coffee, Fox Valley Retail Park, Stocksbridge S36 2AD

Tuesday 21st August, 10:00am - 12:00pm  
The Ball, 171-173 Crookes S10 1UD

Wednesday 22nd August, 5:00 - 6:30pm  
Cafe Rouge, St Paul's Place (The Peace Gardens) S1 2JL

Friday 24th August, 2:00 - 3:30pm  
Marks and Spencer Cafe, Crystal Peaks Shopping Centre S20 7PQ

Wednesday 5th September, 2:00 - 3:30pm  
Costa Coffee, Fox Valley Retail Park, Stocksbridge S36 2AD

Tuesday 11th September, 11:15am - 12:45pm  
Costa Coffee, 872a Chesterfield Road, Woodseats S8 0SH

### Sheffield Tai Chi Classes

Thursdays 12th July, and  
6th and 20th September, 1:00pm  
(No class on 26th July)

Victoria Hall, Chapel Walk S1 2JB

### **\*New\*** Arts and Crafts Group

Wednesdays 11th  
and 25th July, and  
29th August  
1:00 - 3:00pm

Room 6, The Circle,  
33 Rockingham  
Lane S1 4FW

P.T.O.

## Sheffield Drop-Ins continued

Tuesday 18th September, 10:00am - 12:00pm  
The Ball, 171-173 Crookes S10 1UD

Wednesday 19th September, 2:00 - 3:30pm  
Blue Moon Cafe, 2 St James Row S1 2EW

Monday 24th September, 2:00 - 3:30pm  
Angelica's Tea and Cake, Atkinson's (first floor), 78-82 The Moor S1 3LT

Wednesday 26th September, 5:00 - 6:30pm  
Cafe Rouge, St Paul's Place (The Peace Gardens) S1 2JL

## Chesterfield and Barlborough Drop-In Meetings

Wednesday 11th July, 10:30am - 12:00pm  
Dobbies Garden Centre, 4 High Wood Way, Barlborough Links S43 4XN

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

Wednesday 8th August, 10:30am - 12:00pm  
Dobbies Garden Centre, 4 High Wood Way, Barlborough Links S43 4XN

Tuesday 14th August, 10:30am - 12:00pm  
Miss Poppy's Cafe, Eyre's Furniture Store, 19 Holywell Street S41 7SA

Wednesday 5th September, 11:00am - 12:30pm  
Debenhams Cafe, Ravenside Retail Park S40 1TB

Wednesday 12th September, 10:30am - 12:00pm  
Dobbies Garden Centre, 4 High Wood Way, Barlborough Links S43 4XN

### Chesterfield Seated Tai Chi Classes:

Wednesdays 4th and 18th July, 2:30 - 3:30pm  
Summer break

Wednesdays 5th and 19th September, 2:30 - 3:30pm  
All at Central Methodist Church, Saltergate S40 1UH  
£3 members/£4 non-members



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?

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 new Chair

Hi everyone, I'm writing to introduce myself as the new Chair of the Board of Trustees.

I only recently became involved in Sheffield ME and Fibromyalgia Group. Last November I came to the annual conference at which Unrest was shown, a film I'd heard about for some time and had been wanting to see. I was very moved and impressed by the film but also met a group of really lovely people there. I was particularly inspired by the idea that people with ME and fibromyalgia could make their voices heard through the #MillionsMissing campaign, and so chatted with Hilary, Chris and Carol about how to get involved.



A little about me first: I'm currently programme director at CRESST, a charity running conflict resolution training for young people in schools, and have past experience both setting up and leading charities and campaigns. I am also a carer for my 24 year old daughter, Sian, who has been housebound for five and a half years with severe ME and I've had previous experience of ME through caring for a friend who was bedbound and lived with myself and my partner for five years in the early 1990s. ME has had a huge effect on our family, and both Sian and I want to campaign actively and be involved in supporting and linking up with others affected by this and similar diseases.

Sian and I took on coordinating this year's #MillionsMissing with a lot of help from others. For me it was an incredibly powerful experience to be in touch with so many people, especially those more severely affected, and I feel like I have learnt an enormous amount through doing this. I'm really struck by how much people are wanting to do and how willingly they offer their limited energy even when their illness is working against them. Our online live feed of the day has had over 8000 views on Facebook and our short film has had over 3000. This is way beyond anything I expected! We have another 13 minute film of the day coming out soon that we intend to use in our advocacy efforts over the coming year.

Having now taken on being Chair, I'm really keen to work with everyone to make this a really well-run charity. We've got lots to do to raise funds to support the group's activities in the coming year and increase our membership. All offers for volunteering, however small or large, will be very gratefully received. There's so much to help with, from running drop-ins, to organising events, to admin in the office. If you have any ideas about things you could do, or even if you're not sure but want to be involved, do just get in touch.

I'm optimistic about the year ahead, about working with those already involved and meeting new people, about the support this group continues to give, about raising awareness, and about joining with other allies to work towards a better Sheffield, and a better United Kingdom, for people with these illnesses.

Carolyn

# Letter from our retiring Chair

Dear All,

I hope you're all as well as possible and enjoying the lovely weather while it lasts. I've heard we're due to have a "Flaming June" which would be fantastic after the long and dreary Winter we all had to cope with, so enjoy it while you can!

