

Calls for government support for people with ME

It is “only a matter of time” before someone with ME dies in Scotland as a result of poor healthcare support.

The lack of healthcare support for people with ME or Chronic Fatigue Syndrome is being raised at Holyrood this week alongside a demand that MSPs take action.

The #MEAction Scotland volunteers will be at Holyrood all week telling politicians about the condition Myalgic Encephalomyelitis (ME), also known as Chronic Fatigue Syndrome, including thousands who have developed ME following Covid-19.

The Scottish Chief Medical Officer issued recommendations in 2002 for ME services to be rolled out. More than two decades on and there are no specialists and only NHS Lothian treats people with ME in Scotland. Not one doctor in NHS Scotland specialises in treatment of the condition.

The Scottish Government’s commitment to implementing the 2021 NICE guideline on ME/CFS gave some hope of improvement, but three years later the ME and Long Covid communities are still waiting for the support and services they need.

Judith Stark, spokesperson for #MEAction Scotland says “We believe it is only a matter of time before a patient with severe/very severe ME dies in Scotland due to the lack of health care provision and the extremely limited training for healthcare professionals.”

Janet Sylvester, founder of #MEAAction Scotland, first discovered the lack of understanding of ME and the gaps in support when her daughter, Emma, was diagnosed with ME in 2012.

She said: "The lack of support for people with ME has been recognised in numerous Government reports over the past 22 years."

"14 years after Emma was diagnosed, very little has changed and I really feel that implementing the NICE guideline in Scotland would make a huge difference in helping health professionals understand what they can do, as well as leading to the development of services across Scotland."

#MEScotland believes the urgent need for support has been underlined following the inquest into the death of Maeve Boothby O'Neill, a 27-year-old woman who had severe ME. She tragically died of malnutrition in 2021 as the hospital lacked the knowledge to treat her.

A Prevention of Future Deaths report was issued last month. Whilst the report's recommendations are focussed on NHS England, the situation in NHS Scotland is even worse for people with ME due to the lack of specialists and specialist services.

The campaign for support for people with ME in Scotland has gathered pace since Covid-19, with evidence suggesting that around 50% of people with Long Covid have ME. A conservative estimate is that the number of people with ME has increased at least threefold since Covid, with an estimate of 58,000 people now having ME. This is five times more than the number of people with Multiple Sclerosis and seven times more than Parkinson's.



Ben Macpherson MSP is sponsoring the information stall at The Scottish Parliament.

He said: "It's a privilege to be collaborating with #MEAction Scotland, and to assist them in their work to support people with ME across Scotland.

"Currently around 58,000 people in Scotland are affected by ME, and engaging with MSPs helps to raise awareness of ME, its connection to Long Covid, and the debilitating impact on those living with the condition.

"The volunteers at #MEAction Scotland deserve huge credit for their dedication to campaigning to help make sure that those with ME in Scotland have access to the appropriate care, support, and specialist treatment."

#MEAction Scotland volunteers will be in the Parliament from 5th to 7th November to engage with MSPs. They will be asking

MSPs to support their call for ME services and specialist leads for ME across NHS Scotland.

