

# MND Matters: Episode 24: Support MND Carers

## Intro

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

## Charlotte Hawkins

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A big hello from me. I'm Charlotte Hawkins, you may know me best as a journalist on ITV's Good Morning Britain, or as a host on Classic FM every Sunday evening. But today I'm delighted to be here guest presenting this episode of the MND Matters podcast as patron of the MND Association. It's a cause very close to my heart. We lost my dad to MND, eight years ago back in January 2015. He was diagnosed in 2011. And it came as a huge shock to me that I found out that there was nothing we could do to make it better with no cure, no effective treatments. He was so dignified, and brave throughout. But it was so tough watching him go through it. And that's what drives me on to want to push for so much more for those with MND. So that it's not the terminal illness, it is currently. To find a cure to find treatments to get better access to equipment, and adaptations for the home where needed and to get the specialist care that is so important. It is a horrific situation for the person going through it, but also desperately hard for those around them, who very often have to care for them day and night.

So today to highlight the importance of recognizing that we're going to be chatting with carers of people living with MND, and discussing the newly launched *Support MND Carers* campaign. So I would like to welcome Kuai Peng and, David. Thank you both for being here to tell your stories today. And hello to you both.

So Kuai Peng, let's start with you. And I'm sorry, because I know that this is something that you're living with at the moment. You're caring for your husband, who has MND, tell us a bit about how you became a carer what it's like being a carer for your husband.

## Kuai Peng

So my name is Kuai Peng. My husband was diagnosed with MND in June 18 2015. And it's you know, how this dates been seared into your memory, you know that you've always remember that day? And how can we not forget it, you know, it's like a lightning bolt. And we're giving this big, you know, life limiting diagnosis, and is essentially a long goodbye, you know, was looking after him on my own for a number of years. So we started in 2015. He started with his fingers, they were getting weak, he was a pharmacist, we thought he was being lazy, and not going in and not climbing up on the steps to reach

for the medicine. He just didn't use the step. So we thought maybe it was repetitive strain injury. So we went to the hospital. And he was seen by several doctors and is as in is commonly in display in this case, you know, diagnosis by process of elimination, you know, there is no way that they actually go straight to that. We saw hand consultants, shoulder consultants, you know, you name it, we've seen them, and eventually we had an EMG and the EMG then, you know, told us that he had motor neurone disease. So it was devastating news. And so we went home and we got a call from the neuro nurse. Luckily we have a neuro nurse. Oh, we had a neuro nurse, we don't have her anymore sadly. What I needed was handholding. I needed someone to hold my hands right from the get go. She was referred me to the MND Association. And MND Association sent me this huge envelope with a thick manual of you know what to do see, which is now all available online. And I found a manual very good, but I'm very daunted by manuals. I'm not the kind of person who look into manuals and say, you know, how do you operate the computer or the cooker? You know, so they gave me this manual and I was very daunted by that I just couldn't cope with it.

And for the first four years, I was looking after my husband by myself, I had to turn him every night. I had no help. And I didn't know about to carers assessment. So no one came, no one pointed me a signpost that needed any help at all. So I had to help turn him about seven or eight times a night, I would have to turn him and, and, you know, get him a bottle etc. And one day, we went out, and I fell asleep at the wheel, and I crashed into three oncoming cars. And that was awful. And then it really was just, you know, just like, you know, the, I just remember this airbag because I was asleep, you know, and I just remember this airbag coming out. And I don't know, if you ever one of you have ever been involved in a crash, where the airbag comes out. It's like this huge white flower with a black, you know, middle. And, and I said, When I woke up, and I thought, Oh, my God, have I killed anyone. And I wasn't even concerned about my husband. And I kept saying to people, have I killed anyone, have I killed anyone.

And nobody would help my husband because they could see that he was paralysed, and they wouldn't move him. And smoke was coming out with a car. And it was just awful. And it was just because I was sleep deprived. So there was this, this awful moment that I realised that I really needed help.

#### Charlotte Hawkins

So for you Kuai Peng, it sounds like it has been a an overwhelming and intense and an isolating experience being a carer in a sense. There's a lot to a lot to get to grips with. And a lot of the time you're having to do that on your own. David, let's come to you because you know, I'm so sorry, because I know you lost your wife just a few months ago. And for you, you were your wife's carer. For several years, weren't you? Do you recognise those sort of stories that Kuai Peng's talking about there that kind of, you know, the overwhelming nature of it, the intensity of it, the fact that it's just you having to get on and do it all.

