

Dr Charles Shepherd Presentation to Stockport ME Group

Ben: Everyone probably already knows who Dr Charles Shepherd is. He's the medical advisor for the ME Association, which is one of the largest and most important national ME charities. I think you now say it's in a way like an ME and Post Covid charity because there's a lot of work that's done, not just with people who've got ME, but people who've got Post Covid or other related conditions and he's very kindly agreed to talk to us today. So, with that, I'll hand over to you, Charles.

Dr Charles Shepherd, Honorary Medical Adviser to the ME Association:

Right, thanks, Ben.

So what I'm going to do is really just cover what I term the sort of hot topics that are around at the moment, rather than, try and give you what I used to do in the old days, which was a lecture on diagnosing management and everything else of ME, because I think people are pretty familiar with most of that territory. And if there's something specific on that, obviously we can do that in the questions and answers.

So I'm going to cover these hot topics in a sort of almost A to Z fashion. Just to quickly enlarge on my CV, which Ben quickly introduced, but for those people who are not aware, I've got a personal and professional interest and research interest, in ME or ME/CFS, which goes back now about almost 40 years.

And I developed this illness, like most people, fit, young, extremely fit, young adult. Got a viral infection. It was a nasty dose of chicken pox, which I actually caught from one of my hospital patients, didn't recover, and went on to be diagnosed with ME. Actually by Dr. Melvin Ramsey, who was at the Royal Free Hospital at that time. But like many people, certainly in those days, and sadly, a few people still today, it took me two years to get a diagnosis.

And by that time I'd gone through all the wrong process of management - I'd tried to exercise my way out of it and I'd made myself considerably worse by bad management in the very early stages. And I think that's a very important thing that we need to try and get across to people, is early diagnosis, accurate diagnosis and good early management.

And that's something that is, of course, in the NICE guidelines. As Ben said, I've been medical advisor to the ME Association for, I think, probably about 30 years. And I supervise and look after all our research that we fund through the ME Research Fund, Ramsay Research Fund. At the moment, I'm also part of the Department of Health and Social Care Delivery Plan Working Group, which I will talk briefly about as, as we go through.

And as people probably know, the ME Association forms part of the secretariat to the all-party parliamentary group on ME so I'm actively involved in these parliamentary matters. Amongst the many things I got involved with in the past, I was a member of the committee that produced the new NICE guideline, the 2021 NICE guideline on ME.

I'm part of, what is now defunct, the Medical Research Council Expert Group on Research into ME, and going back a few years, I was part of a really, quite a landmark report at the time, which came out in 2002, and that was the Chief Medical Officer's Working Group Report.

So, to start with, just sort of going through these A to Z of hot topics.

First of all, the APPG and parliamentary matters. As people may be aware from looking at our website or AFME website, because we share the secretariat with Sonia Choudhury at AFME, we are trying now to reconstitute the All-Party Parliamentary Group on ME. We were fortunate in the last Parliament in having an extremely conscientious and really genuinely concerned Scottish MP, Carol Monaghan. She was an SMP member from Glasgow. And she really wanted to get her teeth into this subject, having met many people with severe ME, in particular, up in Glasgow, and being astonished by the lack of care that these people were receiving. So, it was very sad that we lost Carol at the last election. So, we're now in the process of trying to reconstitute the all-party parliamentary group. What is encouraging is that I know from what we've done and also from what AFME have done, that, we've got a lot of letters back from people who've written to their MPs and new MPs who have expressed a genuine interest in this subject and expressing a willingness that they would like to join the APPG.

So, as far as numbers of members are concerned, there's not really a problem. And if you go to our website, there's a report on it. There on Monday this week, the ME Association was at a meeting, it was a half day meeting in Portcullis house, part of the estate at Westminster, for MPs, on carers. The main subject was carers. So we did that in conjunction with Carers UK and several other charities and during the course of the afternoon we had, I think it was 111 to count the actual number of MPs, including various ministers, come through and attend this meeting. It was tables out, talk to people, whatever. So we had over 100 MPs there and at our particular stand, we had at least 25. I think it was MPs who expressed a real genuine interest in wanting to get involved with this subject. And quite a few of those this was because of some sort of personal involvement or knowledge of someone with ME. So we've got a lot of MPs, new MPs, who are genuinely interested in helping.

