# Guildford ME/CFS Support Group
(& West Surrey)

# Newsletter

## March 2019

www.redbubble.com/shop/me+cfs?ref=search_box

## Future dates

Open to all members and carers

**Please email for details of upcoming meetings:**
**guildfordme@hotmail.co.uk**

# Parliamentary Debate: Kids being taken into care by medics who refuse to believe ME/CFS is real

## One in five families caring for a child with ME/CFS has been referred for child protection proceedings

Source: www.prohealth.com/me-cfs/library/kids-taken-care-medics-refuse-believe-cfs-real-89749
Press Release: January 25, 2019, John Siddle, ME Association (UK).
30th January 2019

Children with the devastating illness ME face the threat of being taken into care because medics refuse to accept their disease is real, parliament was today told.

ME – myalgic encephalomyelitis – is a cruel disease affecting a quarter of a million people in the UK who are being "failed" in a "national disgrace".

While classed as a neurological disease, the stigmatised condition is still considered wrongly by some health professionals to be psychological. It means that often patients struggle to get the support they so desperately need.

ME manifests as activity-induced muscle fatigue, post-exertional malaise, problems with cognitive function, widespread muscle pain, unrefreshing sleep and ongoing flu-like symptoms.

In the debate today – the first in 20 years on ME – the House of Commons was told how one in five children with the disease are being threatened with the prospect of being forced into care. MP Carol Monaghan, who brought today's motion, led calls for more funding for research and better medical training to help support patients.

She said: "There is currently no cure for ME and many with the condition experience inadequate care and support. "But there are an estimated quarter of a million people in the UK suffering from ME, and currently we are letting these people down. "The cause of the disease is unknown, but many patients report that it developed after a viral infection such as flu or glandular fever.

- Link to Hansard Transcript
  https://hansard.parliament.uk/commons/2019-01-24/debates/FA1BBC27-37A7-4BFD-A2C0-A58B57F41D4D/AppropriateMETreatment

- Link to Video of the debate
  https://youtu.be/79BaSpvHywI

"Many adults cannot maintain employment or relationships with family and friends, while children frequently fall behind in school. The ignorance surrounding the condition makes it harder to access benefits with DWP assessors often deciding the sufferer is fit for work."

Several quality of life research studies have shown that the level of disability in ME can be just as great as many other serious medical conditions, including cancer and multiple sclerosis. While some people with ME do improve over the course of time, it is only a small minority that return to full normal health. And the disease is indiscriminate, affecting both sexes, all ages and all races.

Mrs Monaghan, (SNP, Glasgow North West) added:
"Some with severe ME spend their days in darkened rooms, unable even to watch TV or listen to music. Even touch is intolerable. Many are tube fed. For these individuals, ME is a life sentence, but a life spent existing, not living.

"This condition is largely unknown because those affected are often hidden away. I commend the ME community for lobbying so successfully to ensure so many members are here today.

“Leading up to this debate, I have been asked repeatedly what I hope to achieve. Ultimately what I want, and what the ME community wants, is better treatment and care for those with ME.”

**Child protection proceedings**
The debate was told how one in five families caring for a child with the devastating disease ME have been referred for child protection proceedings.

The Commons told how an eight-year-old – Girl B – was almost taken from her family by social services after medics said her condition was psychological.

Mrs Monaghan continued: “B’s parents were warned that if they did not fully comply, child protection proceeding would be initiated. Social services specified graded exercise, despite being warned of the dangers. As a result, B deteriorated rapidly until she became wheelchair bound. “

Under threat of court action, the girl’s parents were then forced to take her to a children’s hospital and threatened with the prospect of their daughter being taken into foster care.
Mrs Monaghan continued: “B was in constant pain, unable to sit upright, with her head hanging down the side, crying in distress.

“This continued for five months and her parents were threatened that if B didn’t progress, she’d be transferred to a psychiatric unit or placed in foster care.”

It was only when the girl’s parents sought the intervention of the secretary of state that the girl was allowed home and removed from the ‘at risk’ register.

**Suspension of controversial therapies**
Ms Monaghan, who also called for the suspension of controversial Graded Exercise Therapy and Cognitive Behaviour Therapy as recommended treatment programmes, added: “A firm diagnosis of ME protects the child from these proceedings but unfortunately paediatricians are often reluctant to give this – simply because they do not understand the condition – which leaves the child open to social service intervention.

