

# MND Matters: Episode 20: NHS Continuing healthcare (CHC)

## Intro:

You're listening to MND Matters, a podcast from the MND Association.

## Chris:

Welcome to MND Matters brought to you by the MND Association and sponsored by Toyota GB and Toyota Financial Services. My name is Chris James and I'm Director of External Affairs at the MND Association. This podcast is about the subject of continuing health care, or CHC, as it's probably better known. And what we're hoping to do with this podcast is to ensure that people can have a better understanding of CHC and how they might be able to access it and understand some of the positive impacts of having a CHC package. We'll also be exploring the difficulties people often face during their assessment and the review process. And indeed, where they can turn for more information and support. And we'll also talk a bit about what the MND Association can do to support them in the process of trying to access CHC. I'm really pleased to be joined by a number of guests today to talk about this issue. Firstly, we have Dan Harbour, who is managing director of Beacon CHC, which is a social enterprise providing support and information for people accessing CHC. They offer free advice with their specialists as well as a paid service for additional support as needed. Welcome, Dan.

## Dan:

Thank you very much, Chris. Good to be with you today.

## Chris:

I'm also joined by Dave Setters. Dave is living with MND, and amongst many things, campaigns for better services for people with living with MND and their families and has a very specific interest in CHC and getting better access for people to make sure that they can they can get the positive benefits from it. And I'm also joined by Marian Ward, Marian, Marian's husband sadly died with MND in June 2022. And she'll be talking about their experience in accessing CHC from, from her perspective as a carer, and so welcome, Dave.

## Dave:

Good morning Chris and good morning to all the rest of the panelists and the audience. Thanks.

## Chris:

And welcome, Marian.

## Marian:

Good morning. Welcome, everyone.

## Chris:

So maybe if we could start Dan, if I can come to you first. I think one of the issues with continuing healthcare and CHC is that there's perhaps a lack of understanding of what it is. And I wonder if you could start as much as possible in layman's terms by telling us what CHC actually is.

Dan

Yes, it's a bit of a misunderstood subject continuing healthcare, so I'll do my best. Well continuing healthcare to give you the layman's technical Spiel if you like, it's a name given to a package of care, which is arranged and funded by the NHS for people who have a primary health need. And actually there's the eligibility criteria the primary health need. It's for people who have a primary health need as a result of an accident, illness or disability. So for example, that could be somebody suffering with Alzheimer's disease, having had a stroke, an acquired brain injury, or learning disability, or indeed motor neurone disease, and where that person has significant ongoing care needs. Now, one of the important things here is that this is not about the diagnosis itself. Eligibility for continuing health care has to be based purely on your care needs only, and it can be delivered in any setting outside of hospital. There's another thing, there's another missed myth that we need to bust. So if you are eligible for continuing health care that can be delivered in your own home, or it can be in a nursing home, or it can be in a non nursing residential home. And effectively it means that the NHS are responsible for commissioning funding the full cost of your assessed health and social care needs.

Chris

That's interesting you mentioned social care actually in in in that and I think one thing that confuses people sometimes is how does CHC, which is NHS provided, differ from social care?

Dan:

So nursing care in this country is provided free at the point of delivery. So those who are eligible for continuing health care should have the full cost of their care, health and social care and residential accommodation paid for by the NHS, whereas social care is of course means tested. And if we look at the average cost of care in this country, we're looking at any anything between £50,000 to £70,000 pounds, it's a lot of money. Continuing healthcare is therefore the difference between paying nothing so effectively free care, or potentially selling the family home to fund almost everything if you were to go into residential care. Yeah, so significant, significant differences there, there are some other differences just to be aware of. So for example, that there is no requirement for a contribution from your pension or from your savings if you're eligible for continuing health care, and also top ups, third party top ups to top up your care that is strictly not permissible in continuing health care, whereas it may be permissible in certain circumstances in social care.

Chris:

Excellent, thank you. That's very interesting. And just a final question, I'm going to move on to Dave and Marian in a moment talk about their experiences. This might be quite a broad question, but how do people generally access CHC? What's the what's the process by which they know if there is a normal way of doing it?