#### David

Aspects of it I can do. Our situations seem very different. My wife, Sandy and I were very close prior to having her MND diagnosis. She was diagnosed in the early part of 2017. Mostly through she felt she was slurring and bit of trouble with a swallowing. We went to the GP who happened to be a family friend as well. He said, well, there's no neurological referrals being made in Shropshire at the moment. So at

that point, we were stuck. He said, but if you want to go private, then we can do that for you. So we said yes, definitely. So went private. And within a week, we were we were seeing the neurological consultant. And it took three sessions for us to get the diagnosis of MND. Took us back a little bit because that wasn't what we were expecting. From that day on then we were able to face our track. Now. My circumstances are very different to Kuai Peng's because I'm actually a trained nurse. I have 22 years nursing in palliative care. And my wife worked with me in palliative care also as a player leader and a counselor. I looked after her solely on my own without any help, but the whole time since April 2019. The longest we were apart and that time was four hours. That's the only time that we had a part that was four hours. But that was more choice really. Because we were very lucky with where we live geographically in the country. We had everything. Once we got our diagnosis from the private consultation, we will then refer to the local hospice. Luckily for us, they had a clinical specialist MND person there. As a nurse, I was able to meet every one of Sandy's needs quite easily. We had no home adaptations. So there was all we had really was a stair lift. And I was able to give Sandy in the home for the whole time. And we just adapted because I virtually knew what I was doing because I've been dealing with disability for the last 22 years. And we just hit every day running. We were just so lucky that a very different sides of story that Kuai Peng was just saying about.

Christmas of 2019 was horrendous. And we again, we weren't sleeping Kuai Peng just like you, we were up every half an hour, when she couldn't turn. So we went onto Lisa the MND specialist and she got us a rising recline chair for the lounge. And once Sandy had that she could control her on her own position. And I slept on a sofa for three and a half years in the lounge with her and we just slept. We were able to sleep. So from no sleep. We were getting seven hours a night to the point where we were able to set an alarm to wake up in the morning. One day we slept through to half past 11!

A carer's assessment was mentioned at times. But that was never completed. So I don't actually know what the outcome of that would have been.

#### Charlotte Hawkins

But let's talk about the carer's assessments because we know that research from the MND Association's new *Support MND Carers* campaign has found only 25% of carers of people with MND have either received a carer's assessment, or were in the process of having one and 40% were unaware of their right to a carer's assessment. So Kuai Peng you mentioned the carer's assessment before as well, didn't you? Did you have one? What happened?

#### Kuai Peng

Yes, I did. My husband had a very good care, social worker. And so she referred me to who did the carer's assessment, but I only had two. And I had one back in 2017. And they did assessment, they came, they visited, they went through a list of questions. And then they offered me you know, things like respite and, they have a grant for me to go and do whatever I wanted. So they gave me a small amount of money. And then another one was done. And the same again, you know, that was done over the phone because of COVID. And, again, you know, quick assessment of what's going on how am I coping etc. And then another grant. Yesterday, I rang up the social services and said, you know, and asked about carer's assessment, and the first thing that lady said, "Why do you need a care assessment? Are you not coping?" And I said, well, no, I'm I am coping. But you know, I, you know, I

think I just need one to review the situation, because things have changed since 2021. And so I'm hoping to get another one soon.

Charlotte Hawkins

Okay, yeah. Because it would make a big difference. I mean, David, do you think that this situation with the carer's assessment is working for people then?

David

I can only go on my own experience of that, because it was mentioned to us but the figures you were quoting, it sounds very disappointing that you have to keep doing it again. And again, I thought once you would have done it once, then that's that you should have been sufficient for the entire time that you were caring for the person you were looking after? I know things change, but they don't get any better than when they start really do they. You know, you think that once you once you've had the assessment, then that should be that should be it and that should be you them for the entire time that you are having the care. But but those figures are very low. And that is very disappointing to hear that.

