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*ME patients 'risk dying of starvation' under NHS care*

Alice Barrett, 25, and Sami Berry, 43, are both suffering from severe ME

The families of two women being treated in NHS hospitals fear that they are at risk of dying from starvation.

Alice Barrett, 25, has severe myalgic encephalomyelitis (ME) and is being cared for by Royal Devon University Healthcare NHS Foundation Trust.

Her father, Mark, said that doctors were ignoring advice from family and ME experts on how best to treat her. "Alice will die. And we haven't got much time at all," he warned.

Barrett is being treated at the same hospital where Maeve Boothby- O'Neill, the daughter of Times journalist Sean O'Neill, died of ME two years ago.

Barrett needs to be fed via a tube, and the hospital has said it is NHS policy that she must be inclined at 30 degrees for this to happen. However, her condition means she cannot tolerate being anything other than horizontal.

"It makes her crash, with all her ME symptoms being worse," her older sister Rosie said. "An ME specialist has informed us that it is safe to feed as low as 5 degrees if the person is lying on their right side and doesn't move. We have to try this. Alice is running out of options and time."

The family say it is the latest example of doctors at the trust failing to understand the extent of Barrett's illness and insisting on actions that make things worse for the Newcastle University graduate, who was a "passionate and social" person before becoming ill in 2020.

Meanwhile, relatives of Sami Berry, a 43-year-old mother of three, fear she is close to death in Royal Berkshire Hospital (RBH).

Berry, a mother of three, has multiple illnesses including epilepsy, Ehlers-Danlos syndrome (EDS) and severe ME.

"I am slowly watching my wife die in front of my eyes," Craig Berry, her husband, said. "The doctors at the hospital are refusing to provide her with drugs that previously helped her regain nutritional levels. Her epilepsy has returned after three years." He said that her NHS consultant had refused to take the advice of outside specialists in EDS.

"I'm terrified I'm going to lose my wife because the doctors refuse to treat her inability to absorb nutrients," he said.

Berry was first admitted to hospital for a ten-week period over the new year because she was unable to keep down any food, liquid or medication.

Doctors fitted her with a tube that provided nutrition and drugs directly to the small intestine. She was discharged on anti-emetic (anti-vomiting) drugs that could be injected into muscles after finding that the tablet and liquid forms delivered via that tube were not helpful.

When those drugs ran out 12 days after discharge, community and hospital doctors refused to prescribe more.

“This resulted in Sami having an epileptic seizure at the top of the stairs and falling down them, forcing her to be readmitted to RBH where she has been since January 30,” said her husband.

“The doctors have treated my wife like a drug seeker since arrival, still refusing the anti-emetics they tested during the last stay.” He said that although tests showed that her tube had become dislodged, she has not been told when it might be replaced.

Campaigners fear that the women are falling foul of a misconception of ME as a psychological illness, and a lack of training for NHS staff on the most severe forms of the condition.

Dr William Weir, a retired consultant in infectious diseases with a special interest in ME, said: “There’s a fault line which runs through the medical profession, on the one side of which are doctors and [on the] other medical professionals who think that this condition — ME, chronic fatigue syndrome, has a psychological basis.

“Nothing could be further from the truth because there’s now a lot of scientific evidence which supports the proposition that this condition has a primary physical, pathological basis.” Weir authored a paper published last year describing five cases in which NHS hospitals had denied treatment to patients with severe ME, which can be triggered by an infection.

The campaign group ME Action said: “The complex chronic illness communities have mourned too many losses. We will not stand for one more. The NHS should and can do better.”

A spokesman for Royal Berkshire Hospital said: “Our clinical teams are in ongoing talks with Ms Berry and her family about her condition and most appropriate treatment. We cannot comment on the specifics to preserve patient confidentiality. However, as a trust, our highest priority is always providing safe, appropriate and high-quality care to Ms Berry.”

Professor Adrian Harris, chief medical officer at Royal Devon University Healthcare NHS Foundation Trust, said: “ME is an incredibly complex and poorly understood disease. It is recognised that there is a global lack of evidence for the safe treatment and maintenance of people living with ME. This was highlighted in recent Nice guidance, particularly when it comes to those with severe ME.

“The safety of all of our patients is of paramount importance to us. We are always focused on providing the best possible care and experience for all of our patients, in line with national clinical guidance.”