As you'll probably be aware, I stepped down as Chair recently due to a combination of ill-health and getting on in years. I very much regretted having to take Doctor's orders and finally retire, but now know it was the right decision for all concerned. All charities need a strong management committee who work together as a team whilst taking some personal responsibility for which their life experience and skills are appropriate - no one person can do everything!

My time as Chair was a whirlwind of highs and lows, tears and laughter. I met some amazing people and made lots of new friends, hopefully for life. I also learned a lot about listening to members' stories and about why and how the group exists. I'm enormously proud of how much the group has achieved, especially the wonderful Winter Gardens Week and Millions Missing Event in May. It's great to know that everyone made such a huge effort to make these so successful. Well done everyone!

I'm still involved with the group in a very small way, by co-ordinating the Chesterfield Network group and hope that some of you will come to join us at one of our drop-ins - the details are on the Diary page. I also hope to get to some of the Sheffield drop-ins, which sadly I didn't have the time to do before – and to be a volunteer at forthcoming events, so you haven't seen the last of me yet!

I feel sure the present Management Committee will work together to raise the profile of the group and continue to offer the support and services you all so richly deserve and I wish them all the best in their endeavours.

Thank you to all those people who have kept in touch and for the good wishes which have come my way - it has been a privilege to know you all.

Warmest wishes,

Hilary

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## Receive your Magazine by email

Would you like to receive your quarterly magazines by email (as a .pdf attachment)? Some people find it more convenient, and it saves the Group money on printing and postage. They also get them in colour! (Please note, if you choose to receive your magazines by email, you won't also receive a paper copy.) If you'd like to receive your quarterly magazine this way, please email us at [info@sheffieldmegroup.co.uk](mailto:info@sheffieldmegroup.co.uk) to let us know, marking your email "magazine by email". Thank you.

# Outreach Worker's Report

Well, to say the last couple of months have been eventful is a huge understatement, and I believe that they have made a huge impact on the Group itself, and hopefully the membership.

Some of you will have seen that I asked via Facebook a few weeks ago if we had anybody who would like to volunteer to do various jobs in the office or attend events or do a bit of fundraising. We had an excellent response, and since then we have met up with new members who have offered to help. But the one reply that stood out from all the rest was one that said, "What are you doing about the Millions Missing campaign?" and, "I have a number of people here just waiting to offer our help in putting the Sheffield part of the campaign into practice". The rest, as they say, is history.

A huge thank you goes to Carolyn Leary and her daughter Sian. Carolyn not only initiated the whole Sheffield campaign, and made it the success it was on Friday 11th May 2018 on Fargate, but then also found herself Acting Chair of the Group.

I will not go into great detail here about the Millions Missing day on Fargate as I am sure others will cover it in these pages, but I would like to say a very big thank you to those volunteers who turned out to help us during the day. It was certainly the most successful of all the events that the Group has been involved with in my time, and I am convinced it has put Sheffield ME Group even more firmly on the map.

There were dozens of photos taken on the day and some will be in this magazine, but do take the time to see the finished 2-minute film from the day on YouTube, which is accompanied by the most beautiful song - written by a person with severe ME not too far away from Sheffield. It really was the icing on the cake and we have that memory for ever.

Please read all the information about the day in the rest of this magazine, and please share it with your friends and family. The more people that read about the day and spread the message the better.

A month earlier we had our annual Information and Awareness Event in the Winter Gardens, which once again proved hugely successful thanks to our regular band of volunteers who turned up each day to make the event a success. It is not an event that is easy to organise as there is always red tape to overcome, and risk assessments to contend with, but once everything is in place the "easy" bit is actually meeting new people who need support.

This time we met over 125 people, and many of them have since become members, so if you have not heard from us since please do contact the office. We seem to have a database which is made out of chocolate and it has been difficult to know who is on it, who is a member, who has received magazines, etc., so please bear with us. Everyone is doing their best to sort this out but don't be surprised if you receive a request to "update" your details

My very grateful thanks go out to the volunteers (you know who you are!) who



helped out at the Winter Gardens to make it a great week, even though the temperature did not know what to do with itself!

On a completely different subject, and not a popular one, I'll be writing an article for the Autumn magazine on the Department of Work and Pensions and their strange antics when they come to dealing with people applying for PIP.

They have made some weird and strange decisions over the last few months, some of which make no sense whatsoever, and I can only assume they have a bigger backlog and workload than ever as they seem to be ignoring really serious claims.

However, it is important that people do NOT give in and let them win. I say many times it is a gruelling process but hopefully I will be arranging some training sessions on PIP so please look out for the dates on the Facebook page and the website. They will be held for 3 hours at a time, but with plenty of breaks, so no one needs to worry about listening to me drone on without being able to get up and have a walk around!

Take care and enjoy this glorious summer weather... that's a cue for rain, if ever I heard one!

Chris

## Volunteers' Meeting

Some of our fantastic volunteers, pictured at a meeting in March, where plans were drawn up for helping at the Winter Garden, AGM and Social, and Millions Missing.

It was also a chance for a chat, and for a big thank you to be said to them on behalf of the members.

We always need volunteers, please contact the office if you'd like to join in. Thanks!



# Raising M.E. awareness

THE Sheffield M.E. Group hosted a stall in Sheffield Winter Gardens last month to raise awareness and offer information on chronic pain conditions.