“This is a national disgrace and needs urgent action. Children who are already blighted by ME must not be subjected to this trauma.”

**Improving medical education**
Steve Brine, parliamentary under-secretary for health, responded to the debate, saying that, “The Government do not for one-minute underestimate ME.”

“We know that the condition has a devastating impact,” adding, “we cannot for one minute begin to understand what it must be like to suffer from this condition.”

Mr Brine said nobody with ME should ever “be fobbed off by the medical profession.” He said that before the debate he had spoken with the chair of the Royal College of GPs – Prof. Helen Stokes-Lampard – and will organise a future discussion on improving medical education and awareness.

“The NICE guidance is clear on a number of important points. There is no one form of treatment to suit every patient; that is self-evident. The needs and preferences of patients should absolutely be taken into account. Doctors should explain that no single strategy will be successful for all patients, which is a hallmark of this condition.

“In common with people receiving any NHS care, ME patients have the absolute right to refuse or withdraw from any part of their treatment; nobody is making this happen. Those with severe symptoms may require access to a wider range of support, managed by a specialist.”
Research funding

On the subject of research funding for ME, Mr Brine said that it wasn't the Governments responsibility to allocate specific funding, and that the problem lay with the quality of research applications.

He said, "The truth is – sometimes it is a hard and inconvenient truth to hear—there have not been good enough research proposals in the ME space, partly because of the stigma and partly because of the division in the medical community. We need people to come forward with good research proposals in this space; that can only be advantageous."

In closing, Mrs Monaghan replied that, "On the question of medical research, I am sure that many researchers will have heard what he said. However, it is notable that although there is some excellent biomedical research going on just now, it is being funded by charities, and not by the Government. The Government need to take this seriously."

**The ME Association**
The ME Association is at the forefront of improving access to care, treatment and research and removing the disease's stigma.

Despite being recognised by the World Health Organisation as a neurological disease, and a report from the Chief Medical Officer of Health calling for more research and a network of hospital-based clinics, many doctors still don't know how to diagnose and manage ME/CFS and lack or research means that we still don't have any effective forms of treatment. Dr Charles Shepherd, the charity's medical adviser, added: "There are major problems with both undergraduate and postgraduate medical education on ME.

"Undergraduate education on ME is inadequate, or even non-existent, in many medical schools. So, doctors are qualifying knowing little or nothing about the diagnosis or management of ME and without ever seeing a patient with ME. This is particularly so in medical schools where there is nobody carrying out research, or a clinician seeing patients with ME.

"Continuing lack of medical education means that many doctors in primary care/general practice are then unsure about how to make a diagnosis (leading to a late or misdiagnosis) and/or being unable to provide guidance on even basic aspects of management.

"This is a completely unacceptable situation for a disease that is twice as common as multiple sclerosis and where a new report has estimated that is costing the UK economy around £3.5 billion in lost taxes, healthcare and benefit costs."

The motion was passed unanimously:
"That this House calls on the Government to provide increased funding for biomedical research into the diagnosis and treatment of ME, supports the suspension of Graded Exercise Therapy and Cognitive Behaviour Therapy as means of treatment, supports updated training of GPs and medical professionals to ensure they are equipped with clear guidance on diagnosis of ME and appropriate management advice to reflect international consensus on best practice, and is concerned about the current trends of subjecting ME families to unjustified child protection procedures."

**Comment on the Debate**
Dr Charles Shepherd, Hon. Medical Adviser, ME Association

"Overall, I thought it was an excellent debate and although the House of Commons chamber looked rather empty at times, it is quite an achievement to get around 40 MPs to attend a backbench chamber debate for 90 minutes at the end of Thursday afternoon – when most are heading home to their constituencies.

"Carol Monaghan made an excellent opening speech which was followed by shorter speeches from over 20 MPs.

“MPs from all political parties made very similar points covering all the key concerns that have been put to them by the Forward ME Group in our briefing document – lack of medical education, need for biomedical research, NICE recommendations on CBT and GET, the PACE trial etc.

“Most MPs also referred to personal issues that had been raised by their constituents – some of which very clearly illustrated the need for an urgent change of attitude by some sections of the medical profession.

