



Omega Newsletter

Volume 109

Spring 2020

Share your stories for ME Awareness Day and Week

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Dear readers,

Illness is on everyone's lips at the moment, whether they have ME/CFS or not. Healthy people are wondering how they will be able to cope with isolating themselves for two weeks after being in contact with a coronavirus case. We at OMEGA have some experience of being confined to the house! In fact, an ME person said (on Facebook):

"I'd always hoped I would rejoin the world, but instead the world has joined me."

The current advice as we went to press is as follows:

Social distancing. Avoid gatherings. Stay home

if at all possible.

And of course wash your hands and surfaces, and don't touch your face unless your hands are clean. There is more information about the coronavirus on page 3, and on page 5 there are some tips on preparing for a stay in hospital.

Jo Moss's article on page 6 has some thoughts to ponder, about facing chronic and long-term illness, and making the most of the life you have.

There is news on page 2 about a new website with resources for people with ME, including physiotherapists who have a special interest in ME.

There's some exciting news on page 9: readers can now support Karl Morten's research by donating online, to help understand the causes of ME.

Readers of the *The Oxford Times* may have

spotted a letter from OMEGA on its pages! In case you missed it, we have reproduced the letter on page 16.

We have included two OMEGA leaflets with this edition of the newsletter, to help you raise awareness of OMEGA and what we do. Please see page 2 for advice on starting this conversation (OMEGA leaflets can raise awareness article).

ME Awareness Week is coming up soon. Two organisations are asking for contributions from people with ME, to help raise awareness of the devastating effects of the illness. Please see pages 11 and 12.

Unfortunately, we have missed the deadline for submissions to the ME Association, but there is still time to contribute a message for MEAction. Short messages on 10 inch squares will be made into quilts, which were to be displayed in Parliament Square in May (now cancelled). Or you could contact your MP to share your story and your hopes for the future.

There is an update on the all-party parliamentary group on ME on page 14.

Pages 15 and 16 feature some information about our AGM, including the help we had from GoodGym. There will be a full report on the AGM in the summer edition of the newsletter.

As usual, if you would like to do some further reading, there are weblinks on page 17 towards the end of the newsletter, which includes the popular virology blog.

There are the usual details of our social groups on pages 19 and 20, but please be aware that these may change in the current climate.

If you would like to contribute to the newsletter, remember to get in touch on newsletter.omega@gmail.com.

If you feel you would be able to help OMEGA with the work that we do, please take a look at the article on page 10.

As ever, we hope you enjoy this edition. Happy reading!

Useful new website with resources for patients, parents of children with ME, and physiotherapists

We are Physios for ME

We are a group of physiotherapists in the United Kingdom with a special interest in Myalgic Encephalomyelitis (ME) often known as Chronic Fatigue Syndrome (CFS).

www.physiosforme.com

There is an interesting page about pacing, introducing the concepts of:

1. "Symptom contingent pacing"; activities are driven by perceived symptom levels, with the aim of avoiding symptoms/conserving energy
2. "Quota-contingent pacing"; undertaking activities according to an amount/distance/goal with the aim of improving function

www.physiosforme.com/post/physios-for-me-comment-on-pacing-guidelines

OMEGA leaflets can raise awareness

Lots of people with ME have other health problems sometimes – of course. Recently I was referred to the local NHS 'Musculo-Skeletal Hub' for some physiotherapy. At the initial appointment the very nice physio took my history, as medics do; all the illnesses and operations I've had. I said I'd also had ME for a long time but that it was a bit better at the moment. "Oh, what's ME?" she said, and my heart did sink. "It's sometimes called CFS/ME," I volunteered. "Oh, chronic fatigue syndrome," she said "Oh yes, we have several patients with that." (Now, there is a series of articles to be written about what to call the illness, or illnesses/sub-groups, the various diagnostic criteria, and so forth. But now wasn't the time for all that.)

I offered her an OMEGA leaflet (which I had taken with me, just in case) and told her that this was the local support group for people with ME. (If you've ever done this, you'll know that this move can go different ways. Health care professionals are often polite enough, but

have to get on with the job/the appointment you are there for, and don't have time to chat. I often do wonder if the leaflet goes into the bin.) But on this occasion my physiotherapist said, "Oh good, I didn't know there was a group. We could put some leaflets in our waiting room." Result! (I'll let her have some more.)

So, the moral of this story is: do try taking a few leaflets with you to medical appointments. We have just had a whole lot more printed. (There should be two in with your newsletter if you have the print version.) Probably best not to make a big issue of it, it's the drip drip drip of information that is needed. Your committee would like everyone in Oxfordshire to know about OMEGA – that there is a support group for people with ME.

Patricia Wells

Coronavirus Covid-19

The situation is changing daily, and it seems that the advice is too. Here are some things that seemed relevant at the time of writing, along with some links which might be useful for people with chronic illness.

"**COVID19** is a serious disease. It is not deadly to most people, but it can kill. We're all responsible for reducing our own risk of infection, and if we're infected, for reducing our risk of infecting others."