Chris Wintle, an M.E. sufferer, has been the outreach worker for the group since May, 2011.

He told me: "I became involved with the Sheffield M.E. Group as I had previously helped set up the North Derbyshire M.E. Group in the 1990s. That group finished in 1999 which was a great shame."

Fibromyalgia and Chronic Fatigue Syndrome, otherwise known as M.E., are serious pain disorders which affect people in a multitude of ways. Both illnesses can cause sleep problems, concentration problems, flu-like symptoms, mental fatigue, muscle pain and stiffness as well as muscle spasms, headaches and widespread pain.

Similarly, both illnesses have no known direct cause, however risk factors for Fibromyalgia include traumatic injury, rheumatoid arthritis and other autoimmune disorders such as lupus, and



*The Winter Gardens exhibition*

genetic factors.

In ME/CFS, onset is often linked to a viral infection.

Other triggers may include an operation or an accident, although some people experience a slow, insidious onset.

My mum, Angela Colton, 46,



*Student journalist Ellie Colton reports on a recent health exhibition in the Winter Gardens*

explained how she copes living with both disorders: "Fibromyalgia pain is widespread and chronic and can be accompanied by fatigue. However, in Chronic Fatigue Syndrome it can be so severe sometimes that it prevents a person from doing anything".

In order to raise awareness, Chris said: "The media could help in so many ways by giving publicity to how the illness affects people and not keep coming out with old-fashioned terms such as 'yuppie flu'. It is not yuppie flu, it is a chronic disabling condition which destroys lives."

National M.E. Awareness week 2018 is May 7th-13th and Chris said: "We will be on Fargate on Friday, 11th May, from 10am-6pm for the 'Millions Missing' programme where dozens of pairs of shoes will be laid out with a message in each of them. This represents someone who cannot use these shoes anymore because they have M.E.."

This article appeared in May's edition of Active8, a free magazine for Sheffield 8. It is reproduced with permission.

Thank you to Active8 and Ellie Colton.

## Some Upcoming Group Activities

### Tai Chi Classes in Sheffield and Chesterfield

There is a Sheffield class on Thursday 12th July, but not 26th. There may be classes in August, depending upon demand (please see Facebook or contact the office). Classes resume fortnightly, as normal, from Thursday 6th September.

Chesterfield classes take a summer break after 18th July, returning 5th September.

### New Arts and Crafts Group

Our new Arts and Crafts Group will be meeting in room 6 at The Circle, from 1:00 to 3:00pm, on Wednesdays 11th and 25th July, and 29th August. Please bring along any craft - knitting, crochet, needlework, anything - and have fun socialising.

### Rollers and Strollers

This is a new social walking group for people with ME or Fibromyalgia, who are limited in their walking or travel by scooter. Meetings are advertised at a week's notice on our Facebook page but if you'd like to be notified by text message or email, please let us know at the office.

# AGM and Social

## Guest speaker, Dr Simon Duffy



This year our Annual General Meeting and Social, with Guest Speaker (not the catchiest title - suggestions on a postcard, please!) took place on Thursday 10th May at The Circle in Sheffield. 34 members attended.

### AGM

The event began with the business of the AGM - the presentation of the 2017 Annual Report, a short talk on the Group's plans for the coming year, and the election of Trustees.

Our Constitution allows for 10 Trustees: for the first time, we exceeded 10 nominations as 12 people put their names forward. It is fantastic that so many want to get involved and help others with ME and Fibromyalgia. The Board will sort this issue out at their first meetings.



### Dr Simon Duffy

Simon (pictured top left) is the founder and Director of the Centre of Welfare Reform, a think tank based in Sheffield.

He speaks regularly on television and radio about the welfare state and social policy. He is best known for inventing personal budgets and for designing systems of self-directed support to reform the organisation of social care. He works as a consultant and researcher with local social innovators and national governments.

His work has led to significant changes in social policy in England and Scotland. He has published many proposals of reform including overhauling the current system of health and social services and replacing it with a system which gives people control of their own care. In 2008



he was awarded RSA's Prince Albert Medal, and in 2011 the SPA Award for outstanding contribution to social policy. He has a doctorate in moral philosophy and is also an Honorary Senior Research Fellow at the University of Birmingham's Health Service Management Centre.

Dr Duffy talked about how the benefit system is often described by some politicians or in the media as out of control, in need of cutting back, as having a problem with fraud, and with many people dependent on benefits who need to be forced into work. In fact, he explained, the true picture is that spending on benefits is low and fraud is insignificant, whilst inequality is higher than in almost all comparable countries.

He illustrated this with figures: the total cost of pensions and benefits is £180 billion, tax evasion and avoidance is £122bn, tax fraud is £16bn and benefit fraud is £1bn (2013 figures). The poorest 6.5 million people live on £51 a week (after tax), the richest 6.5m on £580. The difference in income between the poorest 10% and the richest 10% has doubled in a generation (1985-2013).

David Cameron admitted the poor are taxed more than any other group, through paying VAT, Council Tax, Emergency Income Tax and National Insurance they pay 43.5% of their income, while the average for society is 32.7%. Middle-earners receive more benefits (pensions, tax credits) than the poorest.