Charlotte Hawkins

It's really difficult for people, isn't it? Because I think you know, it's, as you say, it only gets harder doesn't it as the disease progresses. And just going through here, carer's assessments help to end identify the needs of carers so they can be offered the appropriate services and assistance to feel supported within their role. Potential support offered might include practical help with housework, breaks from caring, respite care, you mentioned that Kuai Peng, didn't you for the person you care for or advice about benefits and Kuai Peng presumably it's this kind of support that you really need, isn't it when you're going through this?

Kuai Peng

Yes, 100%, you know, really, really need. But as David said, you know, it is I am quite shocked by those statistics, you know, when I found out, you know, I mean, I, perhaps I'm lucky to be in the 25%, we've been offered one, you know, but the rest of the people. 40% don't know about it, and that is quite an amazing figure is something that should be, you know, out there, and people should know, that, we have a right to have a care assessment, because that is like a lifeline. You know, even if we don't get anything, someone is aware that you exist, you know, you as the carer is out there, you are working, you know, and even if you don't get a grant, you know, somebody knows about you.

David

It shouldn't be a form filling exercise, you know, as good as getting the assessment done is, even though the assessments done, you can't guarantee the right people are going to come and look after you, you know, that the care that you're going to get is going to be sufficient and appropriate, that type of need that that will manifest over time.

You see people going into care jobs now, because there's nothing else that is out there to do. But it's easy to give someone a job in care, but do they actually know what the care is that they need to give? You know, and are they able to think like you or me, you know, in what our loved ones need. They've got to be appropriately trained, you know, they've got to have those communication skills, not only not

only speaking but listening to what is going on. Maybe working with somebody with an eye gaze, you know, that can take a lot of time, and they've got to be properly trained in using that, to understand then what your husband would need. Got to know about his manual handling needs, got to know about his dietary needs. There's so many things that you have to think about. Someone just coming into your house, filling a form in, and it doesn't take all that into consideration.

So having an assessment that is all well and good. But you've got to have the people around to who can put that assessment into practice, and be realistic about the care they can actually give

#### Charlotte Hawkins

You know, it's not a question of ticking boxes, it doesn't conform, everybody has different symptoms at different times, they're going to progress differently. And you do need people who are going to understand it, and it is one of those diseases where quite often there are there are such complex needs in all sorts of different areas aren't there. So like you say, having those people that are able to understand it, and it's It's you two who are sort of at the forefront of that, that understand it best, but it is difficult, I imagine needing that support, because like Kuai Peng is saying it's really full on, isn't it if you're trying to do that all yourself. I mean, David, you've obviously had the expertise to be able to do that and sound pretty superhuman, if I may say so, from the point of view that –

#### David

I just made a promise to my wife to look after her, so I was just keeping the promise.

#### Charlotte Hawkins

I'm sure she was very grateful. But you know, Kuai Peng it must be it must be so hard when you have people like that that just you know when they come and assess and they don't have the understanding of it because for you you're living it day to day and I desperately need the support don't you in the right way.

#### Kuai Peng

Yes, yes, it is very, very hard. What I am a nurse as well David, but I didn't specialise I when I finished nursing when I finished training. I went and became a midwife so I actually didn't didn't nurse adults you know, I just you know delivered babies and scans and you know, so I've never ever seen a you know, obviously seen tracheostomy but never ever handle and nurse anyone with trache before and you're absolutely right. You know, it is very difficult because you need people who are currently trained, you know, the carers are sent here are not trained. Now, I had to learn very quickly and with my nursing background, I luckily was able to learn very quickly how to deal with tracheostomy. So what has been happening is that they have given these carers basic training on how to do traches. And they've come here to get the practical training from me. So I'm actually having to do that. I'm having to troubleshoot because they don't know what to do. It's actually quite scary because when KT was discharged from a hospital after having his tracheostomy inserted, he was in hospital for six months, we came home. And I remember he came into the bedroom. And then this nurse from the hospital came in, and she dropped four black bags, and said, "Here are your tubings" she said, and "good luck. Bye". And, and the district nurse never came. She was supposed to come she didn't never came. The agency had had a nurse who was supposed to be trache trained. She left that morning, she left company that morning. So the

nurse who came was not trache trained. And I was sort of floundering, you know? And, and I eventually thought, why didn't the district nurses come? I would ring them. And they would not even reply my calls, you know, I would ring them in fear, I was scared. And they wouldn't answer my call. And I understand why now, because they actually not used to looking after people with tracheostomy in the community. I all I need was someone to say, you're doing fine. You know, that's all we need. Just have a phone call to say, you're doing a good job. And that's it. But no, nobody came. And it was really frustrating. And the agency, you know, also in a very, very difficult because they paying their carers minimum wages, they have zero hour contract. And, and a lot of who stay with us are staying out of goodwill. Yeah, they like my husband. He's a lovely man. And they enjoy his company. And they you know, despite the lower pay, they stay.

