

## **MND Matters: Episode 6: Finding your way when someone you love dies from MND**

**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 you stories, information, and expertise direct to your ears. Subscribe to ensure you don't miss an episode. I'm Becky and I work in the regional care team.

**Steph:** And I'm Steph. I work in the fundraising team.

**Becky:** This episode is all about grief and bereavement but from the perspective of what you learn about yourself through the difficulties of navigating MND and loss.

We are delighted today to be joined by Matthew and Natalie. Matthew lost his dad to MND when he was just 12, and he's in his 30's now and is actually the age his dad was when he sadly died from MND.

And Natalie lost her dad last year to MND but has been relentlessly and tirelessly fundraising for us ever since she heard about her dad's diagnosis.

The episode today is quite a heavy one but it's also an uplifting one. But if you're affected by anything that you hear us talking about or any of the topics that are raised then please do check out the links that we're going to include in the description of this podcast. Also, we have our MND Connect helpline that's always available for you to talk to and our website has got lots of support around bereavement, loss, MND and links to the Tribute Fund that we mention, and also some support for young carers.

Okay, so Natalie, could you just talk to us about your experiences with MND.

**Natalie:** So, for me, years ago when I was at university my grandpa died and he actually had MND. At the time, he only found out the day he died so I didn't know he'd got it. It was back when, you know, the knowledge around MND was far less prolific I suppose, but what was lovely was he had all of us with him as he went and the last voices he heard were his wife, my dad, and the grandchildren, so it was as peaceful a passing I suppose you could get. And obviously now I realise that, you know, he had MND, but I didn't really know what that was going to be like.

And so, fast forward to 2018 and my dad came to visit me, and he had done a visit to my sister and a visit to me within the same weekend to say 'I've got some news. It's not great. I've got motor neurone disease.' And we were just flawed. He'd retired in the January. He had plans to set up a little photography business in Snowdonia doing landscapes and obviously this was going to change everything. So, I think that was when I was at my worst in a way because I think I grieved then for what was to come, because I knew now what MND was and that there is no real happy ending. So, I had a few weeks off work where I was just properly shellshocked, couldn't quite get my head round it and I then learned to live with the fact that my dad had a terminal diagnosis and that the clock was ticking. And for the first few months I think you sort of think, you know, everything seems normal, then you'd see him, and he had a stick and then you'd see him and his voice was starting to change, you know, so I knew things were happening and then he died just a year ago, July 2020.

And so, he had inspired me to do various fundraising activities and events that involve running, cycling, and walking. You know, my motto, my mantra is 'I have a body that works and I'm going to use it.' So, it's made me realise that that's not a privilege given to everybody and MND certainly

opens your eyes to that so, for as long as I can, I'm just going to keep using my body to do as much good work for MNDA as I can and help sort of promote what you do and make sure people know that you're there so, you know, if ever MND comes into their lives then you are the people to talk to.

**Steph:** It sounds like you're not giving yourself any space to rest. You'll just keep going, doing absolutely everything that you can. I mean, I'm so sorry to hear about your dad and your grandad but it's amazing what you've gone on to do for the Association since then and we're just really grateful to you. Thank you.

**Becky:** And Matthew, do you want to tell us a little bit about yourself.

**Matthew:** A bit about me. So, I was 12 when my dad died of MND, He was the same age I am now when he died so he was 31, so relatively young I think in terms of diagnosis and actually passing. It was a slightly strange one for us really. My dad, similar to what Natalie said, started dropping things, dropping lemonade bottles and whatnot and it was a fairly long process of understanding what was going on. And, strangely, no-one actually ever told me or my siblings I guess what was going on. It was just a case of your dad's not very well, you know, and he's going to have to go for a few tests and a bit of treatment. And, similarly, he actually never told us either. He was very anti saying he was unwell, or I guess really acknowledging that anything was wrong really and that was his general approach. He refused all help. He didn't want anything, kind of 'leave me to it. I'll get stuck in.' And he had a very strong faith that he would be okay, and everything would find its way as it should.