“A number of MPs made very thoughtful contributions (e.g. Nicky Morgan, Ben Lake, David Drew, Dr Phillipa Whitford) and others spoke with real passion (e.g. Stephen Pound).
“And while ministerial responses tend to be disappointing when it comes to actual action, I think that Steve Brine, Minister for Health, had clearly got the message about education, lack of biomedical research, bad management etc… and that he will be talking to his advisers and colleagues about the points that were being made.

“One specific ministerial action, which is clearly going to happen, is a meeting with the President of the Royal College of General Practitioners to discuss GP education – which can obviously follow up the work that the Forward Group have been doing with the RCGP.

“So, a big thank you to Carol for securing this debate; thanks to all the MPs who turned up and spoke, and thanks to everyone who wrote to their MP to ask them to attend.

# New young person’s forum

Source: www.actionforme.org.uk/news/our-new-young-peoples-forum

Research has found that M.E. causes an enormous loss of independence and self-esteem. Our young people’s community combats the isolation and social exclusion faced by many young people with the condition, offering a safe space that promotes friendship and understanding between young people who understand what it’s like to have M.E.

Our Children and Young People’s Service has launched a new forum for young people up to 19 years of age who are affected by M.E. Some people use the forum to gain support and talk about how M.E. affects them, while others use it to talk about things other than M.E., such as hobbies and interests, and to make friends. Managed by our Peer Support Officer, our new Children and young people’s forum is moderated by young people with M.E. and offers a safe space where users can get support, or just make new friends.

One young person told us that, “there are so many great things about the forum, but the best thing for me is how it helps to keep away the feeling of isolation from the rest of the world. The fact that I can communicate with other people on here – who actually understand M.E. – really helps me feel less lonely.”

To access the forum users need to join as a community member at: www.actionforme.org.uk/children-and-young-people and will then receive an email invitation to join the forum.

# America’s CDC (Centres for Disease Control and Prevention) stance on ME/CFS

Source: www.meassociation.org.uk/2019/02/medscape-cdc-chronic-fatigue-syndrome-its-real-and-we-can-do-better-26-february-2019/

My name is Dr Elizabeth Unger and I am chief of CDC’s Chronic Viral Diseases Branch, which houses the myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) program.

An estimated 836,000 to 2.5 million Americans suffer from ME/CFS, a serious, long-term illness that can severely impair the ability of those affected to live normal lives. But the majority of those affected are not diagnosed, and many struggle with symptoms for years before receiving a diagnosis.

The absence of a definitive diagnostic test contributes to this problem. In addition, most medical schools in the United States do not include ME/CFS in their physician training. Less than one third of medical school curricula and less than half of medical textbooks in the United States address ME/CFS, so many healthcare providers need more information about this condition.

When I meet with those living with ME/CFS and their loved ones, the overarching concern that I hear is the difficulty finding good healthcare from informed and compassionate providers.
To address this need, we released an updated CDC website about ME/CFS for healthcare providers in July 2018. The new site was designed specifically with clinicians in mind. It offers information about how clinicians can better assess and help their patients manage this illness. The new content includes:

- presentation and clinical course of ME/CFS;
- prognosis, epidemiology, and possible causes of ME/CFS;
- diagnostic criteria for ME/CFS, released in 2015; and
- proposed approach to caring for people who have been diagnosed with ME/CFS.

ME/CFS is a complex, chronic, debilitating illness with systemic effects. It’s characterized by reduced ability to perform activities that were well tolerated pre-illness, accompanied by profound fatigue not improved by rest, and lasting for more than 6 months.

A hallmark of ME/CFS is that symptoms can worsen after physical, mental, or emotional effort, a manifestation known as post-exertional malaise. Patients with ME/CFS also have unrefreshing sleep.

Other common symptoms are orthostatic intolerance, cognitive impairment, and pain. As can be observed in people with other long-term chronic illnesses, secondary psychological symptoms such as depression and anxiety may also be present in some patients with ME/CFS.

ME/CFS is a biological illness, not a psychological disorder. Patients with ME/CFS are neither malingering nor seeking secondary gain. These patients have a variety of abnormalities that affect multiple systems, such as:

- immune and neuroendocrine;
- cellular metabolism; and
- autonomic system regulating blood pressure and heart rate.

A healthcare provider can make the diagnosis of ME/CFS based on a thorough medical history and physical examination, as well as a targeted workup with screening laboratory tests for other fatiguing illnesses.

