

## HEALTH

Thousands of ME patients 'failed by shockingly poor NHS care'

National treatment guidelines published two years ago are still not widely implemented, says charity

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Symptoms of myalgic encephalomyelitis can include dizziness, fatigue and muscle pain. Some patients become bed-bound and need to be fed through a tube

Thousands of patients with a debilitating condition are being failed by NHS hospitals ignoring treatment guidelines, a report has said.

In 2021 the National Institute for Health and Care Excellence (Nice) produced guidance on how patients with myalgic encephalomyelitis (ME), a complex neurological disorder, should be cared for. However, thousands of people with ME, also known as chronic fatigue syndrome (CFS), remain unable to access specialist care.

Data released under freedom of information laws showed "shockingly poor and patchy provision", according to a report by the charity Action for ME.

ME patients have fluctuating symptoms including prolonged fatigue, dizziness, muscle pain, gastrointestinal problems and “brain fog”. In very severe cases they become bed-bound and may need tube-feeding. Campaigners have fought to correct a misconception of ME as a psychological or behavioural illness. Its causes and best courses of treatment remain poorly understood.

Only 28 per cent of NHS trusts and integrated care boards (ICBs), the bodies responsible for health and care services in a local area, have implemented the Nice guidelines published two years ago.

Only one in five people with ME have a personalised care and support plan in place, as recommended in the guidelines. Most trusts and ICBs held no information at all about their ME patients.

Only one in ten (21,927) of the estimated 250,000 patients are recorded as having ME/CFS in the medical system.

The report said that the data “confirms the instincts of the ME/CFS community that the vast majority of them have fallen through the cracks and are not being taken seriously by the health and social care system”.

Professor David Strain, associate professor of cardiometabolic health at the University of Exeter Medical School, said that the team behind the Nice guidelines had made clear, evidence-based recommendations.

“It is therefore disappointing that their guidance is not being implemented, particularly given that there are very few centres that have expertise in this area,” he said.

“We now need to explore whether the lack of implementation is due to a lack of commissioning of services, or whether it represents centres choosing not to follow the guidance and use alternative strategies without evidence base.”

Until recently, many services offered a course of “graded exercise therapy” to ME patients, despite sufferers reporting that it frequently made things worse.

In May 2022, Sajid Javid, then health secretary, promised the development of a delivery plan for patient care and new research into the condition, but this has been continually delayed.

Sonya Chowdhury, chief executive of Action for ME, said: “The report makes for sober reading and while not a surprise to many, the findings indicate significant gaps in services provided for ME/CFS patients at a primary level across England, emphasising the urgency for increased efforts from the health service and the government.

“It is important that decisive action is taken to address these issues and ensure that ME/CFS patients receive the appropriate care they deserve.”

Chowdhury said that despite the government's delay on the delivery plan, there was optimism that it would be "a step forward for everyone".

A Department of Health spokesman said Nice had "engaged extensively with stakeholders" when developing its guidelines. He added: "We expect patients presenting with symptoms consistent with ME/CFS to be treated according to clinical need regardless of where they live."

'We can't see any way out'

Until she was ten and a half, Karen Gordon was a "fit, happy, energetic, lively girl, very intelligent, hard working at school, enjoying her social life". After a virus she was "plunged" into the world of ME, her mother said.

Like one in four ME patients, Karen, now 36, cannot leave the house. She spends her days in bed, wearing a blindfold because she is so sensitive to light. ME has caused digestive problems and she is fed through a tube.

She was admitted to hospital with abdominal pain in February last year.

Karen Gordon was happy and full of life before ME took hold. Now she spends her days in bed with her eyes shielded from the light

Nice guidelines say that when people with severe ME need hospital

treatment, they should be given a single room if possible, and “stimuli should be kept to a minimum”. The guidelines recognise that such patients “cannot communicate without support and may need to choose someone to be their advocate and communicate for them”.

While Karen’s mother, Heather, was able to stay with her during her treatment for more than a year, she said the environment was not always suitable. Noisy patients and machinery were placed near by and maintenance was carried out with insufficient notice.

The trust frequently suggested moving Karen to another hospital or bed in a bay, where Heather would not have been able to stay. “ME is made worse by stress and exertion, and they’ve put Karen through that all the time,” Heather said.

Now at home, Karen was receiving support including IV fluids from a virtual ward team, but this has been withdrawn. The family say they have been told that a special type of feed she needs would only be possible on a bay at a distant hospital, and that they feel “dumped” by East Sussex Healthcare NHS Trust.

Heather said: “She is literally scared of dying, and so are we, because we can’t see any way out of it all.”

A spokesman for East Sussex Healthcare NHS Trust said: “Patients with ME have a range of needs that often require complex multidisciplinary care.

“All treatment that we provide to patients who have ME is as closely in line with Nice guidance as possible, and ensuring that they have the best clinical care and experience the best possible clinical outcomes remains our highest priority.

“In this instance, we are continuing to work with a range of experienced clinicians and specialist services within the trust and across the wider NHS, as well as the patient’s family, to arrange a course of treatment that will deliver the best outcome for our patient”.