Dr Duffy described current welfare reform as "a disaster of criminal proportions". The introduction of Employment and Support Allowance (ESA), Personal Independence Payment (PIP) and Universal Credit, the austerity programme, with its 50% cut to social care, the benefits freeze, and the use of sanctions by the DWP have, among other measures, made life much harder for the poorest in society. Disabled people have, he said, been the main target for cuts.

Three UN Committees have reported the UK as breaching the human rights of its own citizens through austerity measures. Only the UK responded this way to the global financial crisis.

The shift to Work Capability Assessments for benefits has been associated with 590 suicides, 279,000 case of self-reported mental health problems and 729,000 anti-depressant prescriptions (2015).

Dr Duffy believes in a diverse and decent society, "where everyone matters" and can lead a balanced life, and that the welfare state should help us achieve social justice by supporting family, citizenship and community. He believes in universal services (e.g. NHS and education) and a right to a home and to a basic income.

We are very grateful to Dr Duffy for an interesting talk which was different to any we have hosted before. The Welfare State is an issue for many of our members and this talk provided explanations and food for thought. Feedback was almost wholly positive, some members reported it made them feel less guilty about needing help from the State.

Simon

# Millions Missing

Millions Missing is an annual global event. This year it took place in more than 50 cities across the world, to demand more investment in biomedical research in order to speed up our understanding of ME and to search for effective treatments and a cure. In Sheffield we held an action on 11th May outside Marks and Spencer on Fargate. This was a massive success....

Dozens of pairs of shoes, all donated by members, were placed on Fargate to represent the people who are missing from so many aspects of their own lives because of ME. Each donated pair of shoes had a tag attached, explaining the wearer's situation and what they have lost because of this debilitating disease.

ME is sometimes described as an invisible illness, because the symptoms are not visible to others. It is also out of the public eye and feels forgotten by Government and much of the medical profession.

The campaign aims to enable people with ME to make themselves visible and share their stories, to organise patients, carers, friends, doctors and scientists to make change happen, and to promote research and treatment. This campaign is about everyone affected by ME, but is especially looking to enable those who are most isolated by this illness to have a voice.

Speakers and performances all helped to make ME more visible. As the photos show, many people stopped on a busy Fargate to look, listen and ask questions. We talked to very many people who have ME or who know someone with ME.

Simon

## #MILLIONSMISSING

is a global campaign for ME health equality

Myalgic Encephalomyelitis (ME), sometimes known as Chronic Fatigue Syndrome (CFS) or ME/CFS, is a devastating, complex, multi-system disease, which affects the immune system, nervous system, endocrine system and metabolism.

**WE DEMAND** the following:



### Parity of Research Funding

From 2006-2015 ME had £4 per patient per year spent on research funding, a small percentage of which had a biomedical focus. In comparison MS patients had £80 per patient per year. Funding must reflect the impact and severity of this disease.

### Remove GET & CBT from the NICE Guidelines immediately

Graded Exercise Therapy and Cognitive Behavioural Therapy have been proved as ineffective treatments for ME and in some cases they can be harmful. Yet NICE say it will take 2 years to update their guidelines. In the meantime more patients are being subjected to these ineffective and in some cases harmful therapies which places them at risk of harm and do not offer effective treatment.



#MillionsMissing | #CanYouSeeMEnow?

For more info on ME, how you can help and a fully referenced version of this leaflet go to: [millionsmissing.org](http://millionsmissing.org)



## FACTS ABOUT ME/CFS

Myalgic Encephalomyelitis / Chronic Fatigue Syndrome

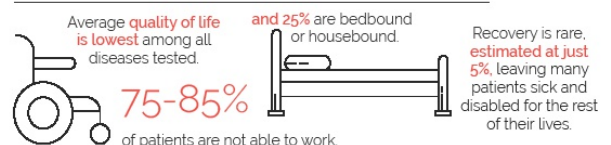
### WHO IS AT RISK?



### WHAT IS THE TREATMENT?



### HOW SERIOUS IS THE DISEASE?



### WHAT DOES IT COST OUR COUNTRY?



# Representing the Millions Missing in Sheffield

By Laura Elliott

Hundreds of people gathered in Sheffield Fargate as part of the global Millions Missing campaign, to raise visibility for people around the world living with ME.

Organised by the Sheffield ME and Fibromyalgia Group, the demonstration was part of a global initiative advocating for ME health equality. On Fargate, as around the world, shoes were sent by sufferers too ill to leave their homes, featuring heart-breaking messages about the lives that have been missed because of this under-funded and ignored disease.

"Lost walks in the sun", read one tag tied onto a pair of sandals, while the note on a pair of baby shoes described how one woman was unable to support her daughter after the birth of her little girl, due to being bed-bound with ME.

Worldwide, ME affects between 15 and 30 million people, but due to it being treated as a psychological illness for many years, it receives only a fraction of the funding of other neurological illnesses, and doctors still aren't trained in how best to treat patients.

One such patient, is Laura Boyles, who spoke from her wheelchair about just how much ME has affected her, saying:

"I am one of the 2,400 people in Sheffield with ME. I'd much rather define myself in other ways: as a confident woman, as an involved mother with two gorgeous boys, as a loving partner, an enthusiastic writer, a creator of crafty things, a caring daughter, and a rather silly friend. But now, above all, I have ME.