Dan:

By theory, there should be a normal way. For most people, there will be a two stage assessment process. And that starts with a screening process. And with the screening, we use a fairly simple tool called the checklist. The checklist divides your care needs into a number of categories or care domains. And your needs are assessed with a pretty quick and simple checklist to work out whether they are a sufficient level of complexity or intensity, or significance to go on and be assessed using the the full assessment process. So if you meet the checklist criteria, you should then go on to a full multidisciplinary assessment of your leads, which takes which is a much more in depth process and takes a little while. That multidisciplinary assessment should result in a recommendation which is made to the integrated care board - integrated care boards are responsible for continuing health care now - and the integrated care board should then make a decision based on that multidisciplinary teams recommendation. To start the process to access it, that checklists screening right at the beginning, that can be completed by any health or social care professional, who has been trained to do so. So we would recommend that people, if you feel you may have a need for continuing health care, you have significant ongoing needs, or you're going into nursing residential care that you speak with your social worker or your GP, or district nurse. If you're struggling to get an assessment completed, contact your local integrated care board, they are responsible.

Chris:

Okay, thank you. That's brilliant. Thanks very much, Dan. That's a really, really nice comprehensive explanation of how CHC works and what it is. So thank you very much for that. It's absolutely brilliant. I'm going to move on to Dave and Marian now to talk a little bit about your own personal experiences of accessing CHC. Dave, can I start with you, and really just sort of gauge how you went through the process? And you know, what, what did you face going through that process?

Dave:

Yeah, no problem at all. So, I read up on stuff from not from the Beacon website, and but also various other websites MNDAs included of course. So I thought I was pretty well researched. And, you know, I knew the process as you know, as best I could from reading and also from chatting to, especially my occupational therapist at the time. But despite all that, I did find it a little bit labyrinthine and difficult to understand and navigate. Also, there was this feeling despite the fact that you know, and, you know, I understood to a large degree this term, you need a primary health care need. It always felt from talking to people, even the most friendly of my social care professional, my health and social care professionals. It always felt I wasn't bad enough, despite the fact for example, I couldn't use my arms and hands. So say for example, you know, I couldn't feed, I couldn't take my drugs. So Blimey, surely you know, in my head, surely that must qualify mustn't it? Because, you know, if eating isn't a primary health care need, I don't know what is, you know, that was very, very basic. And there was that sort of general feeling in the professionals around me that I wasn't bad enough. Even you know, even though I can't live without 24/7 care from my wife Helen. And then we probably did start on the, you know, the checklist and I got through it, first of all in 2019. In, and we went on to the full decision support tool process. That was quite a heavy meet, you know, heavy meeting and we've done reasonably well. But sure enough on first application, we weren't granted CHC funding at the first attempt. I did have a look at the papers that arrived afterwards, I learned a bit more about you know, how they rated me and that kind of thing. But approximately two years later, this time. I think supported this is an important point supported by a specialist MND nurse practitioner. We reapplied and we gathered even more evidence

from other health and social care professionals. I also spoke with fellow patients, you know, I did my own kind of research with my peers to find out what they want, how they've done it. I also remember sitting at a face-to-face campaigning meeting in London, where a carer from up north said to me, Dave, why aren't you getting CHC? My wife does. Anyway you know, I know it does vary the postcode lottery from place to place. But that really sort of reinvigorated me to go again, to see if we can get it. So I made sure that specialist nurse was present at the, you know, the full assessment. The assessment was grueling. It took around three hours. And it seemed to me, you know, fairly confident guy and Helen was there, but it seemed to me, you had to share the most intimate details of your physical and mental health. You know, talking about toileting, we were talking about the strain. I don't want to overdo it, but the strain, because I have to ask Helen for everything, you know, I can't use my hands, I can't scratch my nose, the strain on our relationship, you know, because if I asked for everything, you know, it's difficult for the wife to do everything. Vice versa, that makes me stop asking for everything and therefore feel uncomfortable or whatever. So it was really, you know, that unloading of all our full secrets. It was really grueling. But we persisted, and we were successful on this occasion. I believe the key factors were, as I've already said, the support of our specialist nurse, along with the research, the greater research that that inspired in advance, but also I believe a key thing was the fact that by now I'd started on at least overnight, non invasive ventilation. And this does seem to be a little bit of a key. And that's probably, you know, where we're up to right now. And we are now in receipt of CHC funding.