While there are currently no diagnostic or confirmatory tests, or US Food and Drug Administration–approved drugs specifically for the treatment of ME/CFS, patients benefit from a thorough medical evaluation and good clinical care. Helping patients achieve relief from symptoms and improved quality of life are the main goals of treatment.

In working toward these goals, it's important to prevent harm that can occur from triggering postexertional malaise. It's also vital to acknowledge the clinical significance of the condition and to validate the experience and concerns of patients and their loved ones. This acknowledgement often brings patients and families a sense of support and strengthens trust between patients and providers.

It is important to emphasize that anyone can develop ME/CFS. While it is more common in women, and most common in people between 40 and 60 years of age, the illness affects children, adolescents, and adults of both sexes and all ages.

Besides information for healthcare providers, the updated ME/CFS website lists resources for families, patients, and schools, including patients' personal accounts of living with ME/CFS, called Voice of the Patient.

We invite you to review the information on the website and hope that it will help ensure that clinicians like yourself are informed about how to recognize and manage this debilitating illness. You can provide timely diagnosis and appropriate care for patients with ME/CFS. Thank you.
Web Resources:

- CDC: ME/CFS
- ME/CFS in Children
- ME/CFS Voice of the Patient
- CDC: ME/CFS Programs
- 2015 Institute of Medicine Report on ME/CFS

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# The 2019 edition of the ME Association's Clinical and Research Guide for ME/CFS/PVFS

Source: www.meassociation.org.uk/2019/02/the-2019-edition-of-the-me-association-clinical-and-research-guide-for-me-cfs-pvfs-27-february-2019/

26th February 2019 By Dr Charles Shepherd, Hon. Medical Adviser, ME Association.

We are pleased to announce that the 2019 edition of the ME Association's authoritative Clinical and Research Guide (The 'Purple Book') has now been published and it's easier to access than ever before.

The guide covers symptoms, assessment, diagnosis, illness management, pharmacological treatments and much, much, more. It informs, educates and helps raise awareness of this all too often misunderstood disease.

It directs readers to more detailed ME Association leaflets from our extensive online library, and summarises all relevant published research. And, it also includes over 600 references to key research papers and clinical trial results.

How to buy your 2019 edition of the MEA Purple Book…

- A Kindle e-Book version is now available at Amazon or Amazon Smile.
- Hard-copies can be ordered from the ME Association:
    - using the on-line order form which you return to us in the post with payment;
    - by phone to head office (telephone: 01280 818964 weekdays, between 9.30am and 3.00pm) where we can take card payment; or
    - direct from the website shop, which takes either PayPal or card payments, ….and your book will be sent to you in the post.

Additions, updates and changes contained in the 2019 edition include:

- an enlarged section covering the management of severe ME/CFS
- summaries of all the key research findings relating to genome wide association studies, immune system activation, metabolomics, neuroimaging and red blood cell morphology that have been published during the past year.
- details of all the important research papers that have been published since the 2018 edition was prepared have also been added to the reference section.
- coverage of current ‘hot topics’ – including medical education initiatives being actioned by the Forward ME group, the NICE guideline review and the parliamentary debates on ME/CFS; and
- an index – for the first time.

This 152-page authoritative publication represents the most comprehensive, evidence-based summary currently available and contains everything that health professionals and patients need to know about this devastating neurological disease.

**Kindle Review received from Paul R. Fleischmann, M.D.:**
“I want to thank you for the outstanding Kindle book: ME/CFS/PVFS, 2019 edition. I appreciated the way that almost every sentence in the book is referenced to an authoritative text.”

“The prose was economical, created to convey the highest density information in the briefest time with the busy professional reader in mind.”

“The range of knowledge was astounding and enviable. You walked me around the topic from more angles than I would have expected. Every sentence was carefully toned to avoid conclusion or endorsement that is not justified by the literature.”

“Best of all, the definitive tone backed up by the hundreds of references, makes your eBook simultaneously a perfect vehicle for educating doctors, and a powerful brief against anyone undermining the reality of the diagnosis of ME/CFS.”

“Therefore, your cool scientific text clearly reveals itself to be a passion for compassion.”

**Free Purple Book for health professionals**
We have funds in the ME Association education budget to continue providing free copies of the Purple Book to any health professional who would like one or who is nominated to receive one by a patient.

We just need to know the name(s) and surgery/hospital address. Contact ME Association Head Office via email and please title the email: ‘MEA Purple Book 2018’, or, telephone: 01280 818964 weekdays, between 9.30am and 3.00pm.