"This—often invisible—thief of an illness, has stolen first fragments, then chunks, then entire portions of my life. Parts of me upon which my identity used to hang. Like more than 75% of people with ME, I am unable to work. This illness has stolen my career. I worked for an environmental charity for nearly two decades, planting trees, herding small children in school groups, engaging communities, planning, informing, writing, and making good things happen.



Attracting attention!



Left to right:  
Laura Boyles,  
our patron  
Berlie Doherty,  
our former  
Chair Carol  
Binks, and our  
new Chair  
Carolyn Leary  
all addressed  
the crowds on  
Fargate

“Now, I’m often housebound. Bored as all hell by the same four walls. Frustrated by my need to do, to be, to achieve, when all my body will allow is limited moments of activity, followed by pain, exhaustion, malfunction, [and] a need to rest. Rest, that actually makes little to no difference.”

Sadly, Laura’s story is all too common. Despite its lack of funding, ME is a devastating illness that affects the immune, endocrine, and nervous systems, and for which there is currently no cure. It leaves 25% of patients housebound or bed-bound, and an estimated 75% unable to work.

Part of the problem for UK patients, is that the treatments currently recommended by the National Institute for Health and Care Excellence (NICE), are out-dated and actively harmful, as speaker Carol Binks described to the crowd of gathered campaigners, patients, and their families:

“Research from the US has demonstrated that people with ME have a lower quality of life than people with congestive heart failure, heart attack, [and] MS.

“In spite of the physical devastation wreaked on the bodies of sufferers, and in spite of a reported 9,000 research studies demonstrating biomedical, physical abnormalities in people with ME, the main treatments recommended by NICE are based on behavioural and activity models.

“[These models] follow the assumption that people with ME suffer from false illness beliefs and have a fear of activity. When in reality, people with ME are desperate to get out bed, leave their homes, go out to work, and have a social life.”

The current recommended therapies in the UK, which are Graded Exercise Therapy (GET), and Cognitive Behavioural Therapy (CBT), are no longer recommended by the US National Institute of Health, as there is no good evidence for their efficacy.

In fact, a number of ME patients report being actively harmed by these interventions, with many reporting a permanent deterioration in their symptoms, from being only mildly affected when they began treatment, to becoming permanently disabled afterwards.

NICE is currently reviewing its guidelines, following pressure from the UK ME Association, patients, and scientists, but the reviewed guidelines won't be announced until 2020. In the meantime, they have refused calls for the use of CBT and GET to be stopped immediately, which ME charities and patients say, continues to expose newly-diagnosed and uninformed sufferers to long-term harm.

Without pressure from campaigners, Carol believes, patients simply won't get the care they need:

"Because the treatment for ME in the UK is based on psychological and behavioural models, biomedical research into the true nature of ME has not received anywhere near the level of funding necessary to address such a widespread and devastating illness.

"Medical students are not taught about the biomedical nature of ME in medical school, so most doctors either have no idea, or are extremely poorly-informed about the true nature of ME.

"Many doctors don't even believe that ME exists, even though it has been categorised since 1969 as a neurological illness—as opposed to a psychiatric one—by the World Health Organisation."

Without additional funding for research, patients like Laura, and the rest of the Millions Missing who sent shoes, cards, and messages of hope and heartbreak from around the world, will be left to struggle on without support.

As she concluded her speech, Laura seemed to speak for patients everywhere, as she said:

"I'd like to sit here in my wheelchair and say that I am brave. I want to be courageous. But honestly, this illness is frequently unbearable. I often wonder how I can take even one more day feeling like this.

"We, me, my ME community, my family, we did not choose this. All we want is our lives back, as perfectly imperfect as they were. But the harsh truth is that currently there are no effective treatments, and the recovery rate for ME is a miserable 5%.

"At any one time, it is estimated that 25% of us are too severely affected to leave our homes, or even our beds. UK-wide, that is 62,500 people missing. It means that here, in Sheffield, there are 500–600 people lying in darkness, suffering and silenced, feeling forgotten. We must not let them stay forgotten.

"You can help. There's a swell of action and hope right now. We need to ride that to real change. And we can all be that change.

"Donate. Speak out. Sign petitions. Share on social media. See us. Accept our truths. It doesn't take much to be a hero for us."

Laura Elliott  
Twitter @TinyWriterLaura

# More pictures from Millions Missing



Millions Missing photos by Chris, Duraiya, Laura and Michele

# NICE Scoping Workshop

The National Institute for Health and Care Excellence (NICE) advises doctors within the NHS on what they regard as best practice in treating different illnesses.

For mild and moderate ME/CFS, they recommend Cognitive Behavioural Therapy (CBT) and Graded Exercise Therapy (GET), in accordance with the results of the now much-discredited PACE Trial. This protocol is opposed by patient groups because the recommended form of CBT is based on the idea that ME/CFS is a psychological illness, and GET has caused many ME sufferers to relapse.

In the USA, CBT and GET have been rejected as a way of treating ME. NICE is now reviewing its own recommendations, and will be reporting back in 2020. This scoping workshop is part of their consultative process.