Dr Tedros Adhanom Ghebreyesus, Director General of the WHO (World Health Organisation)
(Twitter: <https://twitter.com/DrTedros>)

Caregiver Training: How to Best Wash Your Hands – 24Hr HomeCare

www.youtube.com/watch?v=d7P5b1q0WLo&feature=emb_logo

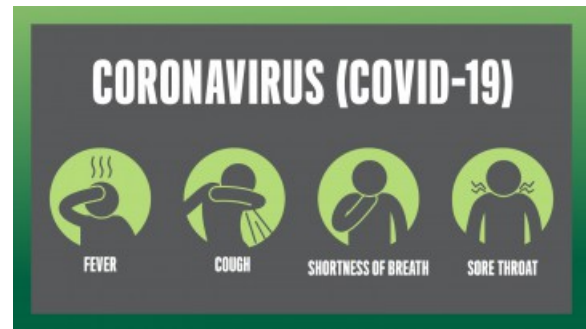
Wash your hands often with soap and water for at least 20 seconds. Air dry or paper towel dry. If soap and water are not available use an alcohol-based hand sanitizer that contains at least 60% alcohol.

COVID-19 Summary for people with chronic illness

A more in-depth article by S. Jade Barclay, an Epidemiologist and Health Science Writer, and

Dr John Whiting, a Physician, Internal Medicine and Infectious Disease Specialist

Know the signs: fever, dry cough, sore throat, shortness of breath. Not a runny nose, and not the common cold.



If you notice these symptoms in yourself or others, self-isolate (stay home) for 14 days, and contact your doctor's office or local hospital *by phone* to request a telehealth consult. Anybody you have had close contact with in the last 14 days should be notified as well.

Don't share towels or tea towels: damp towels can be a breeding ground for all kinds of viruses and bacteria, so it's best not to share, and wash all towels twice a week if possible.

<https://medium.com/@jadebarclay/covid-19-summary-for-people-with-chronic-illness-a6f6a0b02a1a>

COVID-19 Resources for People with ME

From MEAction, with links to a number of articles about coronavirus

Our Hospitalisation Kit is now available for [people with ME](#) to help with upcoming hospital visits. It contains two documents: • one to give to your medical practitioner at the hospital • a packing list for hospital visits. Both are on our [#Covid_19](#) response page

<https://www.meaction.net/covid-19/>

Useful links for disabled people COVID-19-UK

<https://docs.google.com/document/d/1-PpyrWoz-Q5Eoooh0rqfDvsqIGf1aQ8WxaKEaslWhCU/edit#>

Facebook support group The Bunker

This is a support group for disabled people who are having to partially protectively isolate themselves due to being at extra risk from the Corona Virus.

www.facebook.com/groups/thebunkerUK

From two UK charities

Coronavirus Covid-19: Latest Government advice and what it means for people with ME/CFS | 17 March 2020

Dr Charles Shepherd, Hon, Medical Adviser, ME Association.

www.meassociation.org.uk/2020/03/coronavirus-covid-19-latest-government-advice-and-what-it-means-for-people-with-me-cfs-17-march-2020

Coronavirus and ME/CFS

This page has been set up to keep track of up-to-date advice regarding the coronavirus, and support available from Action for ME. We know that the situation is changing quickly and we are monitoring this closely.

www.actionforme.org.uk/living-with-me/coronavirus-and-me-cfs

From the government

Guidance on social distancing for everyone in the UK and protecting older people and vulnerable adults

Published 16 March 2020

www.gov.uk/government/publications/covid-19-guidance-on-social-distancing-and-for-vulnerable-people/guidance-on-social-distancing-for-everyone-in-the-uk-and-protecting-older-people-and-vulnerable-adults

COVID-19: guidance on home care provision

Published 13 March 2020

www.gov.uk/government/publications/covid-19-residential-care-supported-living-and-home-care-guidance/covid-19-guidance-on-home-care-provision

How long can COVID-19 live on surfaces?

Carolyn Machamer, a cell biologist who

specialises in coronaviruses, discusses the latest research on the virus that causes COVID-19

Samuel Volkin, 21 March 2020

According to a recent study published in *The New England Journal of Medicine*, (see www.nejm.org/doi/full/10.1056/NEJMc2004973) SARS-CoV-2, the virus that causes COVID-19, can live in the air and on surfaces between several hours and several days. The study found that the virus is viable for up to 72 hours on plastics, 48 hours on stainless steel, 24 hours on cardboard, and four hours on copper. It is also detectable in the air for three hours.

Machamer: What's getting a lot of press and is presented out of context is that the virus can last on plastic for 72 hours – which sounds really scary. But what's more important is the amount of the virus that remains. It's less than 0.1% of the starting virus material. Infection is theoretically possible but unlikely at the levels remaining after a few days. People need to know this.

What is the best way I can protect myself, knowing that the virus that causes COVID-19 lives on surfaces?

You are more likely to catch the infection through the air if you are next to someone infected than off of a surface. Cleaning surfaces with disinfectant or soap is very effective because once the oily surface coat of the virus is disabled, there is no way the virus can infect a host cell.

- Clean and disinfect surfaces that many people come in contact with. These include tables, doorknobs, light switches, countertops, handles, desks, phones, keyboards, toilets, faucets (taps), and sinks. Avoid touching high-contact surfaces in public.
- Wash your hands often with soap and water for at least 20 seconds immediately when you return home from a public place such as the bank or grocery store.
- When in a public space, put a distance of six feet between yourself and others.
- Most importantly, stay home if you are sick and contact your doctor.