And of course, all the publicity surrounding the sad death of Maeve Boothby-O'Neill at the moment and the inquest and the prevention of death report, and the publicity that has resulted in has increased this interest. What we have to do now is to find an MP of Carols stature who can chair this all-party parliamentary group.

And that is a little bit of a challenge. We haven't found the right person yet. But once we can find a good chair, then I'm confident we can get an all-party parliamentary group going again. At an individual basis, I would still encourage, people, in your vicinity, to write to your MP, tell them about the current issues of concern and encourage them to join the APPG, once we get it going, hopefully again, and to do that if they want any more information, they just get in touch with, either us or AFME as joint secretariats.

Second thing on my list is the Department of Health Social Care delivery plan, which I presume everyone is pretty well aware of by now. Just to put it in background, people may remember that this was actually started quite some time ago by Sajid Javid MP when he was Secretary of State for Health. And it was round about the time or shortly after the time that we published the new NICE guideline and as Minister of Health, it was very, very good news that here was someone who had personal knowledge of a relative of his who'd had, who has, ME and had not been well managed by the National Health Service and really wanted to get something done.

So he set this in process, and the aim, I won't go into any detail it's all out there on the internet, but the aim of the Department of Health delivery plan, was to look at these areas, particularly in relation to service provision, education, training, research, and which obviously all need addressing. And various working groups were set up, as I say, I belong to the one on research, and this produced various initiatives.

Sajid Javid, when he set it up, really wanted this process as I understood it, to be over in a year. And it really should have been over in a year, but, for all kinds of reasons, we've had these delays and delays. And we are, I hope, now that the consultation on the interim delivery plan, is coming to an end, hopefully. That we are now nearing a point where the delivery plan will be delivered in its final form. And it looks at the moment, there was a response to a parliamentary question from Baroness Ros Scott, who's one of our parliamentary champions, from Andrew Gwynne, who's now a minister of state, I think for social care and certainly, seems to answer questions on ME and is one of your local MPs up in Manchester, to indicate that the delivery plan would now be published in the winter to use his language "winter of 2024/2025". My guess is because of what's happened with Maeve Boothby O'Neill and the inquest and the prevention of future deaths reports that's resulted from that and the recommendations in that report that, I think this will probably be more likely to be early 2025 rather than 2024.

At the moment, I have no more idea what is going to be in the final delivery plan than what was in the interim delivery plan. I don't know whether Stockport Group made a submission to that. I have to say we as the MEA, although we were part of the delivery plan, were very critical of certain parts of the interim delivery plan, especially the way it was I felt not dealing adequately with the issue of severe and very severe ME and I hope some lessons have been learned there and that those things will be, will be tightened up.

You may have also seen that one of the things to come out of the delivery plan in relation to education and training of health professionals, is a series of e-learning modules, learning modules for health professionals, two of which have now been put out. One is in the public domain, and the second is out for consultation. But I think it's also being leaked onto the internet. And again, we haven't written those e-learning modules, and although there's quite a lot of good material in them, I think there is quite a lot of room for improvement. And I hope before they are finally launched we can get some improvement where it is needed.

The third thing on my hit list is obviously the inquest into the very sad death of Maeve Boothby O'Neill. And if you've been following the media coverage of this, which has been really exceptional, and with hardly any exceptions it's been extremely supportive of people with ME, particularly severe and very severe ME.

And it has highlighted the situation that most people with severe and very severe ME find themselves in, in relation to lack of care and management being provided by the National Health Service and social care. And in particular, the coverage that's been in the Times, which has largely been due to the fact that Maeve's father, Sean O'Neill, is senior correspondent at the Times, and he has obviously been instrumental in getting a lot of really strong, extensive coverage in that paper.

And I have to say as obviously, we've got to know Sean, Maeve's father, and Sarah Boothby, Maeve's mother, they've both done a tremendous job in, in advocacy, in relation to changing the environment for people with severe ME. And hopefully something much more positive is going to come out of this, especially in the way that people with very severe ME are managed both in the community, at home, with general practice, and also when they go into hospital.