On 25th May 2018, NICE held an engagement workshop with stakeholders, looking at the draft scope for the new guideline on ME/CFS. This is the second workshop held by NICE in which stakeholders were given a chance to influence the development of the new guidelines. The draft scope will be amended based on this workshop and then sent back out to all stakeholders for final consultation period from 21st June to 19th July. At the same time they will be recruiting members for the Guideline Development Group (GDG), which will be tasked with writing the new guideline.

Our new Chair, Carolyn Leary, went along with Nathalie Wright on behalf of #MEAction UK.

There was about a 50:50 split between patient/carer representatives and professionals. The workshop opened with an introductory presentation by staff at NICE, explaining the aims of the workshop and the NICE process and then an introductory speech by Dr Peter Barry who has been appointed as the chair of the guideline development group and a hello from Dame Llori Finlay, the vice chair.

The main part of the meeting, lasting more than 1.5 hours, was a discussion conducted at tables of 12, including two people from NICE's staff acting as facilitator and minute-taker. Each table worked through the first draft of the scope, exploring issues as they came up.

Many vital points came up including:

- Giving greater weight to objective outcomes, which was a common theme among advocates.
- Including harm as a main outcome, which was conspicuously missing from the draft scope.
- Emphasising the importance of considering severely-affected patients and children.
- Using language that accurately represents the devastation this disease is causing and doesn't downplay its effects.
- Questioning why the Lightning Process was even mentioned. NICE staff responded that they had to consider it as there is a published paper, whilst strongly suggesting a recommendation for its use would not be made. Patient advocates

were still very concerned that this highly unethical and flawed study was being given airtime.

Overall it felt like NICE have acknowledged and changed their practices since the 2007 guidelines were created, specifically stating that “we don’t look at evidence in the same way that we did back then”. The facilitators definitely seemed to listen and were able to summarise points from around the tables well. These are positive steps to winning patient trust, and NICE must be commended for this (especially because, as they joked at the session, they aren’t used to receiving praise!)

However, there remains a tangible disconnect between patient/carer representatives and professionals. When Carolyn asked her table who knew of someone who had been harmed by GET, every single patient/carer representative put their hand up yet none of the professionals did. This is despite the patient/carers all coming from different parts of the UK, and stands in stark contrast to Geraghty 2017, where 54-74% of patients deteriorated after a course of GET.

Other examples of professionals being so disconnected from the patient world include:

- One therapist professing shock at the stories being told, then denying it ever happened in their own clinic.
- Another who thought actometers (objective measures of activity) were a great idea, whilst the patient suggesting this was shocked they had never considered such an objective test was possible.
- A clinician who nodded and agreed with patients/carers throughout the process, yet at the end said the guideline development group absolutely must have a psychiatrist – it seemed this person had only attended to make this point. We see no reason to specifically include a psychiatrist, when neurologists and immunologists are only optional.

NICE currently propose that the Guideline Development Group includes 2 GPs, 3 Physicians interested in ME/CFS (e.g. neurologist, infectious diseases, immunologist), 1 Psychologist, 1 Occupational Therapist, 1 Physiotherapist, 1 Dietician, 1 Nurse with special interest, 1 Social worker, and 4 Lay members (to include parent and/or carer).

Although we came away feeling we had been listened to, we have no idea if we were heard; the proof will be in the pudding. The circumstances of the meeting were inadequate: there was not enough time for stakeholders to react to the draft scoping document in preparation for the meeting and there was not enough time in the meeting for stakeholders to put across their input. Many stakeholders also felt that the draft scope was inadequate and had not taken into account enough of the stakeholder input from the initial meeting (pre-scope). However, being despondent at shortcomings is not an option.

Going forwards, it is important to keep an open dialogue with other stakeholder organisations; if we can unite behind key points we are stronger.

Carolyn, Sian and Simon

# Melatonin and Me... and ME

## My personal story, by Gill Watkin

I have trouble sleeping, although not so much as I used to have. The frustration of how long it took to get to sleep, and then waking up frequently and having to go through it all again just wore me out. My body clock is pretty much non-existent and I don't have a natural waking up time. I can't function in the morning and find it difficult to know when to go to bed.

I began to research Melatonin after I saw a programme on the BBC which looked at the effects of lack of sleep, lack of daylight and the cycle of melatonin. I tried to find out if there was a test available, as one was done on the programme, and I attended the Sleep Clinic at a Sheffield hospital and was told there is no such test yet as it was still in research phase. I was diagnosed with periodic limb movement although I don't agree, and my husband says I never wake him up and am like a log when I am asleep! I was put on medication for Parkinsons' Disease as this was supposed to help, but it totally wound me up and I decided to stop taking it. I asked for melatonin but was refused ... the sleep consultant suggested CBT... Haha... and then discharged me.

At the time I had a very supportive GP, who has now retired unfortunately, and he was willing to let me try melatonin, bless him. It really helped and I was so grateful to him, especially when I found out how much it cost to the NHS.

I changed doctors after he retired, and the new surgery changed my melatonin to Circadin, 2mg time-released, as it is much cheaper. I found this to be not as effective, and I have resorted to buying from the internet which is so annoying, as it isn't very expensive and so the NHS is paying over the odds again! I currently use Twinlab Melatonin Dots, 3mg.

My husband has Post Viral Chronic Fatigue and the Circadin does work for him as effectively as the initial melatonin. He had been taking Amitriptyline to help him sleep but struggled with drowsiness in the mornings and it made him gain weight.