Chris:

Okay. Thank you. That's really, thanks. Thank you for sharing that. It's really interesting. And it's interesting talk about the non-invasive ventilation actually being perhaps a key factor within it. Maybe explore that a bit in a bit later. Marian, could I come to you and ask you to talk about your experience as a family with your husband tried to access CHC?

Marian:

Yeah, so he didn't, we didn't actually make a formal application, even though probably about eight months before he died, we felt that he met the criteria. But we had heard of other people who've had bad experiences in making the application, the grueling application process, the being refused once or twice. Quite distressing. So we will reluctant to go forward and apply for it. And I think also we were trying to manage as best we could. And we were reluctant to sort of feel that, you know, we got to that point. And then we started to employ private carers. And over the Christmas period, the agency just couldn't supply anybody at all. And we were really, really struggling. And then we got referred to the palliative care team at the local hospital. And then within a matter of days, we were fast tracked for CHC funding, which was good that we got we got the carers in very quickly and we were lucky enough to get carers from the hospice, but we never had a formal assessment. Never had a package. It was just all ad hoc or a day to day, they come once a day, twice a day, three times a day, and then they come in the night if we needed them. So it just increased like that. And the one thing I felt was because I was caring for Ken 24 hours a day. If I hadn't have been there, they would have had to fund a carer for 24 hours a day. But because I was there, they didn't, and I I want to care for him. But I need a break. So can I have a say four or five hour in one block? Once a week? I think I questioned it with MND connect whether or not as part of CHC funding, I will be able to get a carers break. And they said they didn't think so. We did get carers breaks. But they were from the local hospice, which meant they were charity funded, so they weren't funded as part of the CHC. And the other thing about having the

package from the hospice is we didn't know what was going to happen when Ken's position got such that we needed 24 hour care, people coming in because I couldn't do it single handed. So in summary, really, I think if we hadn't heard that the process was so grueling, we probably would have applied for it sooner and probably would have got it.

Chris:

Interesting yeah. Dan, can I ask you about that? I mean, obviously, one of the things we want to do with this podcast is to really encourage people to to, you know, apply for CHC. And we'll talk about some of the advantages of it in a moment. But both Dave and Marian are both used the word grueling. I just wondered how, yeah, if that is a common experience of people going through the process and why perhaps it has been a barrier to CHC?

17:01

Do you know what Chris, I'm sitting here listening to Dave and Marian's experience and and I think they've said some incredibly important things, which really resonate with the experiences that that we have, and that many people thousands of families have reported to us. Is it a grueling experience? I'm afraid it can be. It's sort of built into the system, if you like. The the distinction between whether somebody has a primary health need or not really goes all the way back to the founding principles of the NHS and the welfare state in the 1940s. We're not gonna get into that. But you know, there is a very, very fine line between what is primarily health and what's primarily social care. And of course, social care are able to fund some health needs provided, those are merely incidental, and ancillary to social care needs. So it all gets very quite confusing. Now, the only way that you can do that, bearing in mind, it's such a complex set of criteria and such a fine dividing line, the only way that you can assess somebody is by going into a great deal of detail. And of course, that means a lengthy assessment process. And as Dave and Marian have both and really going over everything, your psychological needs, your emotional needs, your health needs, your toileting needs, physical needs, and medication, the whole lot. So you know, even your behaviour. So it can be quite an ordeal. It's something that people are often not brilliantly prepared for or supported to be brilliantly prepared for. But it is so so important. And I think one of the key messages that I would like to give which Dave as given as well, is please don't be put off requesting an assessment if you feel that you may need one. There isn't enough information out there in the public domain about continuing health care. There's a lot more information now than there used to be 5-10 years ago, but still not quite enough. And I think the the new integrated care boards, the ICB's are playing catch up in terms of the information that they have on their websites about continuing health care. But if you feel you need an assessment, please do ask one of your health or social care professionals for a continuing health care checklist. Because the checklist will either rule you in or rule you out. And then at least you will know