<https://hub.jhu.edu/2020/03/20/sars-cov-2-survive-on-surfaces/>

And finally, for those who would like some time out to do a bit of virtual travelling

Over 30 virtual field trips with links:

https://docs.google.com/document/d/1SvldgTx9djKO6SjyvPDsoGlkgE3iExmi3qh2KRRku_w/mobilebasic?usp=gmail

Compiled by Pat Williams

Advance preparations for a hospital stay

One never knows what is around the corner in life, and this is particularly so when living with chronic illness. While many healthy people are worried about catching the coronavirus, people with ME or CFS are concerned about how they might cope if they need to be admitted to hospital.

Here are some suggestions, from a couple of people who are already prepared.

- Make a list of what you need the healthcare team treating you to know.
- Make both a handwritten list on paper, have it saved as a note in your phone, and make sure family members and housemates also have a copy.
 - If you contract the virus, you may not be able to speak, or

remember to grab the written list, or properly use your phone – hence others must have a copy and you should have it in a variety of different forms

- List all of your allergies, medical and otherwise.
- List any medications you take, and indicate how vital (or not) these are for you.

Sample notes for medics

I have ME (Myalgic Encephalomyelitis) and POTS (Postural Orthostatic Tachycardia Syndrome). I need to spend most of my time in bed.

Any emergency puts me at risk of relapse. You can help reduce this risk by:

1. Making sure I can lie down safely (on the ground if necessary).
2. Reducing my exposure to noise, light, movement and talking where possible. I will probably have ear plugs, sunglasses and eye mask with me. Please make sure I use them, as they will help a lot. Please minimise talking.
3. Keep me warm.
4. I dehydrate quickly so a drink of water may help.
5. IV saline may also be helpful to those with POTS.

With thanks to the original author of the list – unfortunately I cannot find the reference so am unable to credit them.

Learning how to dance in the rain

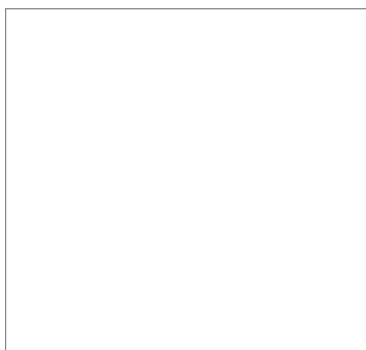
Posted by [Jo Moss](#), 22 [November 2019](#)



Falling ill can put a halt to our plans. When healthy people become muggle sick this nuisance is only temporary; life soon returns to normal. But a chronic illness diagnosis has a long-term impact on our lives, and we have to make substantial adjustments to accommodate the new limitations. Often our lives are put on hold – just surviving each day is hard enough.

But at what point do we restart our lives? At what point do we say, “This is my life now and I will embrace these challenges and move forward”? At what point do we stop searching for a cure and learn to embrace life, just as it is, with all its messiness? At what point do we stop waiting for the storm to pass and learn to dance in the rain?

There is a quote that I often see doing the rounds and it makes me think about my life, and specifically the impact chronic illness has had on my aspirations and happiness;



“Life isn’t about waiting for the storm to pass... It’s about learning to dance in the rain.”

Vivian Greene

I’m sure this quote means different things to different people, but for me it simply means not putting my life on hold until I’m ‘better’. It means making the best of the life I have been given, with all its frustrations and limitations. It means finding purpose and fulfilment despite the pain and exhaustion. It’s about living in the moment, and finding acceptance

and even happiness, right now, without judgement of the past, or expectations of the future.

But I haven’t always thought this way, even when I was relatively well. I have never felt good enough. I have never felt worthy of praise for my achievements. I have never given myself the opportunity to pause and enjoy life. I have never learned how to dance in the rain.

I have always concentrated my efforts on future plans. I have always placed my happiness on future goals; I will be happy once I lose weight, I will stop pushing myself so hard once I have gained that promotion, I will relax once I have saved enough money to be financially secure. I don’t blame myself for this attitude; we are taught to think like this by society from an early age.

But chronic illness forced me to stop. It was an unwelcome and painful slap in the face, but it has taught me so much.

My personal storms

I have weathered many storms throughout my life. Some have been quick showers, while others full-blown hurricanes. Each storm presented its own challenges but they all impacted my life.

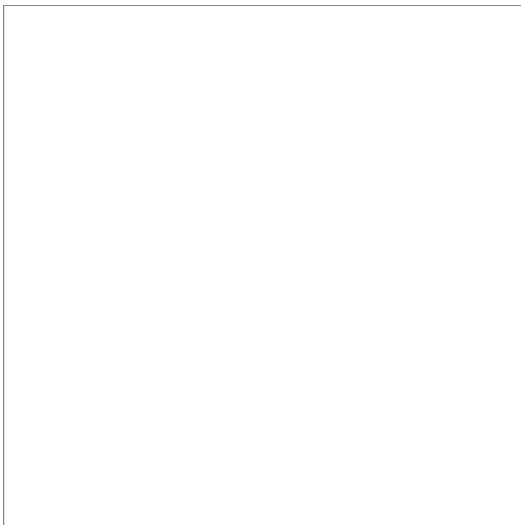
I have battled with depression and anxiety. I have faced the tornado that is anorexia. I have drowned in thoughts of self-loathing, never feeling good enough or worthy of happiness. I have faced grief, been consumed with guilt and struggled with suicidal thoughts. These were my personal storms.