#### Charlotte Hawkins

David for you, do you have you know, if anybody's listening who's going through this themselves, what what advice would you be able to give? Because does it depend you think on what area you live in? Or does it depend you know, you because of your job, I guess knew a bit about the the help that you needed, where you could go. But for other people, it's hard, isn't it? Because you're thinking well, who do I turn to, to get advice on what I need to do to care for my loved one.

#### David

It's an incredible scary position to be in and I feel for Kuai Peng because of the stress that you must have been put under knowing how are you going to find your husband every time you came back home would be would be incredibly scary. All I can say advice is the MND Association have great resources. And don't be afraid to ask for help. It could be from anybody that could be a local support group. Someone somewhere knows something about what you need to do next. You've just got to find a channel into what you need. But don't sit at home thinking there's nobody because that because that's the the worst thing you can do. There's always someone out there who can help. There's got to be the right help you got to get the right answers. But the MND Association should be able to do that for you and help you put you in contact with people to some degree but your medical professionals should be the ones who then will should know that that side of things

#### Charlotte Hawkins

people have to keep pushing sometimes don't they? And just like if you don't get the right answer, just keep asking other people but you know, in my experience and from our family's experience that there is a lovely community, in a sense, of of people going through MND, whether people are living with it, they're caring for somebody with it. They have had a family member who has who sadly died from it. You know, the MND warriors are out there in numbers and people are there to be able to support you if you reach out. I know there's lots of information on the MND website and then also of course all the regional associations as well. Kuai Peng, for you. I know you know you talk about the situation that you have been in for a number of years. What effect do you think it's it's had on you the impact it has had on you because it I just it just my heart goes out to you because it just sounds like a hugely stressful situation.

#### Kuai Peng

Yeah, it is. And it isn't, you know, because this is this really stressful I am sleep deprived, because I'm always having my ears are always, you know, alert, always listening to what's happening, you know what's going on, because he's in the bedroom and the carers are with him, you know, we've had situation where they have connected the wrong tubing to him, rather connecting him to the ventilator in the diff cover connected with him to the cough assist machine, which has no air going in, and the alarm goes off. And I can hear him struggling, he can't walk by he can, you know, sort of struggle, I can hear his bedsheet going. And, you know, sometimes we have very good carers. And when we have good carers, that is when I'm able to, you know, go into London, for example, and enjoy myself well for half a day, and then come back. But other times, I wouldn't even want to go out the front door. But because there isn't enough staff to go around, you know, for for these kinds of care is quite scary that we still have them. But but, you know, I'm always having to be here, always having to troubleshoot, and never not around. My husband wants me to go on holiday. So he's thinking about April, sending me to Morocco, and he's doing all the research on this computer. And, and I'm very reticent about the whole thing, because, you know, do I, you know, do I trust, you know, to leave them at home. He doesn't want to go into hospital for exactly the same reason what happened last time when he was in the hospital, he couldn't communicate, you know, so he doesn't want to go into hospital. And I, you know, and so he doesn't want to go anywhere for respite. You know, he wants to be nursed at home by the carers. But I'm a bit scared. So that's a pressure. The good news is that the ICB hasn't agreed for us to have an carer go in with him anytime he's admitted. So at least that is a positive outcome. So it is stressful, you know, impact on me, you know, is I still don't get enough sleep, I'm still sleep deprived. But if you want a positive out of it is that when I drive, I'm a lot more careful. When I feel tired. I will stop. And I will you know, rest. I found impact on my children. Big thing. My daughter. She, she she was she was very close. She's very close to Father, you know, and, and so her father is her pillar, stillness. But what's her pillar at the time and happened? I had collapsed, you know, and so she couldn't go to him. She would he was drooling. He was salivating, and she would not go near him because, you know, she just couldn't deal with her father being like that. I see. So and so she found it very, very difficult to deal with. And eventually she had to move out. And and so it was difficult. Sorry.