Dave:

it seems just seems like a huge barrier where a lot of people, you know, rightly or wrongly, the perception is that they are being inspected if you like, you know that there are people out there trying to stop them getting the funding, in many cases they deserve. Yeah, it's a huge barrier. Nevertheless, I would yeah, I would support people applying for it. In fact, what if you go back one step, one of the one of the key things is that it doesn't seem that the ICS's is actually promote the availability of CHC in the first place. And that is one of the one of the failures, you know, you can see people on our Facebook

forums, people saying, well, what is CHC, then, you know, and then and then people come in, and they often say, please go for it, but be prepared for a fight. And of course, with MND, particularly, you know, I'm lucky to be a slow progressor up to now. But for many people when it's fast progressing, you don't want me to be fighting for something, when you might not have much time left.

Chris:

Thank you. That's very helpful. I think we've talked about the barriers and the challenges for it. I wonder, David, David, Marian, if I could ask you about kind of the benefits, I suppose the obviously there's an encouragement for people to apply for it. What sort of benefit at the moment do you feel you're getting from from CHC. And then I'll talk to Marian a bit about how that experience worked for them.

Dave:

I mean, we selected a package personal to us, which effectively gives Helen, some respite over a 36 hour period, she goes upstairs to sleep, without having to turn me in middle of the night, twice a week, we could actually get more hours, but we choose to keep it as normal as possible and use that kind of respite, well, you know, help for us all. Because, you know, I don't have to ask Helen for so many things. Because other people there for 36 hours. That package. I think I've done the maths roughly right, you know, it's around about £50 grand a year for 36 hours, I have to add to overnight care, as you know, depending where you are, with your, you know, savings, all the rest of it. It's a huge comfort to know that that is being paid for. And I think that has a knock on effect with other things that, you know, we you know, Chris, that we're campaigning for, you know, if you can't get the all the support you need for housing adaptation, you might not you might think, well, I've got to pay for my care soon. But if you know the care is going to be paid for then you might put that downstairs bathroom in. And you know, if you're on that cusp between having, you know, if you're down to that last £23,500 or whatever, that is a big comfort, psychologically, to know that you haven't got to pay those astronomical fees. So yeah. Yeah. Sorry to say it does feel like winning, I should say here, that I think it's important to some patients and carers. And I have to remind myself, is that this is an NHS funding, it's a lot of people think of it as a benefit. You know, to us, that's actually what it is. But it comes out of a different out of a different budget. But it's important to know that to know who you're fighting really.

Chris

Yes, yeah. No, that's a very good point. I see. That's very, very good point. Marian I know, your experience was more ad hoc with your husband. But did you feel it was a benefit when you when you actually got some of the package?

Marian:

I think like Dave said, It is a huge relief financially, to know that you've not got that worry of whether your savings will cover the care that you need. So that was a huge, a huge benefit. Because we'd already spent a very large chunk of our savings on adapting the house. And also, it made it easier to get carers because the funding was the whoever was providing the care knows that the funding's there. So it was easier to get the carers in as well.

Chris

Yes, yes. And do you think your as a carer, do you think in terms of the assessment, your needs were taken into account?

Marian:

That's where the weakness was. I think. I mean, the care that we had was lovely, it was great. But this big thing about not having a respite break was very difficult. And like Dave said, its lack of sleep really. And being able to get to appointments for myself. So that that perhaps had carers assessment as well as part of the package, you know, when they're looking at the whole whole package would would have been better, but things were definitely better once we got the CHC.