So, I think the key parts from the inquest, which concluded after, I think it was five days of submissions back in August, was the decision of the coroner to then have a special hearing, which took place, two or three weeks ago, at which Dr. Hemsley, the medical director of the NHS Trust down in Devon came to give his evidence. He didn't give it during the actual inquest hearing. And then her conclusion, then the main part of her conclusion, was the preparation of what we call this section 28 prevention of future deaths report, and that has been published on the internet and is available on our website, if you want to go and have a look at it.

But there are four key points that the coroner has made, if you like lessons to be learnt, from what happened with Maeve, and they are fairly predictable. First of all, is the need for more biomedical research, which we've been banging on about for years and years and years, particularly, of course, into people with very severe and severe ME. What may be causing people to develop a more severe form of this condition? And how do we better manage people with very severe ME? But there is the need obviously for education and training. And we have the statement from the head of the NHS trust that, in a way, they just didn't know what to do with Maeve. They didn't have the expertise there, to deal with Maeve. And so the third point that the coroner made in this section 28 report was that we do need some special dedicated inpatient beds, which we used to have. They were there at the Burswood Hospital, in Kent with Dr Paul Worsley, and also at Romford Hospital, later Queen's Hospital, down in Essex. Certainly that they didn't suit everyone, but certainly, they were there and there were physicians there with considerable expertise in dealing with complex, severe cases of ME/CFS and a multi-disciplinary team as well and the staff on the ward. Certainly, at Burswood they knew how to deal with people with severe ME especially from the point of view of things like light sensitivity, sensitivity to touch, and all these things that go with severe ME. So, the coroner made this recommendation that we do need some specialised, inpatient facilities for people at the most severe end who require complex care.

But also, and I think this is very important, that she highlighted the need for better community care. Because, you know, 99.9 percent of people with severe and very severe ME, even the people who are bed-bound, or in some cases being tube fed, are being cared for and managed at home. And it's not really accurate to say that they're being "managed at home" because most of the management, which is very good, is coming from partners, parents, friends, relatives etc.

The medical management of people with very severe ME at home, from general practitioners and community medical services is almost zero in many cases. So, as we've been trying to highlight in the media, in response to the inquest, we have this situation where people with the most severe form of the disease are the most severely neglected group of people with this disease and that has got to change. So hopefully something positive is going to come out of this very sad case of Maeve and the coroner's report. The coroner's report, has gone to NICE. I've had an email discussion with my senior colleagues at NICE from the guideline committee on some of the points that were emerging from this. It's gone to NHS England, it's gone to Wes Streeting, the new health minister, it's gone to the MLC, it's gone to NIHR, National Institute of Health Research. So, it's gone to everyone who has got responsibilities in these areas. It's also gone to Medical Schools Council who are responsible for medical student training and education.

So, hopefully, as I say, something really positive and good should emerge. I'd be very disappointed if it doesn't. And it will also, I hope, have an influence and effect on what is in the final version of the DHSC delivery plan. And I think this may be a reason why the projected publication of this document is now going to be early 2025 rather than late 2024.

Next thing on my list is Long COVID and ME/CFS. As I'm sure everyone's aware, there is now a recognition- it's something I and various other people have been pointing out since around about May 2020- that there's a great deal of overlap between Long COVID and ME/CFS. And that most people with Long COVID have some degree of ME/CFS type symptomatology, especially the fatigue and the brain fog. And it's interesting now that we've got several research papers coming out which have looked at what percentage of people with Long COVID would meet a diagnostic criteria for ME/CFS and their figures from these different studies are all coming out around about 50 percent which comes as no surprise.

I don't personally think it's as high as 50%, but there's a very significant proportion of people who've got Long COVID who basically got post COVID ME/CFS. And although right at the beginning, people may recall this, there was tremendous, antagonism, towards any of us who suggested that Long COVID may actually be, or certainly some parts of, Long COVID may actually be ME/CFS.

And we didn't want anything to do with ME/CFS because that's just, you know, an "all in the mind" condition and we've got a real medical condition. So there was this great antagonism from particularly the Long COVID patient community that didn't want anything to do with ME/CFS and the research community that got involved with Long COVID weren't very

interested either because most of them suddenly saw this as a new research opportunity and most of them didn't know anything about ME/CFS.

So we have this great divide/chasm between the two conditions, but gradually over time, there's been this recognition that there is this great overlap, both from research community, and I think also from the patient community. And we, certainly at the MEA, are starting to work quite closely with the Long COVID charities. We've also got a good relationship, I've got a good relationship with several of the key Long COVID research people, some of whom were interested in making use of samples at the Biobank, and wanting to compare abnormalities in Long COVID and abnormalities in ME/CFS.

