

MND Matters: Episode 8: Working after MND diagnosis

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

Becky: Welcome to MND Matters, brought to you by the MND Association. Alongside members of the MND community, including people affected by the disease, health and social care professionals, and supporters, we will be bringing stories, information, and expertise direct to your ears. Subscribe now to ensure that you don't miss an episode.

I'm Becky and I'm from the Regional Care Team and we've also got Steph who's from our Fundraising team and, in this episode, we're joined by Chris Johnson who's a former Assistant Chief Constable of the West Midlands Police. He was diagnosed with MND six months after he was promoted to this prestigious role. Following a 30 year policing career that he loved, Chris decided to carry on working after receiving his MND diagnosis but what led him to make that decision and what support is available for people living with MND if they want to continue their jobs and in their roles too.

We started out by asking Chris why he wanted to join the Police Force.

Chris: So, I was a 24 year old working on a building site and I had the pleasure of meeting a couple of police officers that came to deal with an incident that happened on the building site and they just came and talked to me with such passion about the work that they were doing. But also, it was a pivotal moment I guess when you're that kind of age, you've probably started a career that you thought was right but I wanted something that was a bit more. So I kind of wanted that bit of excitement, variety, something that helped to, you know, make our communities better. I guess it was just a great coincidence of timing that, as I was thinking about what on earth am I going to do with the rest of my life, I met these two really great police officers and I thought 'crikey, I want a bit of that. What they're doing sounds great, you know'. Running round in fast cars, arresting people, just all that kind of great stuff that feels a bit like the television. And that night I went home, and there was no such thing as the internet obviously, but I made a couple of phone calls and wrote a letter - imagine that, a letter now - wrote a letter asking for an application form and I managed somehow to get through that process without any knock backs or anything really. I kind of just took each stage as it went and got in. 24 years old and had the most fantastic policing career and enjoyed every day. Every day at work was just great. Yeah, so it was a long time ago and a long journey but 30 years in policing is genuinely a great experience and I would recommend it to anybody if they're thinking of doing that and joining. It's great.

Steph: And what would you say are the main bits that you enjoyed? Have you got like, well you will, I'm sure you will have lots of standout moments, but anything you could share with us, like the real peaks of your career.

Chris: There were loads really. Probably the stand out, most important thing for me, having spent so long working throughout the West Midlands, was being appointed as an Assistant Chief Constable having gone through, you know, me and my family had gone through a couple of years of working really hard to get through the selection process for that, going away for a few months, away from the family, on the course to do that, with the prospect of, if I got the job it could be anywhere in the country and to get that in my home force was just honestly unbelievable and a genuine, genuine surprise but a delight at the same time. And, you know, we dealt with so many things, you know. I led the response for, there was a bomb that was found in Birmingham in the middle of Aston, where it was the largest unexploded World War II munition. We'd got the motorway closed, Cross City line closed in terms of the railway, we'd got parts of airspace closed. It was, you know, three days of really the city being brought to a halt but at least being able to kind of lead that, make sure that the

communities that were disrupted because of that were, to the best of our ability, you know we didn't get all of that right, to the best of our ability we tried to make sure that people were impacted as little as possible.

Becky: When you achieved, like you said, that career highlight around getting the Assistant Chief Constable role and where you live as well, your community where you've worked so hard, can you tell us more about your MND diagnosis was shortly after that wasn't it?

Chris: Yeah, it was. So, having been promoted, I took the family away. We went away on the Disney trip, you know, the trip that we'd all looked forward to for many years and talked about. And to celebrate my promotion and also to thank my kids for all the kind of turmoil I'd put them through for the last 18 months we kind of went away, had 3 fabulous weeks in America, came back and a few weeks later I didn't feel hugely well. I'd noticed, and completely taken no notice of the fact, that my left foot was getting a little bit weaker. Just kind of wrote it off as, you know, must have a bit of a muscle ache or pain or whatever but my left foot was definitely getting a bit weaker. I was catching my toes as I was kind of walking which I just told myself off about, but coming back from America I was feeling a little bit breathless, so I went along to my GP and he was just brilliant because he kind of listened to this 50 year old fella who was telling him he was feeling a bit breathless. One of the reasons for that was, you know, I was really fortunate that in 30 years of policing and before, I never had a day off sick so, you know, I had managed to live my life and avoid flus and any other conditions so it was my first trip to the doctors surgery for about 25 years and I think, because of that, he listened which was great and he told me later he'd never met a patient who was presenting early with MND so, you know, he'd learned something I think from that experience as well but he sent me off for some tests just to make sure that I hadn't got a thrombosis, having gone through the flight, and also to have a check on my heart.

