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Photos available

Before long Covid there were already #MillionsMissing from society - those with ME

The devastating effects of long Covid are now being realised around the world. Researchers, clinicians and governments are waking up to the urgent action needed to offer science-backed treatment to the estimated ten percent of people who contract Covid-19 but don't recover in a short time - those suffering from long Covid. Some of those have ongoing organ problems, such as lung and heart damage, but many of these suffer from symptoms similar to ME.

There is one community who knows that there is nothing new about the long-term consequences of infection. Before people came down with long Covid there were already **#MillionsMissing** around the world, made up of individuals who got sick from infection and never recovered. They are those people who have **Myalgic Encephalomyelitis (ME)**, a severely debilitating condition that affects millions of people across the world.

#MEAction is an organisation that fights for the **#MillionsMissing** who have ME. To highlight this fight, **on May 12th, #MEAction will hold #MillionsMissing events**, calling for governments to urgently respond to the ever growing crisis of ME since there will be **#MillionsMore** after Covid -19. Sadly, as the UK sees rapidly growing numbers of sufferers of long Covid who are experiencing ME-like symptoms, the ME community is growing.

A large body of research shows that long-term illness and disability can be triggered by viral infections. Up to 80% of cases of ME are initiated by an infection. Research has shown that viruses ranging from influenza and glandular fever to Ebola, have caused ME in patients. Now, the majority of people with long Covid are reporting symptoms that resemble ME/CFS, most notably post-exertional malaise, a worsening of symptoms after exertion.

Dr Sue Pemberton, an Occupational Therapist who specialises in working with people with ME comments, "The dysregulation in the body seen in ME is also presenting in many people after COVID infection, for example experiencing the symptom of

post-exertional malaise. Therefore, it is important for everyone that we learn the lessons from conditions such as ME, to reduce ignorance and help all those whose lives are limited by these illnesses.”

#MEAction UK is highlighting the risk to people experiencing post-exertional malaise from Graded Exercise Therapy, which is a programme of increasing amounts of exercise, encouraging patients to ignore ill-effects and “push through” their symptoms.

Charlotte, who was living in Leicestershire at the time, recalls her experience, “A consultant psychiatrist prescribed me antidepressants and graded exercise. In hindsight I would say the graded exercise significantly slowed my recovery. I was continually pushing my body further than it was capable of managing. Overexerting myself was causing me more harm and delaying the healing process. I was also told not to sleep and even not to lie down during the day. I would strongly advise against this approach to anyone who is suffering with ME or long Covid.”

Recently a draft updated guideline for ME/CFS from the National Institute for Health and Care Excellence (NICE) removed the recommendation for Graded Exercise Therapy for ME, highlighting the poor research behind it and the thousands of patients who reported they had been harmed by it. NICE also issued a warning about its use for people who had had Covid-19. Despite this, there are clinics and clinicians recommending graded exercise. There is not, at this time, any official way to report harm from such therapies, meaning their use can continue unchecked.

“This is a problem of extreme magnitude that cannot be ignored, especially if the ME community is expected to double.” said Julia Miele, Executive Director of #MEAction. #MEAction is a voice for those who have been isolated in their own personal lockdown, for decades. This year, the #MillionsMissing events emphasises that, while this crisis is dark, #YouAreNotAlone.

#MEAction and the #MillionsMissing will not stop fighting until there is action and equity. Now, more than ever, we need results from good quality research for all of those with ME, including those with long Covid and those who have been neglected for decades. Anyone can join this fight.

About #MillionsMissing

#MillionsMissing is an international movement fighting for equality for people with ME, spearheaded by #MEAction. This is our fifth global #MillionsMissing demonstration.

<https://millionsmissing.meaction.net/>

#MEAction is an international network of patients and allies empowering each other to fight for health equality for ME.

<https://www.meaction.net/>

Stories from the #MillionsMissing:

http://www.meaction.net/wp-content/uploads/2019/03/SMALLFORMAT_98_ProfilesMM2.pdf

I got a virus, I didn't die, but I never recovered - Video

<https://www.youtube.com/watch?v=e3Pd0o-rwrU>

Photos of previous #MillionsMissing events

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