When the Purple Book is sent to health professionals, it is accompanied by a covering letter from me and a copy of a letter from the Workwell Foundation in America which points out the dangers of inappropriate graded exercise therapy (GET).

The new edition, with its updates and new index, is a weightier book than previously and unfortunately postage charges for and from the UK will be increasing from April this year. So, it has been necessary for us to increase the cost from £8.00 to £9.00 for UK orders (and similarly for orders to Europe and the ROW) and we have done similarly for the Kindle version to keep things fair.

As a relatively small charity it is necessary I am afraid for us to charge for this extensive guide which incurs the time-costs relating to research, preparation, printing/collation and distribution. And much of what we receive in payment is spent on providing free copies to health professionals which we do almost daily via post and at medical and research conferences and parliamentary events etc…

We are always happy to receive feedback from people with ME/CFS and from health professionals and if you would like to do so, then please get in touch.

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# Whatever you do today, let it be enough

Source: www.prohealth.com/me-cfs/library/whatever-today-let-enough-90498
By Jo Moss   11th March 2019

"Your self-worth is not measured by your productivity"
We live in a society that teaches us that unless we are pushing ourselves outside our comfort zone, constantly striving to do more, we are not embracing life or living to our full potential. But how does this expectation affect people whose lives are already filled with the daily challenges that accompany ill-health?

I have spent the majority of life feeling like I need to prove myself worthy. That somehow, if I'm not striving for 100% everyday, then I'm not a successful and productive member of society. I have pushed myself way beyond my limits on many occasions, and it's part of the reason why my health has deteriorated so badly over the years. I decided to take a few minutes to contemplate the reasoning behind my need to push myself. Why do I feel unworthy if I'm not constantly striving to better myself? Where does this compulsion to challenge my limitations, at the cost of my health, come from?

A recent conversation with a friend came to mind:
A good friend of mine was telling me about two job offers she had. She felt the need to justify the decision she had made. One job was very similar to the work she had been doing for years, and she's damn good at her job. The other was more challenging and would take her outside her comfort zone. Neither job was better or worse than the other. This is what she said about her decision; "I know I took the easy road, but…" She said it in a negative way, like she had to justify not pushing herself beyond what she felt comfortable with. But why should she, or any of us for that matter, feel guilty about making a decision that makes our lives a little easier? Why should we feel the need to constantly challenge ourselves to prove our self-worth? Who dictated that life had to be so tough?

The truth is, society expects us to constantly challenge ourselves. We are bombarded by this message on a daily basis. We are encouraged to constantly push ourselves beyond our comfort zone; and we are made to feel like we are wasting our life, or just plain lazy, if we don't conform. These messages are hard enough to deal with for the healthy, but when you live with chronic illness or mental ill-health they can be even more damaging. When I was diagnosed with ME/CFS, after being unwell for many years, I still felt unable to rest and give my body the time it needed to heal. I felt like I had to push myself to prove I was worthy—to strive to achieve the most from every day. Looking back, I can see how this pushing and striving caused my health to continue to deteriorate even after diagnosis.

**The unhealthy messages**

Exactly what messages are we being encouraged to conform to? Here are a few motivational quotes I found online. There are hundreds more I could have included.

- Do one thing everyday that scares you
- If it doesn't challenge you, it won't change you
- Great things never came from comfort zones
- The harder you work for something, the greater you feel when you achieve it
- Scared? good. We don't grow when we stay inside our comfort zone
- You can't get much done in life if you only work on the days you feel good
- Become the hardest working person you know
- Life begins at the end of your comfort zone
- Life shrinks or expands in proportion to one's courage
- Push yourself, because no one else is going to do it for you
- Don't take the easy road

These messages can be damaging to someone living with a chronic illness.
People with chronic illness often live within a carefully orchestrated routine; a routine we have created for ourselves that allows us to function without aggravating our symptoms too much. It allows us to live within our limitations. This routine may be considered our "comfort zone." But it's quite common amongst spoonies that every once in a while we challenge our limitations. It's like we forget how bad things get when we do too much. Or we feel guilty about not doing more, and the pressure gets too much—pushed along by society's expectations and the messages we're being force fed.

Constantly being bombarded by these messages can be damaging to us, both mentally and physically. We can feel like a failure when we can't meet up to society's expectations, but pushing leads to a worsening of our symptoms.