So, a couple of weeks later, I went along to the doctors. Doctor did some tests and then kind of test results come back, everything was okay, you know, there's no problem with your heart, you've got nothing on your lungs but we want to re-run the ECG on your heart just to make sure. So, I went along to the hospital, they ran the ECG and there was no problem. They then did a blood test and there were just some odd results with the blood test. That led to straightaway they did the arterial blood test and the levels of carbon dioxide in my blood were really high and I'd also got a build up of, I think its bicarbonate, in my blood which indicated that my breathing was really poor. I didn't feel it, I just thought it was a little bit laboured, so taken into hospital and a number of different tests obviously, loads of scans, all that other stuff. As you and your listeners will know, it's a differential diagnosis isn't it? In the absence of anything else it's MND. So, they did the nerve conductivity test and that's when I was given the news that I'd got motor neurone disease which was a complete and utter shock and surprise as you can imagine.

Like most people, I didn't really know what MND was. I kind of Googled it and thought that's very serious isn't it? You know, that's life changing stuff. So, went through all of the stuff with the family that you'd kind of expect with that. I think it did, of course, upset me as you kind of think about your future, but I think what upset me probably the most was not the kind of prognosis because, other than it bringing things forward, we're all here for a certain period of time. What I think was the hardest thing for me to deal with was the impact on my children. You know, I've got what would have been at the time any way a 9 year old and a 14 year old, obviously we're a few years past that now so we've got an 11 year old and 16 year old currently. And, you know, I really wanted to see my kids grow up. You know, I really wanted to see my son kind of finish school, I wanted to walk my daughter down the aisle on her wedding day and all that stuff that I think every dad would want to do with their daughter on their wedding day and every parent would want to do with their kids

throughout their lives really. I think that was the big shock actually, genuinely the hardest thing to come to terms with, in terms of the diagnosis, you know, what would happen to my family?

Becky: Not everyone feels able to talk so openly about their experience with MND – what makes you want to take the brave step of speaking out?

Chris: I honestly don't feel very brave. I just think it's really important for us to talk. I think it's okay for people to say I'm not okay, that I need help, I need support, and part of the challenge I think, and I'm new to this MND thing, it will be three years quite soon, but that's the problem isn't it? Most people with MND are new to it and you don't get long with it and if we can't speak out either personally or collectively then who's going to listen and who's going to help. You know, I felt really strongly on my diagnosis that I wanted to continue working, I wanted to continue to contribute. I love my job and I worked to the point where I couldn't walk any more and I was needing an IV really pretty much from the time I left work to the time I went back to work just to keep my levels right. But, you know, we've got to be part of the conversation. If we want, whether that's the medical profession, researchers, politicians, the broader community to come with us on this journey and to help, you know, help the work that the MND Association are doing, whether that's supporting people who need really practical support, and I've been a grateful recipient of some of that. You know, the convenience that you get from a bio bidet is incredibly valuable because it helps you to maintain your dignity, but, perhaps more than that, if we can get to a point where we're able to identify this disease earlier and help people to either more successfully manage the symptoms or ideally get to a point where we can stop the disease in its track or better still find a cure. We will only do that I really believe by helping to raise awareness and helping to raise the necessary funds to make sure that we've got really targeted, practical research going on across the fantastic research institutes that are there, trying really hard to do this but they need our help. We're the kind of voice of this. The more often that we can say 'this could be you', you know, there's no understanding as to what causes this. This could be any one of us and 1 in 300 will get this during their lifetime. You know, a shocking statistic I heard for the first time probably only a couple of weeks ago was out of the current population, was it 200,000 people are likely to get MND across the United Kingdom. Well, that's a big number isn't it? We've got to push hard to unite that great research in a mission that is about how do we prevent and ultimately cure this disease, because I think they've got the ambition for it. We kind of just need the coordination and support of both the public communities and probably, just as importantly, the kind of political leadership to make this happen. Because through Covid, we've shown we can make great things happen.

Steph: Going back to sort of your decision to continue working, I'm guessing there were open conversations with your employers. How soon did they start and what sort of support did they give to you to enable you to continue working because we can tell just how important that was to you to be able to do and I completely understand from everything you've said about your policing career why you would want to continue working and how much it meant to you.

Chris: Yeah. So, I was completely open from the start from the moment I got the diagnosis, you know, I went back to my Force and told the Chief Constable and the Deputy. I was an Assistant at the time, so across the whole team I was really clear from the beginning. Their personal support was just incredible. I couldn't have asked for anything more and that came into, well perhaps I describe it in three ways really. There was kind of practical support, just in terms of any physical change. They were really keen on that kind of emotional support and what they could do around that but, thirdly, and, probably as importantly, was the support into my family, you know. So, my wife's a serving Police Officer in the same Force as well so giving our family the support and, you know, some of that is kind of professional help and we've got a great Occupational Health department in the Force who were there with the Force doctor and all that sort of stuff. But then just allowing me, I think they

allowed me to do it or maybe they just gave the illusion of allowing me to do it, kind of becoming the master of my own destiny. So, you know, giving me permission to keep going and doing what I wanted and needed to do, so that I could retain my professional dignity because I don't think what any of us want is a big dose of 'there there' cream. I just wanted to go to work and contribute. I just wanted to go and do the job I was doing before as best as I could and if there were some practical problems around that, we'd get round it. And that's really dignifying. It really is.

