

## Transcript: LBC Radio Interview (29.09.24)

**Matthew Wright, LBC Radio presenter:** I'm really interested in the subject of ME, we've talked about it before, used to do it quite a lot on the television, and one of the messages that I took on board very early on was that the medical establishment really lets itself down very often when it comes to this illness.

And we're talking now about a bereaved father who has criticised doctors via a coroner's court at the inquest of his daughter, Maeve Boothby O'Neill, who died in October 2021 at age 27 after suffering from myalgic encephalomyelitis for years.

And the inquest into her death found that a lack of understanding by medical staff led to failings in the treatment that Miss Boothby O'Neill received, and ultimately contributed to her death, which is, you know, it's appalling, really, because we've been talking about ME now for probably 40 years, something like that.

Well, Dr Charles Shepherd knows more about it than most. He's an honorary medical advisor to the ME Association and joins me now in morning, Charles.

**Dr Charles Shepherd, Honorary Medical Adviser to the MEA:** Morning, Matthew. Firstly, can I say, I listened to your program, and I know you covered it back in August, the inquest back in August, and I think you covered it extremely well.

**Matthew Wright, LBC Radio Presenter:** Thank you. It bothers me that we just seem to be going round in circles, and here, we have another broken hearted father with what appears to be a legitimate grievance against the medical establishment.

**Dr Charles Shepherd, Honorary Medical Adviser to the MEA:** Yeah, I mean, no one should be dying of malnutrition in hospital, and people with ME should not be dying of malnutrition in hospital.

And clearly the inquest has identified a number of very serious failings in the way that the National Health Service cares and manages for people with ME, especially those at the very severe end of the spectrum. But, I think probably the most important things to come out of this inquest and what was called a special hearing, which took place on Friday last week, where we heard some more evidence from Dr Helmsley, who was the medical director of the NHS Trust that looked after Maeve down in Devon.

I think there's two important things to emerge from that. I mean, first of all, Dr. Hemsley expressed his frustration at not having the expertise to call on, people with clinical expertise to call on, when a local hospital like that, which may not have specialists, you know, who are used to dealing with people with very severe ME that that was not available. I'm going on press reports here from Sean O'Neill, Maeve's father, who as you know, is the senior reporter at the Times. But, I understand that he has raised these concerns with Sir Stephen Powys, who is the top person at NHS England and not got a satisfactory reply to that, as to why there

is no specialist referral services or expertise available for these people.

**Matthew Wright, LBC Radio Presenter:** Well, that's really unfortunate, because I was going to ask you exactly the same question. Why? Why is there not?

**Dr Charles Shepherd, Honorary Medical Adviser to the MEA:** Why? Why? Well, we did have two, I mean, we're going back several years now. We did have two hospitals, one in Essex, one in Kent, where these, you know very expertise, clinical skills of dealing with this particular group of patients have been built up. They no longer exist.

What we do have, which is a separate strand, but it also comes out of the inquest and the decision of the coroner, to produce what's called a preventable deaths report, in other words, lessons to be learned. What we do have, and very sadly, Maeve died in October 2021, as you mentioned.

And that was the same month when we got a new NICE guideline on the management of ME/CFS, which I was part of the committee that produced this guideline. This replaced a really very flawed guideline which was based on almost on a sort of mental health model of ME/CFS - with a guidance which acknowledged that this was a complex and serious multi-system disease it involves, you know, various body systems and in particular brain, muscle and the immune system and that it could not be treated by you know, Cognitive Behaviour Therapy and Graded Exercise Therapy, that was not the answer.

And it concentrated, and this was not in the previous NICE guideline, it concentrated on providing recommendations on how people with very severe ME should be managed and they should have a care and management plan in place.

This must be put in place by the existing outpatient services for people with ME/CFS, which sadly do not cater in most cases for people with ME/CFS at the severe end of the spectrum, do not provide domiciliary or home visiting care. So, we need to implement the recommendations in the new NICE guideline and get community care sorted out for these people.

I know you go on about preventative medicine. 99 percent of people in this category, you know, these people who are bed bound, they are requiring 24 hour care. They're often living in a dark room, they're in pain, they're having difficulty with the eating, swallowing and digestion of food.

So, they need this community care input which we recommended in the NICE guideline, and they also need this inpatient hospital care when things, you know, have gone wrong, but it is just not there at the moment.

**Matthew Wright, LBC Radio Presenter:** Dr Charles Shepherd, I'm not a praying guy, so I can only offer hope, but I really hope that this happens.

I just can't believe I'm still talking about it in this sort of really dismal way, 30, 40 years down the line.