I was a fat teenager. I always believed that once I lost weight I would be happy. So I put my life on hold and pinned all my happiness on a day in the future, when I would become a socially acceptable weight. But guess what? I’m sure it’s no surprise to anyone, but being slim did not solve all my problems. It did not magically fix my mental health issues. It did not erase my childhood trauma. It did not remove all my insecurities or my desperate need to be liked. It did not make me happy. If anything, it added a whole new level of pressure and anxiety to the mix.

And then chronic illness reared its ugly head. I was not prepared for the loss of confidence

and feeling of worthlessness that came with my new chronic life. I felt useless and desperate. I certainly couldn't see a way of accepting this new and painful life, let alone finding a way to be happy and fulfilled. I spent each day just surviving and making promises to myself; once I'm better I will embrace life, I will not take anything for granted, I will start being kind to myself, I will prioritise self-care and I will be proud of my achievements. But what if I never got better? What if this was what the rest of my life was destined to be like? How much longer would I put my life on hold, waiting for an unknown future when I would allow myself to be happy?

I'm not sure at what point it happened, but I knew I needed to find a way to accept myself and my life with all its messiness. I knew that unless I found a way to be kinder to myself, I would spend my whole life consumed by a war I could not win. I knew that if I could find a way to love myself and accept my life while at rock bottom, I could build from there. I didn't want to keep putting my life on hold. I knew I was just sacrificing my present happiness for a future full of unknown promises.



Dancing in the rain – what I have learned

When you live with chronic ill health, the storm can represent some pretty difficult times. The chronic nature of our illnesses means the storm never fully passes. Yes, we can experience less turbulent times when our health may stabilise, but waiting for the storm to pass is not really an option for us.

There are ways for us to embrace life, and to find happiness and fulfilment amongst the

unpredictability. Here are my tips for finding ways to dance in the rain:

1. Put yourself first

To learn how to embrace life, we often have to be a bit selfish. Prioritise your well-being over others – put yourself first.

2. Acknowledge you are worthy of love and happiness

We are often our own worst critic and being chronically ill often acts to amplify this judgment. You are worthy of happiness, you are enough just as you are, right now. Give yourself a break – and a big hug.

3. Make time for fun stuff

Learning to dance in the rain, and finding ways to enjoy life means making time for fun stuff. Don't feel guilty for expending precious energy on things that make you smile, even if they don't feel 'productive'. Laughter is often the best medicine.

4. Try to live in the now – practise mindfulness

It is very easy to get consumed by the grief of our old self, or the fear of our unknown future. But I have learned that the best way to embrace life is to focus on the present. I have wasted too many years either ruminating over past mistakes, or panicking about all the 'what-ifs' of life. I find Mindfulness meditation particularly effective as a way to ground myself in the now. I intend to write more about this in a future post.

5. Try to find a place of acceptance

It's very hard to make the most of life if we are constantly fighting against ourselves and the limitations of chronic ill health. Finding a place of **acceptance** doesn't mean giving up, but rather recognising your limitations and being at peace with how things are right now. It's about focusing on what you can do rather than what you can't do. It's about acknowledging your flaws and learning to accept the person you are right now.

6. Make self-compassion your first priority

To dance in the rain is to be kind to yourself. This comes naturally to some. However, my need for perfection and always berating myself for not being good enough means I find self-

love and self-compassion difficult. I have spent a lot of time over the past couple of years researching ways to be kinder to myself, and putting these into practice.

Self-compassion simply means being kind to yourself. It's the best way to ease the mental suffering that comes with chronic illness. How can we embrace life and fulfil our potential if we are constantly criticising ourselves?

7. Don't be afraid to plan for the future and strive to achieve new goals

I know planning ahead is hard when you live with chronic ill health, but it doesn't mean we have to let go of our aspirations altogether – we may just need to adjust them to more realistic goals.

8. Redefine what success means

Having a chronic illness has changed my perspective on life in many ways, and it has also allowed me to redefine what success actually means to me. I now celebrate all my achievements, however small. By just living and not giving up, I am succeeding in life. A lot of good things have happened in my life since I redefined what success means for me, and I let go of my need to strive for perfection.

Don't wait until you are 'successful' (whatever that means) to celebrate your victories and enjoy your life. Embrace your life (and yourself) and all its messiness, right now. If you choose to wait for the storm to pass, what are you missing?

Life is not about waiting – it's about living

I have no idea what life holds for me – none of us do. But I'm determined to make the most of my life even with its unpredictability, and through all its limitations.

It is not easy to know how to continue living during the worst downpour. But life is not about waiting for the storm to pass, nor is it about avoiding it. It is about learning how to enjoy life and discovering ways to dance in the rain.

What beat will define my dance? I don't know. I used to be a control freak, but now I try to embrace this unpredictability. I look forward to seeing what life has in store for me. I look

forward to embracing everything that life has to offer. What I do know is: if I had waited for the storm to pass before dancing, I would still be frozen in a time filled with self-loathing and self-pity.

Life is never going to be perfect – there will always be challenges. Whatever my future looks like, I plan to continue to dance in the rain. But whatever your personal situation, please don't stop dancing. Life is not about waiting – it's about living.

What does this quote mean to you?

