

BBC Radio Today Transcript

Mishal Husain Radio Presenter: Myalgic Encephalomyelitis, ME for short, also called Chronic Fatigue Syndrome, is a condition neglected by research, by medical guidance and training for doctors. That's the conclusion of a coroner who was reporting after an inquest into the death of 27 Maeve Boothby O'Neill, who had ME for more than a decade before she died in 2021.

Sean O'Neill, journalist at the Times, is her father. He spoke to us in July as the inquest began and joins us again now. Good morning, Sean.

Sean O'Neill: Good morning, Mishal.

Mishal Husain Radio Presenter: Um, this report makes very sobering reading. No specialist services, no guidance on how severe ME should be handled.

Sean O'Neill: That's what we were saying when we went into the inquest back in July and the report is short. It's very stark. Um, I think the most stunning sentence in it is the coroner's finding that the inquest heard that provision of care for patients with severe ME such as that with which Maeve have suffered from was and is non-existent. I think that's shocking because that the NHS has known for three years, it's three years since last week since Maeve died, that there is no care for people with severe ME, and three years later there is still no care and no provision for this desperately needy group of patients.

Mishal Husain Radio Presenter: It's often described as a post-viral illness. How did it begin for Maeve?

Sean O'Neill: It began in her early teens, when she was about 13, with a viral infection, just what seemed like a normal virus at the time. She struggled to recover from it, um, struggled to recover her energy levels really, and over time, it just sort of bit by bit, at a way at her, her energy levels, then her ambition, her hope, her promise.

It ended her education at 18. She couldn't go to university. And during her twenties, she became housebound and in her later months, completely bed-bound and immobile.

Mishal Husain Radio Presenter: And you, the piece you wrote in the Times in August, you said there was an amazing GP who tried to help, but it seems like that GP had nowhere to send her. As, as if there were no specialists into whose category Maeve came.

Sean O'Neill: There were no specialists and she was admitted to hospital in Exeter three times, and there was no, almost nobody there with any knowledge or skill or ability to treat or, you know, very little experience in the condition.

And I think this is a real alarming moment because what Exeter has done since, the medical director at Exeter has actually been incredibly constructive since Maeve died, and has made a lot of local changes. He has instituted training, has changed feeding protocols, so that people can be tube-fed more easily, is training families to use tube feeding at home.

And he has seven patients on the books of his hospital trust, most of them are now being able to be treated at home. I think lives are being saved in Exeter. But what he has done is not been replicated around the country. And if this inquest means anything, it must mean change for patients like Maeve who will suffer unless the NHS takes action, steps up.

Mishal Husain Radio Presenter: The Department of Health and Social Care has given us a statement saying that they do intend to publish a final delivery plan this winter, which is going to focus on boosting research, improving attitudes in education and bettering the lives of people with this debilitating disease.

Do you think the lack of support or any help really for Maeve was because it was seen as psychological?

Sean O'Neill: I think there remains a belief especially amongst older medics, that this is somehow a physical manifestation of a psychological problem. I think that belief is deeply entrenched in the NHS and, and the medical profession, actually. Um, and I think that really has to be addressed and we've been waiting for this delivery plan for a couple of years now.

Sajid Javid started this work on a delivery plan when he was health secretary briefly. So, I know the current public health minister, Andrew Gwynne understands, gets the problem, but really there are hundreds of thousands of people with this illness, as well as the people at the severe end of the spectrum.

And it really needs some concrete action from government. And I think a massive culture change within the medical profession as to what causes this illness. Which, of course, also needs a lot more research into those causes.

Mishal Husain Radio Presenter: Sean O'Neill, thanks for talking to us.