For any employer to be able to treat your staff with that level of dignity and respect I think is critical because, you know, one, it's important because of the dignity of the individual but I think it's great for the organisation. One of the real surprises to me because, a couple of weeks after my diagnosis I had that kind of decision to make about how public do you make it internally and externally, so one of the great things about being an Assistant Chief Constable is, you know, it's a big organisation and there's a few of you. Hopefully, occasionally, some of the people that work for you do listen to you so I was able to do an internal, if you like, comms piece back into the organisation. Honestly, the level of support I got from staff, you know, right across the service in West Midlands and into other Forces was just phenomenal. And like many people I'm sure that are listening, it's amazing the number of people that come back to you and say, I heard what happened, I'm really sorry. They don't particularly say that but my aunt, my uncle, my dad, my grandad, my friend, you know, they sadly had MND, and the number of people that come back to you and you see really clearly how quietly MND touches everybody and it is quite silent, you know. I'd describe it for you as being it silently touches lots and lots of families but it's not until you're talking about it do you realise just how broad that is. But their support was fantastic and, you know, I had a difficult decision to make at the end of last year which was just simply how much longer and, hopefully, I timed that right. You know, I was I think still contributing, still able to perform, but just got to that period of time where I was pretty much confined to my wheelchair and needing the IV more really so it just made that pretty impossible. But that was absolutely my decision and, whilst it was incredibly regretful, it was the right one I think at the time.

Steph: But you didn't do it silently, let's put it. Or, you know, you came out of there and I believe that you completed 5,000 steps as you left your office, and you've obviously just said previously that you were pretty much in your wheelchair the whole time when you came to that decision to retire, but what was going through your mind at the moment and what are the reasons behind you doing that? It's absolutely incredible.

Chris: Well, obviously the MND Association were running Mission 5,000 at the time. Now I couldn't run 5,000 kilometres but what I wanted to do was to take 5,000 steps which was kind of my equivalent of trying to take a step for everybody living with the disease and do that as a fundraiser really. And, again, it was just amazing how that took off, you know. People got right behind it. We got some news crews on the day from BBC and from ITV came out, kind of did a bit of filming at home, and the pride that I got taking my 5,000 steps walking out the front door of Lloyd House. You know, finishing my service, that was it, that was me handing my warrant card in but doing that, completing that challenge, was just great and, again, it comes back to that thing about how do you use those opportunities, hopefully, to just try and garner a little bit of interest, some support, help to spread the message. You know, how do you build on, people are really interested but how do you keep building on that. You know, you look at, I look in great awe and envy at the likes of Doddie, Stephen and, of course, Rob who've done such tremendous work on helping to raise awareness and, you know, their kind of bravery, their willingness to stand up, you know, all three of them as elite sport people but you look at the kind of devastation that undoubtedly the disease does to your body, this must have been incredibly painful for them, like it is for everybody else, but, you know, they've used their platform I think for good. You know, they've used that kind of network of how people come together in terms of sport to be able to kind of corral people, to be able to kind of

motivate people, raise awareness, obviously do a significant amount of fundraising which has just been brilliant obviously. To have the ability to at least send the message and allow people to hear what you've got to say, I think you've got a responsibility to the MND community to do it.

Becky: Yeah, 'cause you mentioned that quite a bit when you were talking about when you'd told your employers, you told the Police Force and your Chief about your diagnosis and then they empowered you to design how you then tell your colleagues and the comms around it and I wanted to just call back to that and just ask if there were any things in particular that you or your employer put in place, little things, that enabled you to retain your dignity at work or empower you to be in control of how your work flows, because that's the sort of thing that I think other people listening to this who are maybe going through the decision of should I leave work or can I continue because work's important to me. Like, what are the little things that you might not be able to read about online or, you know, that practical stuff.