For more personal stories, reviews, news, inspirational quotes and in-depth discussion, please head over to my [Facebook](#) page www.facebook.com/ajourneythroughthefog

Posted by [Jo Moss](#), 22 [November 2019](#)

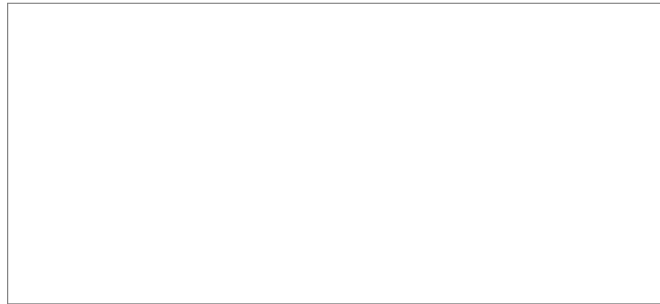
www.ajourneythroughthefog.co.uk/2019/11/learning-how-to-dance-in-the-rain

Understanding the causes of ME/CFS: support Karl Morten's research

Karl Morten has been to speak to OMEGA on several occasions, about the biomedical research into ME/CFS being undertaken by The Morten Group – based at the John Radcliffe Hospital, Oxford, University of Oxford.

Now we have the chance to donate to the latest research online, which we know that many OMEGA members have been waiting for.

Understanding the causes of ME/CFS



Myalgic Encephalomyelitis/Chronic Fatigue Syndrome is a condition affecting 20 million people worldwide, but it remains a puzzle to both the medical profession and patients.

Complex symptoms make it difficult to diagnose and only 5% of patients make a full recovery.

Research into the causes has been limited due to lack of funding, but the recent identification of high levels of L-form bacteria in the blood of ME/CFS patients suggests a compromised immune system could be a biological cause of the illness.

[Dr Karl Morten](#) at the University of Oxford proposes to lead a major research project to investigate this possible cause in detail. It will be the largest project of its kind in Europe, involving three ME/CFS research centres over four to five years.

With your support, we hope it will be a game-changer for this debilitating condition.

More information and donate online here:

www.development.ox.ac.uk/mecfs

From Karl Morten:

After another large grant application failure to a major UK funder we are now having a final

throw of the dice to support a large European ME/CFS project led by Oxford using a donations campaign.

We need to raise £1.6 million to run a four to five year project with a target of £150,000 by the end of 2020 to allow us to start. I announced the project at the UK CMRC Bristol meeting where I talked about our recent work.



See YouTube video:

<https://youtu.be/-yyusmxizQk>

The discoveries on L-form bacteria covered in the second half of the talk could be a major discovery in ME/CFS and other chronic conditions. The last slide gives an overview of the new project. We have a donations page on the University of Oxford Development website and more details on my uni webpage (see below) on the other ME/CFS projects we are working on. I will put more detail on the new project on my webpage, including a full breakdown of the proposal and a section on where the money will go. A \$1 from every ME/CFS patient and family member in the world would take us way over the amount we need.

Donations link:

www.development.ox.ac.uk/mecfs

My university webpage:

www.wrh.ox.ac.uk/team/karl-morten

We can only do what we can do

This has been our motto for ages; it means accepting our limitations. Everyone with ME knows we can't do all we want. We have to do the most important things, get some help if possible, and leave a lot undone. We hope and

plan, but illness gets in the way. It is very frustrating. And, of course, there are other issues that take our time and energy; work, organising the way we live, family – in short, life events.

This applies to your committee too; we have a great long list of things we'd like to do (I'll put some of them below) but for the time being we are concentrating on the essential activities. These are the production of the Newsletter, organising the AGM and our summer and winter social events, posting on Facebook and Twitter, and keeping in touch with the area social groups. Some crucial administration makes all these possible. This includes organising our finances, committee meetings for those who are well enough, and regular emails among the committee.

So, we haven't been able even to take up some offers of help. If you have offered to help in the past, we are very sorry if no one has been in touch. If you'd still like to help, could you email us on the enquire.omega@gmail.com address with the header 'Help OMEGA'?

Here are some things we could do:

- On page 9 you'll see that Karl Morten has now got his webpage up. Help raise funds for this important research.
- Help organise events like the AGM, find a venue for committee meetings.
- We always need more publicity: this can include keeping the website up-to-date, distributing our leaflets to libraries, GP surgeries etc.
- Be able to speak to the media.
- We'd like to distribute information about ME in children and young people to schools and colleges. This builds on our survey of young peoples' experiences, which is on the website.
- We'd like to remind clinicians and managers in the NHS about our needs.

Do email us if you'd like to help with any of these, or if you have ideas about what you'd like to do.

Patricia Wells

Send your stories for London

#MillionsMissing for 2020 will be completely virtual on 12 May, **ME Awareness Day**:

<https://millionsmissing.meaction.net>

Now it is the time to send your stories, or to give us your ideas for a virtual #MillionsMissing event.

#MillionsMissing had planned to display quilts in London. Part of the quilt would then be displayed by the Florence Nightingale Museum.

This is what they wrote:

London #Millions Missing is thrilled to announce that they are collaborating with the Florence Nightingale Museum in her bicentennial year, 200 years after her birth.

Those of you who think of Florence as a nurse might be surprised to hear that she was bedridden for 30 years on her return from the Crimea with an ME-like fluctuating illness. Her persistent campaigning #FromHerBed changed the face of nursing and health care around the world. Her efforts were not universally welcomed and she faced resistance from politicians and doctors. Despite her own ill health she continued to campaign for many years using lobbying, personal contacts and her gift for statistics to prove her point.

