

Times Radio Transcript

Jane Garvey Presenter: Now in the October of 2021, Maeve Boothby O'Neill, died from malnutrition after suffering from ME, sometimes known as chronic fatigue syndrome.

Now the health secretary and NHS officials have been told they have to urgently address what's been described as the non-existent care available to people who have ME. The 27-year-old's care highlighted a string of issues about ME and the poor care currently on offer.

Fiona Hamilton has been covering this story for The Times. So, tell us Fiona about the significance of this order.

Fiona Hamilton Times Reporter: Well, this is a landmark moment really in the battle to have ME taken more seriously by the health authorities, because it's the first time that a coroner has issued a prevention of future deaths warning that the authorities must consider.

So, they have to look at responding to the concerns raised by Coroner Deborah Archer today. Although I should say it's not legally, they're not legally bound to actually do anything about it. But this case has attracted a huge amount of publicity and campaigning and it's hoped that it will be a way forward.

Jane Garvey Presenter: One of the really significant issues here is the, the paucity of, of specialist beds. They're just not available across the country for people with severe ME. Why, why is that the case?

Fiona Hamilton Times Reporter: Well, that's a great question. And actually, before issuing this, what's known as the Regulation 28 report, the coroner held a hearing a week or so ago about Maeve's case and actually, it was really striking that three years after her death, which, as I say, has resulted in many, many calls for improvements to this situation at the highest levels of the NHS. There's no active work going on to address this issue.

Uh, and Maeve died after three admissions to the Royal Devon Hospital and Exeter Hospital, and the bosses at that hospital have actually made some really sweeping changes in the way that they handle ME patients, but they've been lobbying NHS bosses for help and urging, uh, the importance of this being taken more seriously nationally, and it seems that that has fallen on deaf ears.

The reason for that, I can't fully understand or explain. However, I suspect that resourcing is certainly an issue. We all know that the NHS is on its knees in many ways and also, of course, ME patients have for a long time been faced with scepticism about the nature of their condition. Well, I was going to ask you about that because you have to really have to consider that that would be a major factor that some people in the medical world, well, frankly, don't believe in it.

Fiona Hamilton Times Reporter: Well, that's certainly been, uh, a major concern at the inquest. Now, uh, Maeve's father is Sean O'Neill. He's, uh, my colleague, a senior writer at the Times, and he has written many pieces that examine this issue and highlight concerns that patients have been treated with scepticism and, of course, uh, the old mantra that it was perhaps a psychological illness, not a physical condition.

But the narrative has really changed on that in recent times, and if you look at the outcome of this inquest, it would be very difficult, I think, for any doctor to make that argument in this day and age.

Jane Garvey Presenter: Yeah, and because of that scepticism, some people with ME were treated badly on wards by the people directly involved with their care, the nurses?

Fiona Hamilton Times Reporter: Well, historically, that has been an issue. I would say in Maeve's case, while she certainly, uh, was treated with scepticism over the years, both her parents have, have acknowledged that actually, when it comes to the final few years of her life. It was much more an issue that doctors didn't know how to treat her.

There isn't any funding at the moment for proper research into the condition of ME. And Maeve was deteriorating terribly in 2021. I mean, she couldn't eat, she couldn't drink. She was bed bound. Tiniest bit of light put her in severe pain. She was so sensitive to all external factors and the doctors, they did try artificial feeding on one occasion.

She deteriorated when she went home. They just didn't know how to treat her and some of them absolutely believed in this condition but they did not know how to treat her and that's why the coroner is saying that there needs to be uh funding of research to work out how to address future patients.

Jane Garvey Presenter: Right and you have pointed out that Maeve was a daughter of certainly one senior times journalist, of course most people with this condition do not have links to the media world or to prominent journalists who can campaign on their behalf. I'm not suggesting for one minute that this has been easy for Sean O'Neill. I'm sure it hasn't, but this may be a way of bringing about change.

Fiona Hamilton Times Reporter: Well, no, absolutely. I mean it is fundamentally what Sean has been able to do in terms of campaigning and highlighting this issue and speaking to many, many afflicted families across the country that has propelled this up the news agenda.

And the hope now is that Wes Streeting and NHS officials will be able to treat this as a priority. Fiona, thank you very much indeed.

Jane Garvey Presenter: We do have a statement from the Department of Health and Social

Care. They say, our deepest sympathies are with Maeve's family and friends. Every patient deserves to have their condition understood and treated to the highest standard and this is a heart wrenching example of a patient falling through the cracks. through the cracks.

Maeve and her family were forced to battle a disease alongside the health care system, which repeatedly misunderstood and dismissed her. It is important that we learn the lessons from every prevention of future deaths report, and we'll consider this report carefully before responding appropriately.

That is the statement from the Department of Health and Social Care.