#### David

Doesn't it make a mockery of the whole carer's assessment then when you're when you're still feeling like that Kuai Peng because if care assessments done and this is follow that through with competent carers to not make you feel like that. You should feel happy to be able to go out and come back and find your husband in the same state you left him in, you know, when he was all fine before you went out and not have that worry about what you're going to come back to.

#### Charlotte Hawkins

You can never switch off can you as a carer, so even if you're not there, it's still on your mind. You're still thinking about it. You're still thinking you know what's going on while I'm not there? Can I trust what's happening? And I think also, Kuai Peng for the point of view that you've mentioned there that not only you are a carer but you're a family going through this as well, aren't you? And I think that makes it harder because it's difficult enough, isn't it when you as you say with your daughter and I know watching my dad go through it that it's it's awful. It's just the most cruel, horrific, horrible disease to watch someone you love go through. And I just find it awful that not only are you trying to get your head around that trying to be there for them and support them in all sorts of ways, in emotional ways, in

physical ways in every other kind of way to try and lessen the impact of it on them, but also trying to get your head around it to, to then have the additional feeling that all of that caring burden is on you. It's just yeah, it's just relentless, isn't it?

#### Kuai Peng

It is, you know, and, you know, as a mother, you know, as parents, you know, we try and shield our children from a lot of things, you know, we try not to tell them for a long, long time, I treated my children even though they were in their early 20s, I treated them as children, and I kept in a lot of things. And I was shouldering a lot of, you know, of it, because, because that's what parents do. Because they have their own lives, their own problems, you know, going to university getting jobs, and, you know, so for a long time, I shouldered a lot of that. There is a positive to this, you know, my son lives with us with, you know, he was working, KT was diagnosed in June, he went to university in September, and so he couldn't help me look after KT. So he's when he graduated, he said to me, I'm not going to get a permanent job, you know, I'm just going to get a part time job, and they'll help you look after Daddy, you know, so he did that he did that marvelously. Sad thing was, you know, he had to do CPR on KT, and that made him grow up. You know, we just had this conversation last night, we had a reflective session last night. And, you know, he said to me, that that CPR just, you know, traumatised me so much, you know, but then, you know, he also reflected that, you know, he's, you know, met a lot of carers, and developed a lot of empathy and a lot of compassion.

#### Charlotte Hawkins

David, you know, picking up with you on, on that point, there are, there are so many things aren't there that you have to juggle, and we would say, now, you know, not only as a carer, but as a person sort of getting to grips with it, and going through it yourself as well.

#### David

Running a household, because my wife, when I was working, my wife just did everything for me, you know. And as soon as she couldn't do anything, she had to accept that she couldn't do what she couldn't do. So I said, Well, I'll do it all, you looked after me, and I'll look after you, including taking over the bills and taking over the cooking and taking over the cleaning and doing all the shopping and making sure you're gonna be okay for the hour and a half, I'm out. But everything impacts on every part of your life. Nothing is like it was. You have to embrace that change and adapt. Every minute of the day something, something changes, the impact is immense on every part of your day. You don't get away from it. In no way even though you think at some point, you can relax, you're not actually relaxed, because you've got it just watching all the time. But that little change that little change, how can you make this easier? How can you make it better? Is that struggling? Is that struggling? Can you adapt this? Can you adapt that to you never actually get away from it. No matter how much you have help, that you actually received in the end, you still don't get away from it yourself. So having time away, is always a luxury. But as I said, the biggest time we had apart was four hours in that three and a half years, before she died and you actually become a carer that you lose aspects of being a husband or a wife. And the only time I felt I was a husband, again was the last two days when she went into the hospice. When I when I was cared for as a husband and not having to be your carer. You know, you lose your independence. I was starting to lose myself of who I actually was. Am I a carer and my husband and my, you know what role actually play in a in the scheme of things that you would do in a



job. Rather, rather than being with the person you loved. It's just it's just it just became and then when she died, I just felt totally redundant as if I lost my job. You know, it was I felt that no purpose then, you know, I felt was looking after at this purpose of making sure that she was okay. everything revolved around her. You can't afford to lose who you are in that. Because you can bet you can get bogged down with so much because you start living that condition yourself. You know, and you you start you start being that MND person as well because that's what your life is all about. It just becomes all consuming at times, and, you know, you've got to find a way to keep you in that you become very lost.