Dave:

We also got the impression going through these two different processes, that the local assessors will looking, Helen, you know, my carer, my wife, as being there. So therefore my needs were taken care of don't worry about it. Now, that is clearly not the case. But you could feel that kind of sentiment going through them. That's all I should say. Yeah, I thought it'd be fair to Marian said it earlier. You know, the carer is allowed to go out to work, for example, well, if I go out to work, so I leave my patient wife or husband at home. What do I do then? They're not going to survive the day.

Chris:

Dan, I just come back to you. I wanted, obviously, listening to Dave and Marian's experiences of accessing CHC, and knowing that we talked about the process can be grueling. But we've also talked about the great the benefits of it. You know, Marian and David both kind of expressed the great benefit of getting CHC and the difference it makes. In terms of what Beacon does as an organisation in supporting people, how can you help people through this process?

Dan:

We help anybody in England at any stage of the continuing health care process, it's all we do. All we do is continuing health care. And I've been involved in continuing health care advice and advocacy for nearly 20 years now. We've supported we launched Beacon about nine years ago, and we've supported 50,000 individuals and families during that time. So we run the national information and advice service. We are contracted by the state to provide independent specialist information and advice on continuing healthcare so people can access as much sort of tier one basic information as they need, but also up to 90 minutes of time with a specialist advisor. So we can look at advising you on the specifics of your assessment, preparation or an appeal, those sorts of things. And there's also a load of information on our website, we try to keep that current and we have a set of free brochures, information guides and things that can be downloaded and support you with your assessment or your appeal. So that's kind of half of what we do. The other half of is our casework and advocacy. So I've been delivering casework and advocacy at any stage of the continuing health care assessment or appeal process, all the way through to independent review and to the ombudsman for many, many years. And we have a team of people who do that now. We have to we have to charge for what we do. We don't charge for the free advice, but we have to charge for representation and advocacy. But we're a social enterprise. So we just do to try to be absolutely clear and upfront about fees and any profits are donated to charity.

Chris:

You mentioned you do you provide a service in England? Is there a similar service do you know provided in Wales and Northern Ireland that you're aware of?

28:15

Wales, Scotland and Northern Ireland? Not that we're aware of. So the Welsh system is quite similar to the English system. There are one or two notable differences. We know that Age Cymru, for example, the Age UK equivalent in Wales, can advise give people free advice on continuing health care. But we're not aware of any sort of specialist advice.

Chris:

Right. Okay. Thank you. That's really helpful. Thanks very much. Obviously, I did want to mention that people can obviously contact the MND Connect helpline that the Association runs as well. And we have people working on a local level, to help people with CHC applications where, where possible. The other thing I was going to mention, Dave, as I have you here as a ardent campaigner for the association is, is to talk about other work that we can do in this area, which is around I mean, obviously, we can all think we're looking at our information provision at the moment and looking into making sure that the information that we provide for people is up to date as possible, and people can access that and people have awareness of CHC. So we have a role as an association to make people aware of it. There's also the campaigning side. And I think one of the frustrations a bit with CHC is it's been sort of a bit forgotten about and there hasn't been a huge appetite to from organisations like the Association to campaign on it. I don't know if you wanted to say a little bit about that as well. We can cover all bases in this podcast.

Dave:

Sure campaigning side, you can divide it into two. You can campaign to change the current legislation nationally, and you can campaign locally, regionally, to improve the way that current legislation is applied locally. At a national level, I think one of the big factors is that we do need it. You know, I mean, the association punches above its weight. But there are so many other conditions out there, you know, as Dan was saying, through accident, condition, that could be campaigning on this, and I might, one of my thoughts is that we must get together. This, we can't put it in the 'too hard to address tray'. You know, this is something that it would be massive. We've got, you know, we need to get the other charities, not just neurological charities together to try to change national legislation, you can group with other charities at the local level as well. So yeah, there are groups certainly in Surrey, I'd love to know those others like that, you know, across the, across the country, because there's certainly places we can apply pressure.

Chris:

Yeah, be interesting to know. And I see people listen to this podcast that doing similar things, actually, local level will be interesting to know. Yeah, absolutely. We've covered a huge amount of ground, I think I'm thinking we begin to draw to a close, but I did want to ask everyone, if there was anything else, they'd like to say, Dan is there anything else you wanted to, to add?