The links between her and the #MillionsMissing with ME are obvious. She was sometimes dismissed as an hysterical female or malingerer. Despite this, she used her math genius to prove that her sanitation reforms greatly improved survival rates. She used numbers to fight against prejudice, and outdated and old-fashioned thinking by the medical profession, and she won.

London #MillionsMissing wants to demonstrate the links between disabled campaigners across the centuries and is asking people to send in their demands, comments, stories and statistics. Tell us, and your MPs, what you're missing from life.

Please get in touch by contacting uk@meaction.net

www.meaction.net/2020/03/06/send-your-stories-for-london-millionsmissing

Share your stories for ME Awareness Week: The lost years and a focus on symptoms

6 March 2020

Russell Fleming, Content Manager, ME Association



ME Awareness Week will take place from **Monday 11 to Sunday 17 May** and we would really appreciate hearing about your life with ME.



[Go Blue 4 ME!](#)

This special week provides us with an annual opportunity to tell people who don't know very much about ME what having this disease is like and how it can devastate plans, hopes and dreams. It is also a chance to focus our efforts and reach people who might have the symptoms of ME but not yet a diagnosis.

Raising awareness of the issues we face as a community can also be a great time to fundraise for your favourite charity (see www.meassociation.org.uk/2019/12/mea-fundraising-me-awareness-week-2020-go-blue-4-me-17-december-2019), and this year we will continue our popular Go Blue 4 ME campaign. If you have any fundraising questions then please get in touch with Tony Britton (email: tony.britton@meassociation.org.uk, tel. 07946 760811).

The lost years

Our main theme for ME Awareness Week is **The Lost Years**:

The things people have missed out on because of ME and how has it affected their education, employment, family and social life.

A focus on symptoms

We will also focus on **The Symptoms of ME**:

Each day of ME Awareness Week we will highlight a particular symptom and aim to inform people – especially those who might not yet have a diagnosis – what constitutes ME.

Help us improve medical awareness of ME

We desperately want to increase awareness of ME and get more information out to the medical profession, in particular to your GPs.

There are still so many that do not understand this disease and ME Awareness Week gives us the ideal opportunity to improve the situation with a focused mailing.

Please send us your **GP's name and address** so that we can send them regular copies of *ME Essential Magazine*, the opportunity to receive our information leaflets and a copy of our clinical and research guide (*The Purple Book*).

Your information will remain completely confidential.

Please send this information to: caroline.cavey@meassociation.org.uk.

ME Awareness Week gives us all an opportunity to make sure the world is more informed about this disease and raise awareness about how you cope, the lack of effective treatments and the way ME affects your life. So, whatever your story is, we want to hear it! We have more things planned for May, but for now if you can help then please get in touch – and don't forget to pass on your GPs contact details!



www.meassociation.org.uk/2020/03/share-your-stories-for-me-awareness-week-06-march-2020

**All-Party Parliamentary Group on ME:
Biomedical research meeting summary
17 March 2020**

Dr Charles Shepherd, Hon. Medical Adviser,
ME Association

The All-Party Parliamentary Group (APPG) on ME held its first meeting on Tuesday 3 March, when biomedical research was discussed.

Twenty MPs attended or sent staff to hear about the urgent need for biomedical research, following its inaugural AGM in January.



Carol Monaghan MP, Dr Charles Shepherd with some of the MPs who attended, and the three research presenters (see below).

Chaired by Carol Monaghan MP, the meeting was the first in a series that will focus on key issues facing people with ME in the UK, and will culminate in a parliamentary report setting out actions for change.

Members attending heard short presentations from Professor Chris Ponting, University of Edinburgh; Professor Julia Newton, Newcastle University; and Dr Eliana Lacerda, CureME Biobank, before taking the opportunity to ask questions.

Professor Julia Newton



Prof. Julia Newton, Newcastle University

Professor Newton began by sharing the story of one of her patients with ME, who waited more than ten years for a diagnosis, and how patients were being badly let down by lack of

high-quality research into both causation and treatment.

Describing symptoms involving the brain, muscles, and immune system, Professor Newton highlighted how clear abnormalities are being found.

However, these findings are often based on small research studies with small cohorts, and with small amounts of funding – mainly from the ME charity sector. This must be scaled up if real progress is to be made.

Professor Chris Ponting



Prof. Chris Ponting, Edinburgh University

Professor Ponting picked up this point and highlighted the disparity in research funding allocated to ME when compared to many other medical conditions.

He presented a compelling case for sustained, ring-fenced investment, suggesting that a UK institute for ME research could be a world-leader.

“Funders must recognise that they need to incentivise early-stage career researchers to enter this field,” he said.

“They frequently cite the need for a robust evidence base to support research funding applications – but without funding it is not possible to achieve this. We must break this vicious cycle.”

Highlighting the huge gains from patients, researchers and charities working together – an example being the recent ME/CFS Biomedical Partnership application he is leading – Professor Ponting stressed the need for further and longer-term funding to sustain

this momentum.

Dr Eliana Lacerda



Dr Eliana Lacerda, CureME Biobank

Giving a brief overview of the work of the CureME Biobank, and some examples of research where these blood samples are now being used, Dr Lacerda agreed that sustainability and infrastructure are among the significant challenges facing ME researchers.

MPs' reactions

MPs were taken aback to learn that the basic running costs for the Biobank have all been provided by the ME charity sector, that the bulk of the Biobank's external research funding has come from the National Institutes of Health in the United States; and that Professor Newton has ceased ME research altogether – despite having access to a large patient cohort – because funding is so difficult to secure.