What's so wrong with the "easy road" or living in our "comfort zone"? Why should we have to constantly push ourselves? Why do we have to take the hard route in life? Haven't we got enough to deal with? And who decided life had to be so tough? Who says we constantly have to push to prove ourselves as worthy?

Rather than constantly pushing ourselves, can we not just accept how things are right now—how we are, right now? I would like to propose some more constructive motivational quotes: Instead of these often damaging messages, I propose an approach that embraces chronic life with all its challenges. Here are a few of my favourite quotes;

- Relax. You are enough. You do enough
- Life is too short to spend it at war with yourself
- Resting when tired isn't lazy, it's self-care
- Sometimes the most productive thing you can do is rest
- Just take it one day at a time
- If your compassion does not include yourself then it is incomplete
- Your self-worth is not measured by your productivity
- Forward is still forward, no matter how slow
- Breathe extra deep, let go, and just live right now in the moment.
- In a society that profits from your self-doubt, loving yourself is a rebellious act.
- Don't feel guilty for doing what's best for you.
- Just breathe. You don't have to figure it all out today

It's perfectly ok to live within your comfort zone.
The biggest lesson I've learned over the past few years, is to respect my body rather than fight it. To accept my limitations rather than push my body beyond its limits. To acknowledge that my self–worth is not determined by my productivity. That it's perfectly ok, and beneficial for my health, to live within my comfort zone.

It was only when I accepted this new message that my health started to improve. Of course it’s beneficial to set goals. Setting and achieving these goals can give us purpose and the sense of accomplishment—but not at the detriment of our health.

So please try not be pressured by these often damaging messages. You don’t have to be constantly pushing yourself to prove your self–worth. You have enough to contend with. You don’t have to be challenging yourself everyday, finding enjoyment and happiness is much more important. Whatever message society is sending us, I’m here to say: “Life doesn’t have to be this tough.” Go easy on yourself. Whatever you do today, let it be enough.

Jo Moss is a 43 year old ME/CFS, Fibromyalgia and Mental health awareness campaigner. She has battled with poor health all her life but has learnt a lot along the way. She uses her blog ‘A Journey through the Fog’ to try to help others who are also suffering and to raise awareness of invisible illnesses. She writes about all aspects of her health and aims to give practical advice about coping with a chronic illness, based on her own experiences. You can follow Jo on Facebook, Twitter and Instagram.

## Recommended facebook group

Our Guildford ME Group offers its own facebook page that includes links to the latest related information. However, another ME related facebook group that has been recommended for solution based discussions is called “Elite Wellness Warriors - Healing ME/CFS and fibromyalgia”, check it out.

## Invest in ME conference 2019

The 14th Invest in ME conference is coming up on the 31st May at One Great George Street, London, England SW1P 3AA, from 9am til 5.30pm. It’s £50 for ME patients or carers.

Further details can be seen here:
http://www.investinme.org/IIMEC14.shtml

## International Awareness Day – May 12th

Source: https://www.may12th.org

May 12th has been designated as International Awareness Day for Chronic Immunological and Neurological Diseases (CIND) since 1992. The CIND illnesses include Myalgic Encephalomyelitis (ME), Chronic Fatigue Syndrome (CFS), Fibromyalgia (FM), Gulf War Syndrome (GWS) and Multiple Chemical Sensitivity (MCS).

May 12th was chosen as it is the birthday of Florence Nightingale. She was believed to have suffered from ME/CFS. In 2010, a write-up was done to give a history of May 12th. Every year a number of events are held to mark May 12th. They will either be held on May 12th or sometime during the month of May. So please mark your calendar and join us on every May 12th and help raise awareness. Event news will be available on Facebook, Twitter and this site… www.may12th.org

# #MissionsMissing 2019

Source: https://www.meaction.net/2019/02/26/announcing-millionsmissing-2019-join-us

We are thrilled to announce #MillionsMissing 2019!

This May, we will take to the streets – or demonstrate from our beds – to show the world we are here, we are the #MillionsMissing, we will continue to fight for our demands for people with myalgic encephalomyelitis (ME).

We've made important strides in making our voices heard before our government leaders across the world, but we have so much more to do. More than ever, we need to grow our movement and remain persistent in our demands for large-scale change.