So we have both found that melatonin helps with our sleep and I hope to one day be able to have the test once it is available... but that is so much like waiting for the research for ME, I do wonder if it will ever happen.



"I slept like a baby, I dreamt I took melatonin"

*Please note: this is Gill's experience, the Group cannot and does not endorse any medications.*

## Sheffield Yoga for ME

Classes are held on Tuesday afternoons in Walkley and on Friday mornings in Millhouses. They are designed to be gentle and restorative and to help people with ME. Free transport is available. For further information, please phone 0845 582 0112 (11am - 4pm) or check the website [www.sheffieldyogaforme.org](http://www.sheffieldyogaforme.org)

# 2017 Annual Report: A Summary

2017 was a busy year for the Group, in which we successfully maintained our services and even provided some new ones. This is thanks to our funders and to the hard work of Trustees and volunteers.

## Events

Dr Kim Lawson of Sheffield Hallam University and Fibromyalgia Action UK kindly spoke at our AGM on 12th May, discussing his work, awareness and medication.

We showed the newly-released, award-winning documentary, Unrest, about life with ME, followed by a Q&A, at our Annual Conference on 2nd November. 50 people attended. Feedback was overwhelmingly positive at all our events.

We held a meeting where members could talk to Paul Blomfield, Central Sheffield MP, about ME and Fibromyalgia and other issues that concerned them.

We held Information and Awareness Events at Sheffield Winter Garden, Sheffield Peace and Craft Fair, and the Northern General and Hallamshire Hospitals. These events enable us to reach out to and inform non-members.

The year ended with our annual Christmas Social, where 40 people enjoyed the food, drink and games.

## Activities

We held 75 drop-in meetings in cafes around Sheffield, Chesterfield and Rotherham. These enabled members to get together near to their own homes, chat with others who understand their illness and situation, and gain support and friendship, thereby reducing some of the isolation these illnesses can cause. Two of our volunteers were always present and the meetings were held at no cost to the Group. We also held 8 Knit and Natter drop-ins in cafes in 2017.

We held 14 Tai Chi classes in Sheffield and 27 in Chesterfield. We also offered free Reiki and massage taster sessions to members.

## Keeping in touch with Members

We produced our usual quarterly printed 24-page magazine, which is posted to our 251 members, and maintained our website and 2 very successful Facebook pages (which have 500+ and 160+ members, respectively).

## Information Service

A free telephone and email service manned by volunteers to anyone wanting to find out more about ME, Fibromyalgia, welfare benefits, local services and facilities, or the Group. This is particularly helpful for those who have been recently diagnosed.

## **Welfare Benefits Advice**

Our Outreach Worker helped 14 people with their PIP applications, all of whom were successful (4 on appeal), and 3 with ESA. The benefits process is very stressful for claimants. Also, 16 benefit clinics were held around the city, helping 65 people, and a number of people were helped informally and privately.

## **Volunteers**

We are extremely grateful to all our volunteers, without whom the Group could not exist. Many have learnt new skills, refreshed old ones, gained in self-esteem, and made new friendships through volunteering.

## **Funding and Sponsorship**

We are extremely grateful to the Peoples Health Trust, Sheffield Town Trust, the May Hearnshaw Charitable Trust and all our smaller donors and members.

## **Going Forward**

We have had to increase membership fees from £10 to £12 for 2018, we believe this still represents excellent value compared to other local and national charities. Charles Shepherd, Medical Director of the ME Association, will speak at our Annual Conference in November. We aim to continue working with and for people with ME and Fibromyalgia, informing, supporting and campaigning for them as best we can.

Simon

Thank you to Carolyn and Sian for writing the 2017 Annual Report. For a copy of that or the Financial Report, please contact the office.

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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.