MPs asked what practical steps they could take to support ME research. Insightful follow-up questions focused on research into similar conditions, the search for biomarkers and the stigma still attached to ME, with Professor Newton commenting that she had been “appalled” by attitudes she had seen from some fellow clinicians.

The real possibility of a rise in post-infectious ME following the coronavirus – coronavirus was being debated in the Chamber at same time as this meeting – was also highlighted by Professor Ponting, serving to reiterate the seriousness of his intent, and the urgent need for proper research investment.

The next meeting of the APPG will take place

on Wednesday, 29 April 2020 – please encourage your MP to attend.

www.meassociation.org.uk/2020/03/all-party-parliamentary-group-on-me-biomedical-research-meeting-summary-17-march-2020

Includes list of all MPs who attended the first meeting.

At the end of the article is a link to find your MP, and a sample email to help you write to them.

AGM

The AGM was planned for Saturday 14 March, days before mass gatherings were discouraged in this country. A select few people turned out; the meeting went ahead, Caroline Struthers spoke about ‘My Journey from Ignorance to Activism (Making sense of Medical Research and Academia)’ – and there was delicious food from waste2taste.

Iona filmed the talk – here's a picture of that happening!



In the next newsletter we will have a link to the film itself and also a report of the AGM.

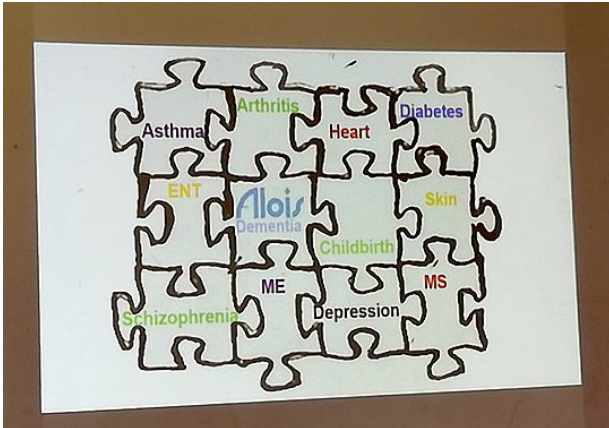
GoodGym report

GG help OMEGA AGM and talk!

Four runners ran to help the OMEGA (Oxfordshire ME Group for Action) in Oxford.

Saturday, 14 of March 2020

Led by [Trev](#)



Four GoodGymers went to help [OMEGA](#), Oxfordshire ME Group for Action with their AGM and talk.

We helped set up chairs, made cups of tea and took photos for their newsletter. We also helped set up their projector and laptop and signposted people where to go when coming to the Rose Hill Community Centre.

It was a smaller gathering as expected due to the coronavirus. But there were enough people to make a valid and legal AGM, which was vital for the group, and to make a video of the talk by Caroline Struthers.

We learned lots about ME; there is more on OMEGA's website and also Science for ME (www.s4me.info). They also referenced the David Tuller talk GoodGym helped at last year.

We also handed out food from Oxford's Waste2Taste (www.waste2taste.co.uk), which tasted yummy!

Report written by [Trev](#)

www.goodgym.org/reports/gg-help-omega-agm-and-talk

Letter from OMEGA published in *The Oxford Times*, Thursday 5 March 2020

Listen to patients

DR Joe McManners wrote about the need for medics to consider the 'whole person' ('The rise of multiple medications', Oxford Times 13 February 2010). Patients appreciate the research and specialised knowledge our doctors have access to. While our wonderful GPs do their best to keep up to date, the patient's lived experience should be noted too.

NICE guidelines are generally useful to doctors but, as Dr McManners points out, guidelines 'and evidence are great, but they tend not to be particular sensitive to individual needs and views'.

This certainly applies to ME/CFS (Myalgic Encephalomyelitis/Chronic Fatigue Syndrome). Research several years ago initially appeared to support the effectiveness of CBT (Cognitive Behaviour Therapy) and GET (Graded Exercise Therapy) as treatments, but reanalysis showed that positive outcomes were overstated. Meanwhile several large national surveys, and the experience of our members, have shown that many people with ME become more ill after taking part in these interventions. 'Guidelines' are just that; only guidance to individual clinical judgement by a doctor.

OMEGA is the Oxfordshire ME Group for Action, a patient support and campaign group for people with ME/CFS. We represent the many people of all ages in Oxfordshire with this disabling neurological illness, which is twice as prevalent as MS. 25% of sufferers become house-bound or bed-bound. The illness is now widely recognised but the causes and effective treatments remain elusive.

For more information about research, and to meet patients and their families and carers, please do come to our AGM on Saturday 14 March, 2-4pm at Rose Hill Community Centre, Carole's Way, Oxford, OX4 4HF.

Priscilla Kew
Chair OMEGA

Weblinks

ME in the media

Chronic fatigue syndrome: Living with an invisible illness

16 February, 2020 2.32 min video

Lorna Bryson, 25, suffers from Myalgic Encephalomyelitis (ME) also known as chronic fatigue syndrome. She has been ill since the age of 14.

The illness means she has a low immune system, gets headaches, sore muscles and joints, and needs at least 12 hours sleep every night.