I mean I was 9/10 when my mum told me, kind of you know, your dad's not very well. Then I was 12 when he died. He died September 11<sup>th</sup> 2002, so a very significant date for most people with the Twin Towers. And for me really, it was the journey after that whereby it all started coming together because I was at an age where, by maturity levels, I didn't really understand illness, especially things like MND. And I guess the journey that I've gone on since then has been really about understanding and I guess going through and building a picture of what he actually went through, you know, because most of our lives are sculpted by our parents, our family. We look at the experiences they've had, and we base our journey on that. And, for me, it was really strange because my journey was leading towards a set end date. You know, I knew my dad only got to 31 and for me it was always a case of being petrified the same was going to happen to me, but also being in a position whereby I didn't know what came past that point. You know, for me, I'd looked at my dad and the journey he'd gone through, and I'd seen so clearly how he'd developed and progressed and, you know, the steps he'd taken but for me it was kind of the journey of the unknown. You know, it was actually quite a relief getting into my 30's. Not a lot of people say that, but it was like 'right. One more bloody year and I can finally know what's beyond that point.

And I think over the last 12 months I've really been an advocate around mental health and driving that message, especially for guys in general. You know, really just speaking out and just going look, we all have our demons, so to speak, and I guess being a bit more open and talking about it. I think my family will be really shocked that I'm openly talking about my feelings, emotions, talking about MND. They'll be like 'what's happened to Matt?' They'll probably call an intervention thinking something's gone massively wrong, but, you know, I think I'm at a point where I think it's really important to have that voice and it would be good to get some of that through today.

**Becky:** Yeah. I think it would be amazing and especially you've hit on such an important message there, especially for men, it's so hard for men to talk about mental health. Grief and bereavement is so complex any way and then you add the layer of MND. To be able to talk about grief, MND and mental health, I think it's amazing that you're choosing to come and do this and talk with us Matthew about that.

Because Natalie, it's amazing that instead of being, I know you said you had to take a bit of time off work to sort of accept and come to terms with what was happening, I think it's amazing that you're just being really relentless with your fundraising and that's what's powering you through.

**Natalie:** Yeah. I think there's basically been 3 fundraising sort of events that I've done since my dad's been diagnosed and since he's died. The first one was Covid hit obviously in the March of 2020. That meant that my dad had to, you know, self-isolate. I couldn't see him. He couldn't perhaps get as much support as he would need as MND was taking hold, so he was struggling on and not in a great place, you know. I felt guilty that my dad was dying, and I couldn't go and see him as often – I couldn't see him full stop. I was trying to think outside the box. What can I do to engage with my dad, to give him some new memories while he's stuck in his house?

It evolved into an idea that I was 42 in June, I'll stick a zero on the end and just do 420 miles. So, I just went up to my dad, sat in his garden, the first time I saw him since Christmas, in the end of May and I just told him my plans and he just shook his head, smiled, and went, you know, of course you are. That's totally you. It's going to be really great fun and I can't wait to see all about it. So off I went. So, it just started with right, I'll take the children to school and back on my bike. So each day I was doing about 15 miles as I was going the long way home when they weren't with me and then I'd do a bike ride in the evening and I started to mix things up and go, I'll do the allotments of Cheltenham or I'll do the parks of Cheltenham and I started to theme it so I had a reason to go somewhere and take photos along the way so I could do an update on Facebook each day with, you know, a bit of a photo diary. And so, my dad loved it and then in each post I also had an MND fact of the day that I borrowed from your infographic on your website. I also had my dad's song of the day so I got him to make me a playlist of all his favourite songs so each day I'd put the link to the video so people could reminisce and listen to some cool 70's rock which was his fave. And so, yeah, these posts grew and then they'd obviously have the Just Giving link and it snowballed. So, over the month of June, I basically hit my target of 420 miles in less than 2 weeks so then I went to his age, 68, and put a zero on the end, so 680 miles, and then I hit that, so I went well I'll round it off to 1,000 miles. Then I hit that and then I thought, this is just silly now, where do I go? So, I just went well my age and his age together make 110 so I'll do 1,110 miles and I ended up going over that, but I just thought I'll keep going until the end. I did a 42-mile bike ride on my 42<sup>nd</sup> birthday with my sister, Melissa, in tow. Dad loved that because he could see his 2 girls together with the full MNDA vests, we had orange lipstick, we had blue nails, we put bunting on our bikes, balloons. You know, we totally embraced the brand of MNDA and made sure that everybody, if they'd not heard of MNDA, they now know at least it was blue and orange and ask Natalie and she can tell you all about it.