And I think one of the really sad, disappointing things from the research point of view is that all these researchers have gone off and chased these different avenues of immune dysfunction, mitochondrial dysfunction, reactivated viral infection- all these things have already been done in ME/CFS and they haven't really come up and told us anything new. They've told us that there may be reactivated viral infection in Long COVID. There's a strong possibility that there's mitochondrial dysfunction. The problem with the way that the muscle mitochondria produce energy. That there's immune dysfunction in Long COVID and that there may be a continuing overactive immune system response causing all these flu-like feelings. We know all that already. We've done it. And it's just so sad that we didn't get this cooperation earlier on. And had we got this cooperation earlier on, I think some of this duplication of research, could have been avoided and we could have gone down some rather more productive lines of research.

So having said all that about Long COVID research, it's also disappointing that despite billions probably rather than millions, huge amounts of money, have been poured into Long COVID research over the past four years. And that's reflected in the fact that we probably get two or three research papers on Long COVID coming out every day or so. But there haven't been any breakthroughs. There's no breakthrough in what causes Long COVID certainly the ME/CFS component, and there's no breakthrough in the treatment of Long COVID certainly from the ME/CFS component point of view. There are some interesting research ideas out there, but they're very controversial, very speculative, particularly the idea that Long COVID is being caused by what are called these micro clots, these tiny, amyloid fibrinogen clots in the capillaries, which have been identified by the research group in particular in South Africa. But that is very speculative at the moment. It's not proven. And certainly, going off to private clinics in Europe and paying up to £10,000 for a phoresis, which removes harmful particles within the blood, is at this point very speculative and it's not without risk as well. So, it's not something that I think we can recommend.

Interestingly enough, they set up all these Long COVID clinics, 92 I think in total, and because we haven't got these breakthroughs in either cause or treatment of Long COVID, the government is certainly, NHS England, I think is losing interest in Long COVID services. I think some of the people in the Long COVID services may also be losing interest because they were

primarily drafted in, for their knowledge of respiratory disease, which of course COVID primarily is, and their expertise doesn't lie in ME/CFS type symptomatology and what appears to be happening in some cases, this is all being done quite positively, there are discussions taking place to join up Long COVID services with ME/CFS services and it has already happened in some places, you're probably aware that it's happened in the Isle of Man, but it's happening elsewhere.

And, I think what is probably going to happen is that we're going to see some of the Long COVID services disappearing and people being directed off towards ME/CFS services. But the problem there is, as I'm hearing from some of the people involved in the ME/CFS services, is that they already have huge waiting lists and that this is just going to add to the long waiting list to get into the Long COVID / ME/CFS services. Unless they've got more resources and more staff, they are not going to be able to cope. So, that is an emerging problem.

Next thing on my hit list is NICE guideline implementation. I think it's fair to say that it is disappointing that we have not made further progress in implementing the recommendations in the NICE guideline, which is a good document, it's a major step forward in diagnosis and management of this condition. The one exception being the removal of Graded Exercise Therapy, but having said that, there are still people around in the services who were not happy about graded exercise being removed. And in some cases, I think graded exercise has been replaced by a new term called "graded activity management", which may be graded exercise therapy by another name- it's certainly not a term that we used in the NICE guideline, and it's not something I particularly approve of. And I think the, the other big disappointment with the NICE guideline, this goes back to Maeve and Severe ME, is that we made some very specific recommendations in the NICE guideline about care of people with severe ME, especially when they've got to go into hospital, but also from the point of view of the specialist services, which are, of course all outpatient services, and the fact that they should provide some sort of domiciliary home visiting service for people with severe ME. And as we know, that is very, very rare- it does happen in a few instances, but it basically is something that's there in the NICE guideline as a recommendation and is not being done. Equally, you know, it's a postcode lottery where you are in the country as to whether there's a local specialist service. And apart from a few instances, again, going back to the Isle of Man, there've been very few new services set up following the NICE guideline. And interestingly enough, if you've been following what's been going on in the Times in relation to Maeve, one of the letters last week was from, Dr. Peter Bowery and Baroness Elora Finley, who were the chair, vice chair of the NICE guideline also pointing out that it's very disappointing that the NICE guideline recommendations are still not being adhered to. You may have seen that, I have been over the past two years, writing a lot of letters to ME/CFS health commissioners, Integrated Care Boards, clinical leads, about the content of their websites and getting them up to date to reflect the recommendations in the NICE guideline. I wouldn't say that we were almost there, but we've had quite a lot of success in getting awful websites changed, but there's still work to do.

