Standing with people with ME/CFS in Scotland



There are an estimated 1.3 million people in the UK with Myalgic Encephalomyelitis (ME, sometimes known as chronic fatigue syndrome or CFS) or ME-like symptoms including post-exertional malaise, the hallmark symptom of ME/CFS.

They also experience debilitating fatigue that is worsened by activity; nrefreshing sleep or sleep disturbance (or both); and cognitive difficulties (or "brain fog").

Historically – and wrongly – ME/CFS has been seen as psychological and is still often dismissed not just by health and social care services but friends and family too.

People with ME/CFS are left isolated and stigmatised without access to basic care, services or support.

People with ME/CFS in the UK are more than sixtimes more likely to die by suicide compared to the general population.

Post-exertional malaise is worsening of symptoms that occurs after any physical, mental or emotional exertion. For some, this can include brushing their teeth or getting our of bed. It's a defining feature of ME/CFS and hard to predict when it will impact.

Disbelief and lack of knowledge and understanding of ME/CFS among GPs is widespread, and the resultant diagnostic delays constitute a risk factor for severe and prolonged disease.

One in four people with ME/CFS are severely affected and not able to leave their own bed or home. They are the least likely to receive care and support as they are too ill and isolated to engage with services.

In September 2024, The Times reported that doctors say NHS patients with severe ME/CFS risk starving to death because of unsafe and "unconscionable" standards of care.

Less than 1 in 10 people with ME/CFS are in full-time paid work, education or training.

97% of people with ME/CFS may be eligible for social care, yet only 16% have had a social care assessment. Of these, only 6% had been awarded a care package.

A third to a half of all GPs do not accept ME/CFS as a genuine clinical entity. Those that do lacked confidence in diagnosing or managing it.

The 2021 NICE guideline and updated Scottish Good Practice Statement for ME/CFS are clear: advice to exercise or push through symptoms causes harm.

Ignoring this advice means people are harmed, reducing their level of functioning, health and Quality of Life, sometimes permanently.



Instead, people with ME/CFS need support to carefully pace their activity to manage their limited energy.



But many professionals still don't know about or use the updated guidance.

"Post-exertional malaise, in a lab setting, has been shown to be biological. Any stereotypes or outdated ideas that have previously circulated about this condition? These studies really put them to bed."
Dr Robin Kerr, Learn about ME webinar, Sep 2024

"I brought this module to the attention of my colleagues in the practice... Every GP should do this module."
GP feedback on Learna module

Action for M.E. stands with people with ME/CFS to tackle unequal treatment and improve access to appropriate healthcare and support.

We address the barriers, inequality and inequity the people with ME face by offering information and resources, and advocating for change.

Anyone of any age living with ME, or caring for someone with the illness, including family members, professionals and friends, can call or email our free Information and Support Service. Our team will:

- help break issues down so they feel less overwhelming
- support people with ME/CFS to explore priorities and possible next steps
- help frame questions to ask professionals
- suggest useful resources which we can send by post or email
- help those that need it to access other free Action for ME services, including Advocacy for adults with ME/CFS, Family Support for parents of young people with ME/CFS and peer-support for all ages
- support self-referrals to Action for M.E.'s doctor, physiotherpy, counselling and chaplaincy services with bursary support for those who need it
- signpost to other expert sources of information and support.

See more at www.actionforme.org.uk/info-support

"Thanks for listening, taking me seriously and understanding, it's really appreciated."
Information and Support service client, May 2024



"The communication you sent me was very comprehensive but clear and simple to understand. I had absolutely no idea prior to contacting you about ANY of these things. I can't thank you enough."
Information and Support service client, July 2024



We promote training for GPs and healthcare professionals to increase confidence in diagnosing and managing ME/CFS.

With funding from Scottish Government, we are working in partnership with the ME Association and #MEAction Scotland to deliver the Learn about ME project. We

- promote Learna's free CPD-accredited learning module on ME/CFS
- produce insightful Learn about ME podcasts and webinars featuring patients and professionals.

See more at www.actionforme.org.uk/learn-about-ME

We work as part of the Neurological Alliance of Scotland and Voluntary Health Scotland's Health Policy Network to give a voice to people with ME/CFS and raise awareness of ME/CFS among policymakers.

We regularly share opportunities to participate in consultations and surveys. People with ME/CFS in Scotland are best placed to co-produce policy on health, social care and other issues that directly impact their daily lives.



We worked with artist Alec Findlay to gather experiences and insights from more than 200 people living with ME/CFS. Alec used these to create a 'found poem,' shining a light on the invisible nature of ME/CFS and the harmful impact of being disbelieved and dismissed.

See more at www.actionforme.org.uk/descriptions

We collaborate to drive research forward via a virtual Genetics Centre of Excellence, and co-delivering DecodeME, the world's largest genetic ME/CFS study, at the University of Edinburgh, ensuring patient and public involvement is at the heart.

"This is a complex disorder and we absolutely know that two-thirds of people have an infection prior to ME/CFS onset. This is telling us that, that infection has meant that it's the environment that contributes hugely to people's risk of ME/CFS."
Prof Chris Ponting, Principal Investigator, DecodeME

Initial analysis of questionnaire data from the first 17,000 DecodeME participants, published by NIHR Open Research in August 2023, show that being female, older and ill for longer all increase the chance of greater severity.

DecodeME is now offering data access to other approved researchers until the end of the study in August 2025 in the hope that it will help accelerate research towards possible diagnostic tests and treatments for ME/CFS.

See more at www.decodeme.org.uk

References

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Action for M.E.
Tel: 0117 927 9551
www.actionforme.org.uk
Find us on Facebook and Twitter @actionforme
Instagram @actionform.e

Action for M.E., Unit 2.2 Streamline, 436-441 Paintworks, Bristol BS4 3AS. Registered charity in England and Wales: 1036419. Registered in Scotland: SC040452. Company limited by guarantee, registered in England no. 2906840.