So that was my first thing, and it was incredible. And, as I did the bike ride I was taking photos of people I met and doing cycle-bys – people who were stuck in their house, I'd go to their house, end of the drive, photo with them and, you know, me in the foreground and I just said the only photo that's missing is one with my dad so I actually drove my bike up to his house, went into the back garden and did like a photo of him in his house, me and my bike at the front and then sadly within the next 2 weeks he declined.

He ended up going into hospital with pneumonia and I knew that that would not be a good outcome, so he had a week in hospital, sadly with no visitors, so I knew it was a really tough time for him. We knew he was not in a great place. The one good thing with Covid, we were allowed to do a Zoom call on an iPad and the nurse would hold it to his face so we could wave at him, but he wasn't really able to communicate very clearly, and we could just tell from his eyes that he was really unhappy and not in a great place. So, I just said to them, you know, my dad needs to know that if he's had enough, that he's got our blessing, but we will be with him. He doesn't have to be on his own or worry, you

know, because he was too poorly to go to a hospice, too poorly to come home, too poorly to go anywhere so we made it very clear that, as difficult as that was for me to say, to hear myself say 'if dad's had enough, he can go but let him know we'll be coming in.' And that's what happened. So, my sister and I and his wife were able to be with him. I mean it's so fortuitous because I know over 50,000 people at that time had died alone in hospital and we were really one of the lucky ones because, although we were in the full PPE and it was a hot, hot day, the minute we walked in that room and he saw us, I could just see the relief. He was at peace. I look back at how it could have gone, and he could have died alone, you know, without us there but actually he was there with us. We all held his hand. We were able to reminisce about our childhood and say how great a dad he was and all the great adventures we'd been on together and everything. So, we were with him as he went and, yeah, I can't thank the NHS enough really for the support that they gave and obviously the MNDA. You know, the support of the MND nurse leading up to that point.

So that was July of last year and then since then I got involved with Rob Burrow's 7 in 7. So, in January this year, I decided to take advantage of that challenge and, being as I didn't know whether to walk, run or cycle, I just thought I'll do them all, so I did a 7-mile walk, run, cycle every day for 7 days. Just recently, to celebrate the year anniversary of him having died, rather than it be a day that we dreaded and one that we just wanted to sort of ignore and wake up the following day, my sister actually said 'I now want to get involved and do something significant with you, a challenge together, the two sisters' so she came up with the idea and I just tagged along for the ride literally. And what we decided was to cycle from our dad's house in Staffordshire to his ashes which are at Snowdon, on the shoreline of Llyn Padarn and Llanberis, just to basically go to dad and then to cycle back home again so a round trip. So, by this point, we had invested in a slightly better bike each. Dad had said make sure you get a good bike because my bike was great and it's very sentimental but it's not the greatest for the distance we were looking at, so we bought a good road bike. We had stickers put on with our dad's nickname 'Bobster.' He was Bob but his photography nickname was Bobster so we got Bobster stickers on our bikes so if it was getting tough and obviously, Snowdonia, the hills are tough, we'd look down at that crossbar and you'd see his name and all we said to ourselves was 'no matter how hard it gets, no matter how much you're struggling to breathe, it'll never be as hard as anyone living with MND so you can keep those feet peddling and you can get to the top and you can get your breath back and, you know, people with MND would love nothing more than to be able to do what we're doing' so, yeah, he totally inspired us all the way round. And it is inspiring for me, for my children to see that I'm leading a healthy, active lifestyle and that this definitely has helped me. You don't get over losing someone but learning to live with the loss, this has definitely been my medication. You know, people choose lots of different ways and it's very unique, there's no right or wrong and this wouldn't work for everybody but, for me, it's definitely worked.

