

# Invest in research to let us be part of Scotland's future



**By Emma Shorter**

ME ACTION SCOTLAND



**ENOUGH:** Emma has been inundated with horror stories about GET treatment

**A**T the beginning of the pandemic, most people were scared of the potential death toll. I was scared for an additional reason. Nine years ago I got a virus and have never recovered. With more and more people developing long-term symptoms after Covid, the general public and medical profession are finally becoming aware of the devastating continuing effects a virus can have.

However, this is not a new phenomenon. Post-viral fatigue syndrome, which often develops into myalgic encephalomyelitis (ME), has been around for decades.

I'm one of more than 21,000 people in Scotland whose life has been devastated by ME. There is no treatment. Most people are so sick they simply disappear from their everyday lives. The majority are unable to work and one in four are unable to leave the house at all.

But, now, ME patients around the country are breathing a little easier after an announcement last month by the National Institute for Health and Care Excellence (NICE).

Finally, after 13 years, they are planning to remove the harmful treatment, graded exercise therapy (GET), in April 2021.

I cried with relief whilst reading the draft NICE guidelines. Myself, and thousands of patients for decades before me, have found the treatment harmful and we have been dismissed and belittled by doctors who refused to believe us.

What is GET? A fairly innocuous sounding 'treatment' that involves increasing exercise each week and making patients push through when they start to feel unwell. The basic idea behind it is ME patients are just deconditioned, and they can push through the symptoms of illness until they get better.

Unfortunately, it hasn't worked. Instead, it has caused great harm. It's an especially cruel treatment for ME as research demonstrates our energy system is broken, and so patients literally can't produce energy properly.

The bitter irony is research suggests patients who rest at the beginning of their illness have the best prognosis. The research that pro-

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vided the basis for GET was done so poorly that Columbia University professors use it as an example of how not to conduct research trials. We are concerned there is already evidence long Covid patients who develop post-viral fatigue are being given GET as treatment.

**T**HE human impact of GET in Scotland has been heartbreaking. When #MEAction Scotland petitioned the Scottish Parliament in 2018, we were inundated with personal stories. There was the child in Dundee who was made to exercise until they blacked out; the adult who was given GET as a child and never recovered; and the parents who were being threatened by child protection services, unless their child continued GET, even as they watched their child deteriorate.

These cases are not isolated to Scotland. In global patient surveys going back decades, the majority of patients have consistently reported deteriorating.

#MEAction Scotland and other ME charities are calling for the urgent removal of GET from Scottish guidance. We can't let this outdated recommendation harm any more ME patients, or be part of care for long Covid patients.

Not harming patients should be

the absolute bare minimum. With no treatment, no specialist consultant in Scotland and no investment in care, ME patients face a bleak future.

The government must act to change this by investing in biomedical research and care. Anyone who remains sick after a viral infection should be given a proper investigation, quick access to aids to improve quality of life, access to benefits if they can't work and advice on management to decrease chances of a flare or relapse.

In previous viral outbreaks, the rate of people who go on to develop ME has been more than one in 10. Coronaviruses have had even higher rates of triggering this sort of disease.

Perhaps the troubles long Covid patients have in finding care would not be happening if the government and medical profession had listened to ME patients decades ago.

So listen to us now.

With the advancement of technology, we have begun to understand post-viral fatigue conditions like ME a little better.

But the lack of funding by governments worldwide has been a major stumbling block. Remove GET as treatment in Scotland.

Invest in research. Invest in care. Give us a chance to be part of Scotland's future.