Doctors didn't believe there was anything wrong with Lorna growing up as she looks visibly healthy, but the debilitating illness means she's unable to work and relies heavily on her parents.

www.bbc.co.uk/news/av/uk-northern-ireland-51467408/chronic-fatigue-syndrome-living-with-an-invisible-illness

Barely able to leave the house, told they are exaggerating and even that their ailment does not exist: Three ME patients reveal their daily struggle with the crippling condition

By [Harry Howard and John Siddle For Mailonline](#)

28 February 2020

Dr Charles Shepherd, medical adviser to the ME Association, said: "There are thousands of people in the UK with severe ME, which is a truly devastating disease.

"The nature of the illness means they are hidden away behind closed curtains and desperate not to be forgotten about.

"We urgently need more funding for research into treatments for ME so people like Nicola, Avani and Marie can have hope of reclaiming their lives."

www.dailymail.co.uk/health/article-7886679/Three-patients-reveal-daily-struggle-

[crippling-condition.html](#)

Latest from Virology Blog

Trial By Error: Shaky Evidence for Signs of Functional Neurological Disorders

30 December 2019

By David Tuller, DrPH

"One of my goals next year (2020) is to write more about so-called 'medically unexplained symptoms', also known as MUS. The term MUS might be useful as a descriptive name for the large category of phenomena that lack a proven pathophysiological pathway. But in the medical literature, and in the minds of those who present themselves as experts in the field, it is framed as an actual diagnosis that can be delivered with full confidence rather than a provisional construct based on the current state of medical understanding.

"Different specialties have their own sub-categories of MUS. In neurology, these are called 'functional neurological disorders', or FND. ... The phrases 'conversion disorder' and 'psychogenic disorder' mean exactly what they say – the idea is that unexpressed psychological distress is transformed into physical symptoms, although how this 'conversion' would occur is not really clear."

www.virology.ws/2019/12/30/trial-by-error-shaky-evidence-for-signs-of-functional-neurological-disorders

www.virology.ws/2020/01/07/trial-by-error-some-more-thoughts-on-functional-neurological-disorder

Trial By Error: CBT Provides No Benefits to Advanced Cancer Patients, Study Finds

15 January 2020

By David Tuller, DrPH

"Since 2008, the National Health Service (NHS) in England has been rolling out a program known as [Improving Access to Psychological Therapies \(IAPT\)](#). Initially focused on patients with mental health issues like depression and anxiety disorders, IAPT was then expanded to

include those who are also simultaneously suffering from ‘long-term conditions’ and so-called ‘medically unexplained symptoms’ (MUS). IAPT has cited 50% ‘recovery’ rates from its interventions, but these claims are not especially credible, as Liverpool consultant psychologist Michael Scott has documented on his informative blog, [CBT Watch](#).

“There is plenty of evidence that the IAPT’s hopes and claims exceed its current grasp.”

www.virology.ws/2020/01/15/trial-by-error-cbt-provides-no-benefits-to-advanced-cancer-patients-study-finds

Trial By Error: New Biopsychosocial Study of Fatigue in HIV Patients

2 March 2020

By David Tuller, DrPH

No matter what disease is being examined – chronic fatigue syndrome/myalgic encephalomyelitis (as these researchers often call the illness in question), irritable bowel syndrome, HIV – the argument seems much the same.

To wit: Patients are catastrophizing, symptom-focusing, engaging in boom-and-bust activity patterns, and/or holding fearful convictions about the dangers of exertion. Moreover, these cognitions, emotions and/or behaviors are unhelpful and/or dysfunctional and are responsible for generating and/or perpetuating core symptoms. (I don’t really understand how patients can be both fearful of exertion and engaging in boom-and-bust activity patterns. If they’re fearful of exertion, why are they ever booming?)

www.virology.ws/2020/03/02/trial-by-error-new-biopsychosocial-study-of-fatigue-in-hiv-patients

Support groups around Oxfordshire

This is an uncertain time for the social groups. Some are changing venue, and all will have to make decisions about whether to hold their meetings each month. This will depend on the coronavirus situation in our area and the country, as well as the usual ME-related difficulties.

As we go to press, some social group meetings are suspended.

OMEGA usually recommends that you check with the organiser before going to a social group meeting, especially if you have not been to one before. This applies even more for the next few months, as there is no guarantee that any of the meetings will take place.

If you are able to keep in touch with other social group members by email or phone, this might be especially valuable at the moment. Remember to check if it is convenient for the person to receive a call; or maybe arrange a time in advance. It is advisable to limit the length of calls, for both your sakes. A 40- minute call may set someone's pacing off kilter for the rest of the day, whereas 20 minutes might boost their mood with no ill effects.

If people can stay in touch at the usual times of support groups, it might help to keep continuity during times of isolation.

Oxfordshire ME Group for Action (OMEGA)

The next newsletter copy deadline is **Friday 5th June**, so please send any info, news, jokes, poems etc. to newsletter.OMEGA@gmail.com. Send articles, jokes, cartoons or letters for publication with 'Editor' in subject line.

To receive your newsletter by email, put 'email newsletter request' in the subject line.

Disclaimer – Please note that views expressed in this newsletter are not necessarily the views of OMEGA.

OMEGA Website: <http://omegaoxon.org>

OMEGA Facebook page – search for Oxfordshire ME Group for Action

www.facebook.com/Oxfordshire-ME-Group-for-Action-122049981208585/

OMEGA on Twitter: @omega_oxon

https://twitter.com/omega_oxon