**Steph:** Wow. That's amazing Natalie. Honestly, incredible. It's amazing to hear how passionate you are about all aspects of it. You know, the cycling, the fundraising but mostly, as you say, the driving force is to keep your dad's memory alive and to spend time presumably with people like your sister, with close family, to reminisce together which is really lovely, you know. And it's so nice that your dad got to see some of the things that you got to do, and I don't doubt that he would have known what you would have gone on to do knowing you very well.

**Natalie:** When we were cycling out of Llanberis, up towards Pen y Pass, so anyone who's been to Snowdonia knows that's a fair old hill, we cycled up there and the sun was glorious, and it just felt like he knew and that he was sort of pulling us up that hill and saying 'come on girls. I've got your back,' you know, we were safe. Our family were very worried about us being on the road as all families would about their children, but it just felt like we were invincible. It was really weird. We got to the top and I just said 'it's like he's actually pulling us up this hill towards him' and we even

stopped at his favourite roadside café for a bacon sandwich because that's where he would have gone and it just felt, we hadn't planned for that to happen, but all these little moments were just like 'dad, can you see us now. We're sat in café whatever it's called having a bacon sandwich and you brought us here.'

**Steph:** Well done. It really is so inspiring to hear you talk about it. And I know Matthew, that Natalie has talked a bit about her driving force for doing what she does. I know you touched earlier upon, you know, open conversations that you want to have about mental health and how important that is to you, it would be good to hear a bit more about why you want to do that and what your driving force behind that is really.

**Matthew:** Yeah, again, so my journey's been really rocky to be honest with regards to the process of I guess going through that grieving process. It took me an exceptionally long time and I mean if I kind of look back, I was 12 when my dad died, kind of a fairly significant age, just before hitting those teenage years, and I loved my dad to bits, you know. He was literally my, you know, I adored him beyond levels. I just probably couldn't really go into words as to how much. I just couldn't accept the fact that he wasn't here anymore, you know, and it was really tough for me to drive through that. And, for me, my acceptance of that really just led me into a bit of a downward spiral, you know. I was bullied at school quite heavily. This became another topic point to get bullied about which was tough at that age and that just led me to a point of just being angry, kind of angry all the time, you know, to the point where, as I got older, I would go out running and I'd punch every lamppost I went past and, you know, I'd be in hospital every other week with broken hands, broken knuckles, what not. And I was just really struggling to overcome that. It doesn't matter what went on, who kind of sat you down, had a chat with you, it was just really tough and all of us as a family strangely kind of isolated away from having that chat and it wasn't intentional. It was just more I don't want to talk about it, no-one else wanted to talk about it and no-one really knew how to, you know, everyone was in that grief process. No-one really knew how to, or what do we do now, you know, it's uncharted territory. And I remember this distinct feeling of everyone feeling a bit sorry for me. It kind of felt like 'oh, I feel really sorry for you' and I thought well, that's not really helping but I guess it's good in some sense but it's no help to me whatsoever.