I'll just say that we, we got the MEA, we've got a new Health and Social Care department set up and in charge of that is a lovely lady called Karren, who is a former nurse, and we also have involvement from Russ Fleming, who you may be aware of. We're trying, within this department to provide information, support and working with Integrated Care Boards to try and get the new NICE guidelines recommendations actually implemented. And in some cases, going into quite, sort of, of detail in producing new clinical care pathways at an individual level. And the one Integrated Care Board that I've been working with in particular on this, is Suffolk and Northeast Essex, where we've reached a point where we have- it's not in public domain- produced, what I think is a good clinical care plan which takes account of all aspects of the NICE guideline. It would be nice if we had this sort of clinical care plan based on the NICE guideline, at a local level all around the country.

Quickly move on to research developments. I don't have any fantastic new breakthroughs to report, sadly. I'll just remind you that we, we have, Ramsay Research Fund at the ME Association. And we're still in the situation where apart from DECODE ME, which is the big genetic study funded by the Medical Research Council, almost all biomedical research in this country is funded by Charities such as the MEA, Medical Research UK. So, we fund the ME Biobank, at the Royal Free Hospital in London, London School of Hygiene and Tropical Medicine. Basic running cost of that is £80,000 a year. Research doesn't come cheap. We've also, you may have seen, just entered into an arrangement with the Manchester Brain Bank, to start carrying out postmortem research again. We're funding Professor Manoj Sivan at Leeds, who's an expert in dysautonomia, which is POTS, or orthostatic intolerance, etc., to carry out a study, and assess various approaches to management, drug and non-drug management of things like POTS and, orthostatic intolerance. And I'm just in the process of assessing, a research grant application, for a clinical trial of low dose naltrexone, which is I know of great interest to the public patient community. So the charities are doing what we can on limited means of resources, human resources and everything else. But we do need parity with, other long term medical conditions when it comes to research funding from the Medical Research Council and the other funding bodies that are involved.

The other thing we're doing is, and we haven't actually commissioned any research into this, but we fully accept- and I know there's a lot of concern in the patient community about- the figure that we use for the number of people who have ME. And we've had this figure of 250,000, really now, for many years, which is based on the only epidemiological evidence that there was at the time and we've got no new epidemiological evidence, but that is almost certainly a significant underestimate. Not only from the fact that this is old information that it's based, but that there's been a significant increase in the population, here in the UK, and also the fact that, as I mentioned, earlier on we've got a lot of people now who've developed ME/CFS after developing COVID.

Okay it's about time I finished my 30 minutes, which is just running over. So I'll just quickly run through, a few quick points on what the ME Association, is doing. In case you haven't seen, all our information leaflets are now free. So you can download any of our information leaflets free from the MEA website. Just go to the MEA website and go to the Information and free literature. We've also got a new feature on the website called Medical Matters, and it's an

archive of frequently asked questions and answers, on all kinds of topics. So it's all set out there in A to Z index. So if you want to ask a question about dysautonomia, problems with temperature regulation, functional neurological disorder, you know, you name it, it should be there on the Medical Matters Q& A. And again, that's free to free to download. We've got a new contact number for ME Connect, which is our seven day a week telephone information and support service. And that is now extended to being an email service as well. We're about to start running an autumn poster and video campaigns. So these are short videos, on ME, which are going into, several thousand GP surgeries. Most people now have a GP surgery where you have a little video board with all kinds of video clips and bits of information coming up. So we should be having something about ME popping up on those. I've just finished writing it this week- and it should actually be available today on the MEA Website- a new information leaflet on flu vaccination for this coming season, and there's also a "to whom it may concern" letter for people who want to use that are having trouble getting an NHS flu vaccination, if you decide you want one. We've got a new MEA information leaflet on the menopause, hormone replacement therapy and female hormone research in ME. And as I mentioned earlier, we've got this new health and social care department.