Now is the time to take our fighting spirit and creativity to the streets once more. Now is the time to spark a groundswell of support from the public for ME. We must send a message to our government representatives that we are here, we are fighting for our lives, and we are not going away. We demand equitable research funding and care, accurate medical education and an end to the harm and stigma.

Last year was our largest global protest ever with 100 cities around the world demonstrating, and even more participating virtually. Our story was told 79 times by the press around the world. And this year will be even larger.

This year, #MillionsMissing will take place over the course of an entire week from Sunday, May 5 to Sunday, May 12 with key events on Sunday, May 12th. How will you participate? Organize a large public demonstration. Gather a small group in a park or at your home. Participate from your bed via social media. Join your local demonstration.

Each demonstration should decide what targets (it can be general or specific) will be most impactful for drawing attention at your location. We aren't dictating specific targets this year by country as we did in previous years. In the UK and Scotland, the #MillionsMissing campaign will focus on increasing funding for biomedical research into the diagnosis and treatment of ME.

Last year's #MillionsMissing movement led to a meeting with the director of the National Institutes of Health in the US to discuss implementing a strategic plan for people with ME. From the meeting, it was clear that NIH is only comfortable with an incremental approach, which is all the more reason that we must continue to fight publicly for our demand to accelerate research for ME now.

The advocacy work of #MEAction, local activists and other ME charities in conjunction with the momentum from #MillionsMissing has led to important developments across the world, but we must continue to show persistence in our demands.

In the UK, 40 MPs voted on a motion last month to increase biomedical funding and suspend graded exercise therapy, among other actions. In Australia, an MP has tabled a motion for ME in Parliament, and recommendations on clinical education and guidelines and research priorities for ME are in the process of being drafted.

In Denmark, Finland and Norway, ME communities are fighting to stop their health leaders from issuing guidelines for ME based on a biopsychosocial model that ignores the biomedical realities – and international scientific consensus – of the disease. Germany recently softened its position of ME as a biopsychosocial disease, but continues to recommend graded exercise and talk therapy as treatment.

**Make a visual impact**
A key goal for 2019 is to use creative visuals to draw attention to our movement.

We encourage each demonstration to undertake creative visual endeavours as we have seen in past years. This is not only important for attracting attention on the day, but also to use as compelling images for our advocacy work throughout the year.

Displaying empty shoes has always been a unifying and dramatic image to represent the millions missing from our lives due to the neglect of this disease. We encourage you to incorporate this visual into your event or social media demonstration this year, in addition to using other dramatic visuals.

Last year, Scotland staged a lie-down, Berlin unravelled a banner for ME at a football game, New York made themselves invisible with blue gauze, and Sheffield showed up in red wings. On social media, a woman took a headshot buried in a pool of pill bottles.

Since the movement lives on through social media and in communications with our representatives and government officials, remember that high-quality photography and videography is key!! We encourage you to hire a professional photographer or videographer, or to find a professional who can volunteer their time.

**Find allies now!**
#MillionsMissing is a key opportunity to build partnerships with allies in our communities. Think of the groups in your hometown who may be willing to show up to support our fight. It may be disability rights groups, religious groups, women's rights groups, philanthropic groups or other organizations fighting for justice, health equality and basic human rights. Also, think about how you can incorporate your family and friends into helping with the logistics of organizing the demonstration. Now, is the time to make that invitation to the people in our lives to join the fight.

**Tell your story**
We plan to connect our story to larger themes that the public is discussing right now, including healthcare inequality, poverty, disability rights, issues of social justice, and the right to be believed for our experience. Think about the story that you want to tell during #MillionsMissing.

Are you comfortable recording your story, and sharing parts of it on social media? Are you willing to reach out to the press as one of the #MillionsMissing? What are some of the themes running through your experience that might connect you to larger narratives being discussed by the general public right now?

#MEAction plans to collect stories from people with ME around the world, and help frame them thematically in a way that is visually arresting, honest and media savvy. There are so many layers to our story. We are neglected. We are harmed. We have not been believed. We live with “invisible” disabilities and sometimes do not “look” sick.

We are recently sick. We have suffered – and fought – for many decades. We are children, in our prime and seniors. We have lost so many freedoms: to walk, work, speak, read, spend time with our loved ones, go out into the sunshine. And, yet, we are here. We are becoming strong together. We are telling our story. We are fighting for our lives. We will find answers and gain compassion. What is your story with ME that you want to tell the world?