I eventually got into kickboxing and started doing kickboxing fairly early on. As a little tubby 12-year-old, it was probably the best thing for me to do to be honest. And I started doing kickboxing and my coach was really key in putting me on the straight and narrow really with regards to just showing me, giving me a bit of a role model would probably be the best terminology and I think also giving me an understanding of I guess right and wrong. I didn't really have that. My mum's absolutely fantastic, you know, I think she's testament that mums can be dads too, you know, and I think she's a real good testament to that. But reality was I just wasn't scared of my mum at all. My mum could say to me 'Matt, no, don't do that' and I'd go 'you're not going to do anything'. It wouldn't really bother me. My coach enabled me to I guess harness some of that negative energy in a positive way. But it just wasn't enough, you know. I think initially in reality I'd started doing it because I quite liked getting hurt, you know. That was the one thing that made me feel somewhat of maybe what my dad would have gone through, but I didn't have the understanding of what he went through but getting hurt and being pushed to the boundaries was I guess to an extent almost a form of self-harm. You know, it didn't bother me. I wasn't bothered what would happen to me. I wasn't bothered how much I got hurt because reality was it still didn't take away how much I hurt for the fact he wasn't here.

I remember, probably I was maybe mid 20's, I went to the cemetery. I thought right, I'm going to go to the cemetery, everyone says to me this is the thing to do, go to the cemetery and, you know, do your thing, and I couldn't find his grave. And I remember feeling just awful, you know, I remember

literally being in tears in the cemetery, just feeling so bad that I couldn't find where he was. And that hit me really in a place that I didn't think it would at that stage because I thought you've really let yourself down. And that for me was the first kick of you know, you're not doing the right thing, you know, something's not working for you, but I just didn't really know what that was.

And then a few years after that again I thought you know what, I don't want to go down that path. It's too upsetting. I don't want to be in the cemetery crying, not being able to find my dad's grave. Put it back in the locker, you'll come back to it another day, you know. Reality was it's just ate away at me my whole life. It's led me down roads I probably naturally wouldn't have gone down. And I got to the point, probably about 3 or 4 years ago now roughly, really successful job in London, working really hard but when I look back it was another way of me just running away, you know. It was a real easy move to London, just get further and further away from it. It still didn't enable me to be happy because my dad wasn't here, you know. I couldn't compute why that was, you know, why I was really struggling to come to terms with that and I think the age thing was really key. I was so young when he died and I wasn't mature enough just yet to really understand what had gone on, and equally I think there was a hesitation for me to even explore completely what had gone on.

Any rate, fast forward maybe 5 years, 6 years after being in London and I was at work, very busy environment I worked in. I was working all hours under the sun, and I've always been a bit of a workaholic any way, probably too much so and I'll just work, work, work. And I started passing out at work really randomly and just everywhere really. I'd just randomly pass out which obviously isn't ideal when you're kind of commuting through London at any given time, and then I started getting really bad tremors in my hands and I was like, my immediate reaction was 'oh God, please don't tell me, you know, that I'm going down the same route.' I immediately thought worst case scenario and it turns out I was just really, I was having panic attacks. Really, really bad panic attacks. And it was really strange for me because I'd always been that individual when someone goes 'I'm having a panic attack' or anxiety, my immediate reaction had always been 'get a grip.' For around about 3 months I was having these, and I remember I was just like, classic me, you'll get over it. Keep doing what you're doing. They'll go away. Put it in the locker, it'll go away. And it didn't.