Charlotte Hawkins

Now, that's an important point, because I imagine, like you say, you get, you kind of get wrapped up with the functionality of it don't do that it's just a series of, of endless tasks that keep on going, it's a really interesting point you make there about going from being the husband or the wife, you know, to the carer, and the sort of how that changes and the impact that can have. Kuai Peng, is that something that you find as well, because I think it's, it's hard, isn't it? Because it's going to change your relationship with that person that you've had for however many years? Because of what's happening?

Kuai Peng

Yes, yeah. I'm, like David said, you become, you know, the patient, in a sense, you know, you, I always refer to care, you know, to, to the cares, as, you know, my carer, our carers, not not my husband's carers, you know, I, you know, we talk about them, as, you know, part of our family, you know, and you just become so engrossed in it, and you just don't have time to think of anything else, you know.

David

And I was quite lucky because I was able to have the odd hour in a day from my wife. So I used to cycle a lot, you know, and I was able to, so that was my mindfulness bit that I could get on my bike, just just on my trainer in the conservatory, that was an hour that I had, just away from the, I was able to detach for that short period of time. And but I could still see my wife in the lounge where she was sitting. So even though it wasn't far away, I could still do that exercise, keep myself going. And, and then raise, raise money for MND in the process, you know, I've raised several 1000 pounds over the years with my cycling, and that's given back to the money that we actually had from them. The small grants that we had.

Charlotte Hawkins

We're coming up to being out of time. So I just wanted to get both of you to sort of reflect for us with it with a final answer on the main things that you want people to know about being a carer for someone with MND, so Kuai Peng, what would you say?

Kuai Peng

I would say, when you're caring for someone who has terminal illness, make time for each other. Yeah. I mean, it may seem horrible, but look at it as a second chance in life. And, and that, you know, and looking at it from a different, a different angle. It is a long goodbye, as I've said, but we see get the chance to say goodbye with meaning, you know, you know, and appreciate the preciousness if there's such a word of life, you know. And so, yes, it is a horrible situation that we're in, and there's so much

pressure, you know, be nice to each other, spend time with each other. And you know, make those few months, days, years meaningful.

#### David

I think I would echo every part of that. But also, try and find each other's wishes as well about what you need. Should the end date become inevitable. Work at what you need to get everything right. And also, don't be afraid to ask for help. It doesn't mean that you're any weaker or any less of a person who's asked for help if you need it. Ask for that help. And someone somewhere should be able to put you on the right track. But don't don't ever be afraid to ask for help.

#### Charlotte Hawkins

Well listen, David coping thank you so much for sharing your experiences with us. It's just been it's been really interesting talking to you both hearing your stories, hearing your perspectives. So thank you so much. And just to say if anyone listening is caring for someone living with MND, our thoughts, obviously are with you. We know how hard it is to let you know that support and advice is available via the MND Association's website. That's [www.MNDassociation.org/support-for-carers/](http://www.MNDassociation.org/support-for-carers/). And the MND has a proud history of campaigning, essentially it's all about pushing for change to make life better for the MND community. Campaigning can and does take shape in all sorts of different ways. And if you'd like to find out more about the *Support MND Carers* campaign and how you can get involved, please visit [MNDassociation.org/supportMNDcarers](http://MNDassociation.org/supportMNDcarers) or you can email [campaigns@mndassociation.org](mailto:campaigns@mndassociation.org).

So David, Kuai Peng, thank you once again, thank you to all our listeners and for you taking the time to join us if it is something you're going through, I just want to say you're not alone. You're part of the MND warrior community. We all stand together in wanting to improve the lives of those with MND. Thanks so much for listening, and bye for me.

#### David and Kuai Peng

Thank you for having us.

#### Outro

You've been listening to MND matters, a podcast from the MND Association. Find more information at [MNDassociation.org](http://MNDassociation.org) If you've been affected by any of the issues raised in this episode, contact our helpline MND connect on 08088026262 or email [MNDconnect@MNDassociation.org](mailto:MNDconnect@MNDassociation.org).