Press Release

Embargoed until 15 May, 2024

M.E. Patients take to the streets to demand research, support and treatment!

Mark Harper, chair of Cambridge M.E. Support Group, is fitting a huge (8 foot by 4 foot) advert on the roof of his car and driving around Cambridge to raise awareness of M.E. (also known as Chronic Fatigue Syndrome or ME/CFS) and Long Covid during M.E. Awareness Week (8th - 14th May). He is taking this action so people realise how serious this condition is, and how little research funding and support is available.

He will be joined by other local patients and supporters outside the Keith Peters Building, Addenbrooke's Hospital Site at 12 noon on May 15th 2024 for a group protest and to deliver a letter of demands to Prof Judy Hirst of the Medical Research Council.

Group members who are housebound will support the action from home by displaying leaflets in their windows, and asking libraries, medical practices and shops and community venues to do likewise.

Cambridge M.E. Group is demanding:

- **Funding of specialist clinics** (that can diagnose, treat and help patients access services such as home care, adaptations, and take part in research trials)

- **Training for doctors, physiotherapists, nurses and other health care workers** on the latest NICE Guidelines for M.E. (these are national guidelines intended to show best practice for the NHS)

- **More funding for research** (the research spend per patient for ME/CFS between 2006 and 2015 was just £40 compared with for those with other serious conditions such as Rheumatoid Arthritis, £320, and £800 for those with Multiple Sclerosis)

The number of people suffering from M.E. has increased massively since the Covid pandemic started – 50% of Long Covid cases are believed to qualify as Myalgic Encephalomyelitis. There are now reckoned to be about 1.25 million people living with the condition in the UK according to the M.E. Assocation.

The condition affects multiple body systems including:

- circulation
- immune system
- energy production in cells
- the nervous system.

Symptoms include an inability to recover normally from exertion which leads to worsening of symptoms, extreme exhaustion, muscle pain, cognitive dysfunction and more. It most often follows a viral infection such as glandular fever or influenza.

Although ME/CFS has a wide range of severity, three quarters of sufferers are too ill to work or attend educational institutions. A quarter are housebound or bedbound. ME/CFS leaves sufferers with very little mental and physical energy and symptoms get worse if they exert themselves beyond limits imposed by the illness.

The billboard will feature our website address where we have information for patients, carers and medical professionals.

www.cambridgeme.org.uk

*** Ends ***

Contact information

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Quotes from Mark Harper, Chair of Cambridge ME Group

“For me and for most of my 180 members the effect of the illness is devastating. We spend most of our daylight hours resting; we cannot exert ourselves and struggle to cook, wash, engage in family life, undertake work or even chat with a friend.

“We 'welcome' new members to our group but are sad that they often find us after years of being given advice to exercise which worsens their long term outcome. We also see our members struggle to get adequate benefits: the process of applying is stringent, exhausting and demoralising. Without support from adequately staffed clinics our members have few places to turn to help and support.

“It's time for scientific research to find a cure. Even now there are new and better ways to manage the condition before a cure is found – doctors need training now so they can help patients more”.

Images

Please find images on www.cambridgeme.org.uk/media

Background information

About prevalence in the UK

The M.E. Association (https://meassociation.org.uk/):

> "We estimate than more than 1.25 Million people in the UK live with a diagnosis of ME/CFS and Long Covid. We don't know how many are undiagnosed. It represents a very real health crisis."

About funding inequality of funding

ME Research UK (https://www.meresearch.org.uk/funding-the-westminster-hall-debate/):

> "While prevalence is only one aspect of a disease that affects the level of research funding, research also indicates that people with ME/CFS experience higher levels of functional impairment and lower levels of wellbeing, compared with conditions including depression, cancer and rheumatoid arthritis (RA). Despite this, the research spend per patient for ME/CFS between 2006 and 2015 was just £40 compared with £320 for those with RA and £800 for those with MS."

About NHS Services following current NICE guidelines on ME/CFS

Source: Action for ME report following Freedom of Information Requests about implementation of the new NICE guidelines by NHS services, see page 6.
(https://www.actionforme.org.uk/uploads/images/2023/05/Action_for_M.E._-_FOI_report.pdf):

> "Of those who indicated that they held an ME/CFS service, 25 services (27.78% respondents with data) said they had implemented the NICE Guideline."