And I remember thinking 'what do I do now? What's my best route to go down?' And I thought I'm not going to the doctors because I just avoid doctors at all costs. I thought I'm not going into the doctors to talk about it and then, strangely, I hurt my hand boxing and I was like my hand is really playing me up boxing and it just kept causing me a lot of grief and that's the one thing I would go to the doctors for. So, I was like 'right, I've hurt my hand. I'm going to the doctors,' and, at the time, I had this really bad tremor in my hand as well. I just wasn't really where I needed to be. I could tell. I didn't feel well. I felt really rubbish. I looked really unwell. I'd lost a lot of weight and I went to the doctors. The doctor asked me why I was there, went through the usual spiel, and I was like my hand, you know, it's really hurting. I keep punching and it catches in a really bad position. And he was like 'no, I mean what's wrong with your other hand? You know, the hand that you're shaking. Are you okay?' And I remember, it couldn't have been planned any better. And at that point, it was like lights out, passed out and I was like 'oh Lord.' And the doctor after that was like 'Look, talk to me. What's going on?' And I remember just being in the doctors and literally, just uncontrollably, couldn't stop crying. And I told him. He was like kind of 'what's brought this on?' In real short terms, not the doctor's exact words but I'll summarise in more laymans terms. He was pretty much like 'you're literally one step away from having a nervous breakdown. You're at the point whereby if you don't stop now, it's not going to end positively for you. And I could feel it and it was only at that point, that pause of actually stopping and going 'right, pull yourself together. What's going on?' you know.

And I'd reflected back. I remember a few months before I was in Brazil. I'd gone out to Brazil again on holiday on my own, again another way to escape. Just run away. Float around and go somewhere

that's not here and I remember I felt really bad then. I just felt always sad and not in a good place and I remember being in my hotel and I remember looking over the balcony and I remember looking and thinking it would be so much easier if I just jumped off. And I remember at the time thinking that's not good. That's not good to have that thought process but I also remember having that understanding of going something's not quite right here Matt because I never had the intention to throw myself off the balcony, you know, and it wasn't down to going right I don't want to be here anymore. But it was the sheer thought process of thinking what you're feeling right now, you would much prefer to not be here than be here and deal with what you're going through. And that for me was one of the first flags that kind of led to the downward spiral and since then I've just been real, I've lost a lot of friends to mental health issues, for varying reasons. And the one thing everyone's always said to me in my life is 'mate, you don't talk enough. You know, about how you're feeling. You don't talk enough' and I've always been like 'well, funny that. Because I don't want to. You know, I don't want to talk about how I feel. I don't want to open up that locker and go through all of that.

And then I did. I started focussing a bit more on mental health and focussing on actually the journey you go through on bereavement because actually a lot of people, you know, I've had people say to me in the past 'you know, Matt, it was almost 20 years ago. Come on.' Or 'it's been this long now. You've got to start moving forwards' and I was like 'I don't think you understand, you know, forward steps when you're going through bereavement. It's not ones and twos, you know, it can take you 2 years to take one step and it can take you a long time to get to maybe the destination you've got to in half that time. It's such an individualised experience that not enough attention is focussed on the aftermath, you know. There's a lot of attention on during, before, you know, the brief period after but not enough is put on to actually 'well look, you're going to go through a bit of a rocky road, you know, and this is what it could look like and, for me, the saving grace in it all really was when I had my son. My son's almost 2 now. It was the first time I understood what my dad was going through. Because I'd always questioned, you know, like 'why didn't you tell us?' There's so many things, so many whys that you just can't get the answer to, and I'd always begrudged that to an extent. It was really challenging for me to comprehend quite what that was and then my son was born, and I sit with him now and seeing him and it makes sense to me, you know, because actually you become secondary. It's not about you anymore, you know. It's about well, what do I need to do to keep you happy and keep you in a place whereby you're in a good place, and that's kind of led me to here now really. Really being passionate about talking openly. I think there's a stigma with mental health at times, that there's a set type of individual or background or whatever that people would go through, and, for me, I like to think I'm very successful in my work, I've been successful in getting to where I am now. But you know what, despite all of that, I've been broken. I've been through the real tough stuff. I still have times today where I don't feel 100% and, you know what, it's completely normal and I think we all should embrace that a bit more and embrace the uncomfortable conversations that we have to have but feel comfortable having them.