Dan:



Yeah I think just a couple of things to leave you with. And firstly, again, just going back to the Accessing continuing healthcare, not everybody will be eligible for continuing health care. But currently, only around about 55,000 people at any one time are eligible. So it's a relatively small number and, as Dave quite rightly pointed out a few minutes ago, you know, that number has, sadly, fallen over the past 10 years. However, if you feel that you have significant ongoing needs, if you may be going into nursing residential care, it is really, really important that you ask for a checklist and get a checklist completed, because that will hopefully give you peace of mind if it's completed correctly. And you will know whether you're progressing on to the full assessment or not. The other thing that I just leave you with, and again, this is something that has been mentioned already, on this podcast. If you do go through for the full assessment for continuing health care, it is absolutely crucial that the professionals who are involved in your assessment are those professionals who are already delivering care, and are familiar with your care needs, and familiar with your treatment and diagnosis. Too often, assessments are carried out just by a nurse assessor, and a social worker, no disrespect to them, but they've never met the individual before. And they certainly don't have the specialist knowledge. The National Framework, which is the policy of continuing healthcare is clear that in order to get to an accurate assessment of needs, it is crucial that multidisciplinary team consists of those health and social care professionals who are already knowledgeable about your needs and includes specialists.

Chris:

Right. That's a really good point. And thank you very much. That said, that's fantastic. Thank you. Dave, was there anything you wanted to add?

Dave:

What Dan just said leads in very nicely. If you've got a specialist MND practitioner, stroke nurse, make sure they're at the meeting and previously they weren't always invited. We now make sure you know, we know about the patient that the MND practitioner nurse is there, and that is all part of the preparation. One other thing we found very useful and we think was influential was to write a care diary. Very simple care diary with what you know I did it from right in the morning from when she takes the NIV mask off my face to then hoisting me on to the shower commode chair to pushing me into the bathroom to pushing me in the shower onto the loo, brushing my teeth. I tell you what, I think it went over two A4 pages, if you think of everything, and that really stresses, the intensity of what the carer is going through and what the patient needs. And it's a really good tool I think to have in place because which leads into those three words that Dan's mentioned them before. Intensity, think about what is the intensity of your condition, and the workload that's on your carer. Think about the complexity, and you know, we have anything up to 15 different therapists looking after us. And then the unpredictability. You know how unpredictable, those are three really crucial words. And if you can show that at the decision to support to assessment, you're probably well on the way to proving your case.

Chris:

Thank you. So those are, those are some top tips.

Dave:

Top tips!

Chris:

No, thank you. All very important. Yeah, absolutely. I think, as you say, I think they do all those things will help make a difference, because I think what's been interesting about this podcast is we've talked about the challenges of application. And that being something that may put people off applying for CHC. But I think also what we've covered is the great advantage of actually having CHC makes a huge difference in a number of different ways for people with motor neurone disease and for their carers and their families. And so, it is definitely worth trying for CHC to see if you can get that package because it will make a huge difference. And I think as we've heard through Dan's work with Beacon and through the MND Association that that support is, is there to try and help people do it and through obviously, the specialist MND care centers as well, people who really know about your disease and how it's progressing and the things that you need. So that's, that's hugely important. So I'm just want to thank everyone. Dan, thank you for your expertise on CHC, that you've guided us through very nicely the complexities of this and that was really helpful, thank you for your advice and words, which I'm sure people will find useful. And obviously, it's Dave and Marian, thank you for sharing your own experiences. We really appreciate that. I mean, it's, it's sometimes hard to talk about your own personal experience of these things. I know and you've been very honest, and very open about how it was for you in terms of getting CHC. So thank you very much for your contribution. It's, it's been fantastic. Thank you very much. And obviously, if people want more information about CHC, then obviously there's Beacon that you can go to for more information but also to the MND Association as well. So thank you all very much for your contributions. And thank you everybody who's listening to this podcast. It's been really interesting. Thank you very much indeed.

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