Chris: That's a great question. Because you're so right, it probably isn't the big things is it? You know, it is how do you sit down, and I think having a conversation with your line manager and your team, so those that you're reporting to and those that report to you if you're in that position, are really important because one of the things that I was really worried about was that people would interpret a loss of function, in terms of physical function, with a loss of cognitive ability. And I wanted them to all be really clear right from the start that my fingers might not work as well, I might not be able to type as quickly but, honestly, I could still think as clearly as before. Now I know that, for some people, MND can affect them with some forms of pre-frontal dementia, so I appreciate what I'm saying isn't applicable to all people with MND but I think it is quite a significant majority and I've been lucky through this journey that it hasn't affected me in that way. But you know, sitting with them and just explaining what the disease means, so really simply, I used to like to talk for the country really. I was really I think okay at standing up in front of a crowd and presenting. That's quite an important part of your job if you're commanding. Now, what that did mean is that I needed to stand up in front of those people, or make them aware beforehand, I hadn't quite got the sentence length that I got before. So, you know, I was a bit, brevity became, you wouldn't think so listening to this would you, brevity became important because I couldn't project the same way and my sentence length was changing. So, what I was able to do was, you know, probably resort a bit more to writing some stuff down but then talking about things in a more succinct way. So, you know, there are tactics that you can use, whatever is the important part of your role, there are some tactics I think you can bring to bear that, just through that conversation with either your boss or the people that you're leading, you can say to them it's going to look a bit different but, in terms of the product, in terms of delivery, you know, we're not budging from that. There's no compromise on that. You know, I'm still going to be the leader that I was but in a slightly different way and that's going to look different because of this. And I think the earlier in the disease diagnosis you have that conversation, I think the easier it is for those that you're leading and your leaders to come on that journey with you.

Becky: Yeah. And I think it's amazing that you worked in an employer that notoriously looks after their staff don't they? You know, you worked for a very good employer and you had a very good open dialogue and there might be people listening to this who could be self-employed or work for some of the lesser known employers that have never come across this before in terms of any sort of adjustment in the workplace. So it's worth just mentioning here that there's ACAS that can support, and we'll include links to this in the podcast description, but there's ACAS and you're protected under the Equality Act and there's lots of advice available on our website and also other disability charities that support people to sort of empower people to stay in their jobs and, you know, you're not disabled by your body, you're disabled by the environment so if you can remove some of those barriers in the workplace, like you say, having an Executive Assistant that can help, I think that's an

amazing adjustment, being able to talk rather than write or type can change everything can't it? And I know from experience that they're some of the things that Access to Work can help fund if funding is an issue, you can pay to have a professional Personal Assistant in the workplace who you dictate to and there are so many amazing, incredible adjustments that can be made, it's about having that conversation and leading it isn't it and being open about what you need.

Chris: It is Becky. And, you know, you are right, I was very fortunate I think to have a great employer. There are tons of amazing employers but there are some that might be less so and you are right, you know, these are moments to be relatively robust because the law is behind you. But you've got to be open, you've got to be honest because what can flow from that is a tremendous amount of support and, probably remiss of me, I did have contact from Access to Work. I didn't, because of the fortunate position I was in, I didn't need to pick up the offers that they made but, you know, even really simple things like getting you a taxi into work because you couldn't drive. There are tons of really practical, you know I had the conversation with them, they were great. Really full of things I hadn't thought about. You know, would this help, would that help? Oh yeah, that's a good idea, you know. I was able to take some of their ideas actually back to the Force but the Force just said we'll do that for you, we don't need to do the Access to Work thing, but it's there and, you're right, it's funded too. So, remember the law is behind you. Nobody needs to feel bullied or cajoled into a position. This is a disability and, you know, the legal environment is there to protect you too.

Steph: I guess really what's next for you? What are your next plans Chris?

Chris: I got a bit of a milestone last week where I managed to take my daughter to her prom. So, when I talked before about some of the things that, you know, saddened me on the day of my diagnosis, being able to take her to her prom was one of those. I remember it vividly – proud dad moment taking her that day as she went and finished school so that was great. In terms of the future, so I want to keep obviously helping the MND Association as much as I can. I want to keep raising some awareness. Doing a little bit of work helping to increase the diversity of applicants into policing which is fantastic and a great opportunity to kind of keep contributing from that end. But, you know, personally I'm really excited by this kind of proposition around United 2 End MND and the work that's, I say early days, it's not is it because some people have been working on this for a number of months but, in terms of propositions for the future, I think it's the best thing I've ever seen. Best thing I've read, you know, the kind of collaboration across, whether that's the academic and research institutions, into government and into key agencies like the Association and the My Name Is, I think is great. So, I want to dedicate some of my time to helping to do what I can to raise awareness of that campaign and what I think will be, if we can get it landed, really transformative, in terms of research but in terms of hope, and don't we all need a good dose of hope and I think it's there on the horizon so really excited by that.

Steph: And I think that's kind of where we're at really with the last question but thank you for being so open and sharing everything that you have. It's been really interesting hearing, well really, particularly about, you know, your career and everything as well.

Chris: It's been an absolute pleasure, really enjoyed today and thank you for the invite and listening to my stories.

Steph: It's a privilege to get up for work every day and want to be there and to love it and to feel like you're making a difference. I'm so glad that you had the support in place from your employers that you were able to because, as Becky said, it's not always going to be the case for people but it should be, you know, it should be there. So thank you for helping us to raise awareness in that respect and, hopefully, help other people.

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