**Becky:** Yeah. I completely agree. And that's such an amazing sort of call to arms for people that might be in a similar position to you, but also you said a really good thing earlier where you said grief is very individualised isn't it and everyone's experiences, and we've heard that through Natalie's experience as well. Very, very different and individual, just like MND affects everybody very individually. So, I think you being here and talking so openly about difficult subjects, but also about what you've come through the other side and the great space you're in now, but also sometimes, you know, you're not in a great space, but also what's amazing to hear is that you're not using that locker anymore. You're actually talking about it like that metaphor you used but you're talking about it and also, it's wonderful that you've got this experience with your own son now so, yeah, you're still thinking about the questions of why, but you understand the why now, so that's closure again isn't it?

**Matthew:** Just to add one point on to that about I guess not keeping it in your locker right. So, I said about going to the cemetery and not being able to find my dad's grave. It was actually Christmas just gone. I was up in Birmingham for Christmas, and I thought it just felt like the right time to go to the cemetery, you know. I've never really understood the cemetery piece of why people would go to the cemetery. I grasp the sentimental value and what that holds for people and the spiritual value 100% but, for me, I just couldn't relate until last year when I actually went and it all made sense to me, you know. It all came together and there was such an element of peace being where, although I know he's physically not there anymore, this is where he is, you know. It's where we said our goodbyes and it held a lot of value to me in just taking the locker door off. Let's not say keeping it open, I took the locker door off, and I've just been able to I guess take steps forward since then which has been good.

**Becky:** Amazing.

**Steph:** I'll just go back to Matthew had mentioned when you finally got to visit your father's grave and how important that was for you but, Natalie, we didn't really touch on this before in terms of, obviously when your father died this was during the pandemic so obviously there were so many restrictions and limitations to funerals, to what we would expect to be part of the normal grieving process. How did that affect you and your family and what sort of situation were you left in at that time and how has it impacted you going forward?

**Natalie:** I mean I didn't have a hug after my dad died for over 6 months. That's not normal. I didn't sit on a friend's sofa and have a good old cry, you know, and just have them say 'I'm here,' you know, so you felt like you were sort of grieving on your own and, I don't live near any family, so I could phone my mum or my sister and WhatsApp video so I could see people but there's something about human touch that I think is very important. And that's another reason why my dad being in hospital on his own for that week, you know, there'll definitely be issues that go round in my head forever because I know that, even if someone's very unwell, just knowing someone's sat there holding your hand or just stroking your arm or whatever it is can make you feel better, you know. And I know the nurses would have done a great job, but they weren't able to do that and, even if they did, they had gloves on any way so it wasn't really skin on skin.

But, yeah, the impact on the funeral meant that we were limited on numbers. We were fortunate that the crematorium that we used had 30 because they were individual, some people were lowering their numbers but 30 was the maximum and we managed to find one with 30. But we couldn't all go in the car together. We had to wear masks in the car so crying with a mask on is really hard. But what was lovely was, because I'd done this bike ride and my dad had given me his playlist, I felt like when it came to music choices, that I knew all his music and I knew all the lyrics inside and out because when you're on your bike for hours at a time you literally get to know every word of every song. So, when it came to us sitting down and discussing order of service and what song would he like, he'd made it very clear what his entrance music was which, for any sci-fi fans out there, he had the theme tune to Star Wars which just made me smile because my dad, he loved a big blockbuster film and he loved sci-fi and he was very much like, you know, he didn't conform. He liked to do what he wanted to do. So, I just thought 'well, good on you dad.' It's a bit crazy but it actually made us smile as we walked into what was going to be a really sad occasion but then when it came to the rest of the music, that was the only one he'd specified, so when it came to making decisions there were just some perfect pieces of music that I knew he loved, and the words were really appropriate. It was just perfect really. So, yeah, the restrictions were there. It meant that in the wake as well we had to sit at tables and not move around but me and my sister somehow



managed to get to speak to people but in a Covid secure, friendly kind of way but one day we'll get to do something where perhaps other people can come together to celebrate his life.