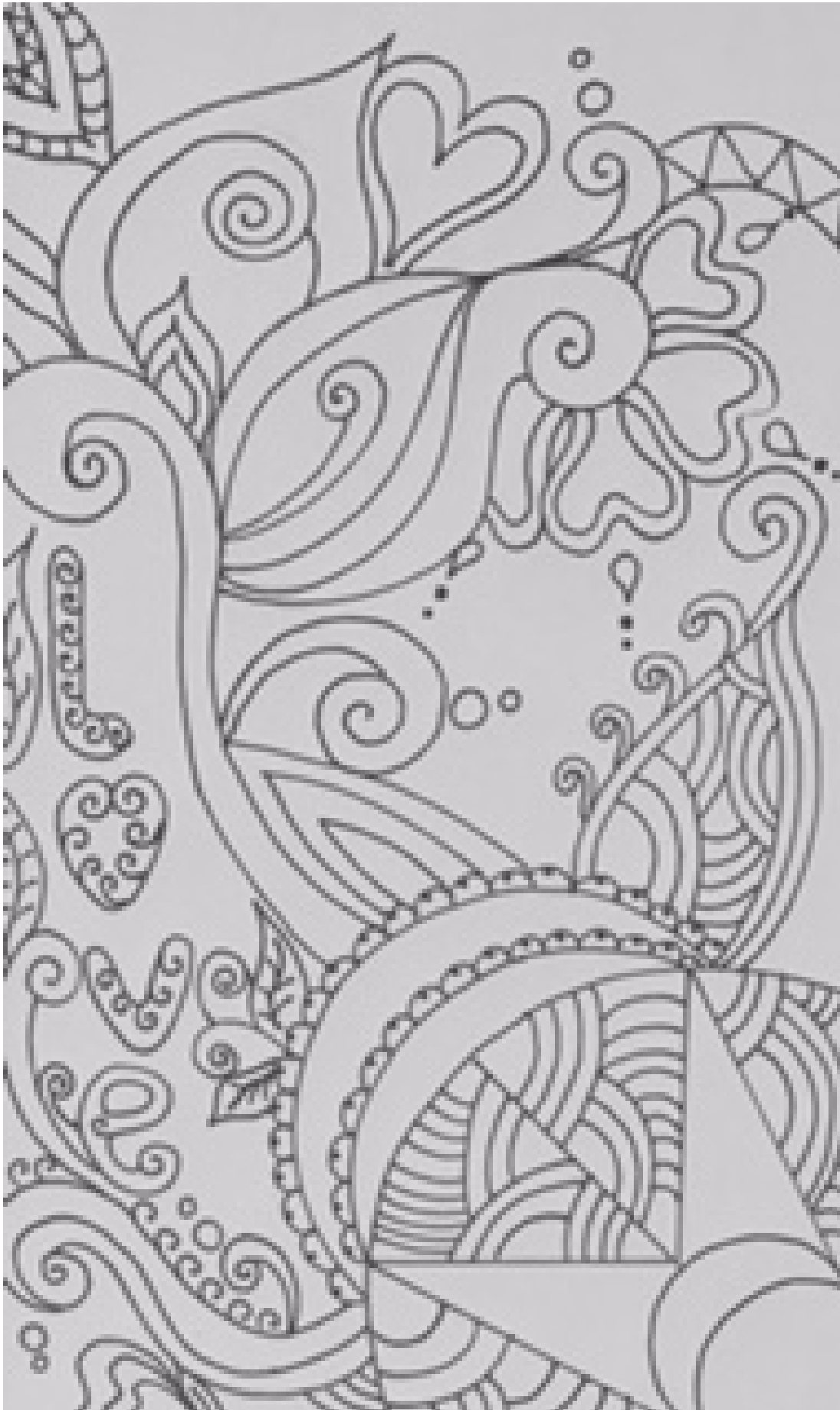
As you know we offer many services: the information line, quarterly magazine, Conference and AGM with speakers, Christmas Social, regular drop-ins, tai chi and other classes, facebook pages, website, lending library, information packs for new members, and more.

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 will feel that by being a member you are helping yourself and others. Thank you!

# **A Picture to Colour**

**by Nupur Chowdhury, Trustee**



# Daft Jokes by Tim Vine

"I'm against hunting. In fact, I'm a hunt saboteur. I go out the night before and shoot the fox."

"Conjunctivitis.com – that's a site for sore eyes."

"I saw this advert in a window that said: 'Television for sale, £1, volume stuck on full.' I thought, 'I can't turn that down.'"

"I went down my local ice-cream shop, and said 'I want to buy an ice-cream'. He said 'Hundreds & thousands?' I said 'We'll start with one.' He said 'Knickerbocker glory?' I said 'I do get a certain amount of freedom in these trousers, yes.'"

"I went in to a pet shop. I said, 'Can I buy a goldfish?' The guy said, 'Do you want an aquarium?' I said, 'I don't care what star sign it is.'"

"I met the bloke who invented crosswords today. I can't remember his name, it's P-something T-something R..."

"A friend of mine always wanted to be run over by a steam train. When it happened, he was chuffed to bits!"

"I've just been on a once-in-a-lifetime holiday. I'll tell you what, never again."

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## Letter from the Editor

Hello everyone,

Summer is here, and as I write this at the end of June, the weather is hot, England look set to win the World Cup (ok, we've only beaten Tunisia and Panama, but I believe!), and ME has been discussed very seriously and sympathetically at Westminster, with several MPs calling for Government-funded biomedical research into ME and the suspension of Graded Exercise Therapy as an NHS "treatment" (as it has done more harm than good to many) - the sun is out, indeed!

It's been a busy time at the Group, what with the Awareness Week in The Winter Garden, the AGM and Social, and the Millions Missing event on Fargate. It was great to see so many of you at these events. We feel they were all big successes in terms of raising awareness and getting information out there.

Thank you to all who contributed articles and photos to this magazine, namely, Carolyn, Chris, Duraiya, Ellie, Gill, Hilary, Laura, Michele, Nupur and Sian, and to Joyce and Beatrice for help with proofing. Much more help is needed; if you think you might like to help with the next magazine, either contributing or proofreading, please get in touch through the office email or postal address. Thank you!

Simon

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Website: [www.sheffieldmegroup.co.uk](http://www.sheffieldmegroup.co.uk)

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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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We would like to reassure you that your details are safe with us and will never be released to any company for marketing purposes. We comply with the Data Protection Act of 1998.

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Please note: The views expressed in this newsletter are not necessarily those of the editorial team and any information given does not constitute or replace individual professional advice. We cannot be held responsible for omissions or errors and reserve the right to edit material submitted for publication. Sheffield ME and Fibromyalgia Group does not endorse or recommend products.