

I'm Dr. Charles Shepherd from the UK. I'm medical adviser to the UK ME Association, which primarily looks after people with ME/CFS, but we're also now looking after people with Long Covid. Especially those people who've got an ME/CFS component to it. So, I was going to briefly do an update, first of all, on where we seem to be with Long Covid in general, and then where we are with Long Covid and ME/CFS.

So clearly COVID, as far as numbers and morbidity and mortality is concerned, is on the decrease, but it hasn't gone away. We're still looking at about 10 percent of people who develop COVID, developing after that what we call Long Covid. And as far as numbers are concerned, clearly we don't know how many people have got Long Covid on a worldwide basis, but people have estimated it could be as high as 60-70 million.

So it's a huge public health issue. And it's not only a public health issue, it's also a great economic issue from loss of productivity and the medical expenses that all these people are costing. Many people with Long Covid are previously fit young adults in employment and they're just not able to go back to work. So it's developing into a long term condition, which just cannot be ignored. As far as what happens to people with Long Covid, there are people who are fortunately recovering, getting back to full normal health with this, there are a group of people who are improving, but there are a significant number of people with Long Covid who are remaining ill, unable to work, and really having a very reduced quality of life.

So not surprisingly there's been a great deal of research being ploughed into Long Covid. The NIH people are probably aware of the NIH recover program costing over one billion pounds. And equally around the world, large amounts of money being ploughed into Long Covid research and three avenues really; to try and find a diagnostic biomarker, to try and find if there is some sort of unique pathology going on as far as this particular post-infectious condition is concerned, and whether we can find some sort of treatment for people with Long Covid. And I have to say, despite huge amounts of money being poured into research into Long Covid, we haven't really got any breakthroughs to report.

We've got an understanding, a better understanding of what the basic problems with this illness may be, there are interesting findings in relation to immune dysfunction, the possibility of persisting viral infection, reactivated viral infection, mitochondrial dysfunction creating problems with energy production, and very similar things that go on in other post-infectious conditions like ME/CFS.

As far as something unique relating to Long Covid is concerned, as I say, no one has made a breakthrough. There's a very controversial area, clearly in relation to whether these micro clots in the capillaries consisting of amyloid and fibrinogen are playing a role, but it's a very controversial area. And despite some people advocating anticoagulation and even apheresis in their circumstances, this is very speculative and uncertain at the moment. So we don't have a biomarker. We have some understanding of what's happening in Long Covid, and we don't have a treatment for Long Covid.

My interest in this obviously relates to the fact that many people with Long Covid have ME/CFS type symptoms. And I suppose in very simple terms if you break down the symptomatology of Long Covid and I think we have to express the fact that this is a very heterogeneous condition in relation to both clinical presentation and what may be going on pathologically, we've got people that suppose at one end of the spectrum who have got organ damage from the initial covid infection, and this may be affecting heart, lungs, kidneys, liver

even the brain. And at the other end of the spectrum, we have this large group of people who have ME/CFS type symptomatology, and a group in the middle who both are organ damage and ME/CFS symptomatology. The research, which has been done looking at the amount of ME/CFS type symptomatology within Long Covid (and I think some of these studies are a bit biased, I don't think it's as high as the figures that have been reported in the literature) but certainly there's three or four studies now suggesting that around about 50 percent of people with Long Covid also meet diagnostic criteria for ME/CFS.

And of course, these are people who have got very typical symptoms of ME/CFS, being the very debilitating activity induced fatigue, the post exertional malaise (which is a delay in an exacerbation of symptoms when people have really exceeded their limitations), the cognitive dysfunction, the brain fog problems with the autonomic nervous system, dysautonomia, where they've got orthostatic intolerance and PoTS (postural orthostatic tachycardia syndrome), pain, which may affect muscles, joints and sleep disturbance. And as I say, there's a group of people with Long Covid who've got that particular clinical picture. And there's people with Long Covid who have got organ damage: heart, lungs, kidneys, whatever, but have also got a degree of ME/CFS component to it.

So I think when it comes to treatment, as I say, treatment is the wrong word here- what we're aiming to do is to try and provide people with sound management on how they can live with this condition and hopefully have a basis of just doing the right things, which creates the basis for some degree of improvement to occur and being able to live with this condition as best that they can. In particular, with specific aspects of the management, with the fatigue, I think it is terribly important to just think about the fact that there are other conditions that COVID seems to be triggering, which can produce fatigue. And so just because someone's got debilitating fatigue with Long Covid, it doesn't necessarily mean that it's a sort of post infectious type thing. We know that COVID can trigger myasthenia gravis in some individuals, it can trigger polymyalgia rheumatica. So, it's important to not just decide that someone's debilitating fatigue is all due to ME/CFS.

So, as we go on into 2025, hopefully all this research which is being ploughed into trying to find a diagnostic biomarker and distinct pathology and some sort of treatment, will start to bear some fruit, at least for some people.

But I think for most people with Long Covid at the moment, it is just learning how to manage your condition and, set the scene for trying to make some degree of improvement by good basic management.