**Steph:** Of course. And I think you are doing absolutely everything in your power to celebrate his life through all of your fundraising already, but I do hope you get to do that with everyone that mattered to him and everyone that thought the world of him as well soon. And I know obviously you've set up a Tribute Fund as well in memory of your dad. What does that mean to you? What do you get out of it and how do you hope that you'll carry on adding funds to that Tribute Fund in the future?

**Natalie:** I mean my dad made the decision that, when I did the bike ride, obviously he was alive, so I said to him how do you want that money to be used by MNDA and it was his decision so everything I raised is what he wanted. And at that time, the money was shared equally between his local Cheshire branch of MNDA and then also for MNDA to do research with because obviously finding a cure is the big thing that everybody wants and then also to help others living with MND. So, I know that my dad was given great advice, had occupational therapy, speech therapy, voice bank recording. There's so much support you get through the charity that, obviously, that costs money so it's great to know that the money raised is going to where he wanted it to go to, but the Tribute Fund basically gives us a grand total, like a running grand total. I think it's in the £17,000ish range at the moment. The Tribute Fund does give you a place to just look at and reflect on all the good things that lots of people have done, not just me but, you know, if anyone had ever given a pound to anything that we have done as a family, it's there in this sort of giant pot and it just makes you think it's all worthwhile and that it will be helping other people. And you can, you know, light a candle for them virtually. You can send a message on their birthday virtually. I know that the charity they acknowledge these significant dates as well and, you know, for some people this might be the way that they go to the cemetery or their last favourite place they used to go to but you can do it from the comfort of your own home so if you find that you haven't got transport or, you know, you're not able or you're not very well, you don't need to miss things. You know, there is a place to go, albeit it's on your laptop or on your phone or your device, so I found it really useful.

And then also, if somebody said to me 'oh Natalie, I want to give you some money for MNDA,' you can give them the link to the Tribute Fund, so you haven't got to be doing a fundraising activity to be able to accept a donation so, you know, it's great on lots of levels and hopefully the words that Matthew and I are able to share might just resonate with someone, somewhere and make them sort of think there is help out there for us. Even if you go to MNDA in the first instance, you then will be able to signpost and refer to all the relevant agencies that can help them.

**Becky:** Yeah, definitely. That's exactly what this whole episode of the podcast is about so if anybody is there listening and feels that something Matthew or Natalie has said has resonated with them, and I'm sure it will because it's two very different experiences of MND and the grief process. One where you're channelling all your energy into making sure people talk more and understand that grief is difficult and is different for everyone and the other where you're channelling it into fundraising to make sure that all the money when we eventually get that cure means that people don't have to go through the same experiences that we in the MND community have been through. So, thank you so much for giving up your time and coming and talking to us today and I hope that you found it, I mean I've definitely found it a cathartic experience listening to you. I also have lost someone, my dad to MND, so I personally feel like I've resonated with what both of you have said at certain points in this and that's very special. And I hope that for yourselves talking about it has also been an enjoyable experience. I know it's a very hard subject and we will mention shortly all the support that's available if anyone's been affected by what you've covered but you both talk about it in such a way that I hope our listeners also feel that, although it's a terrible thing to have happened, it's a positive experience that you're now having as a result.

**Natalie:** I totally agree that there's got to be some good that comes out of this and, you know, any condition that anybody gets. It's like when you see these world disasters, there's always some good going on, in and amongst the chaos, in and amongst the madness and, you know, out of Covid you've got the NHS and how wonderful the staff have been and the vaccination programme and all that and I just think when I think back to our situation, the one thing, I mean I'd love my dad back at the drop of a hat like I'm sure you guys would. I'd do anything to have one more chat, one more walk with him, one more anything, but I just think I've been reminded about how lucky I've been to have had a great dad. So, it's because of my dad that we're having this chat today. It's because of this chat that I've met Matt and heard his story and, you know, that I'm aware that grief is just so unique, and I think, depending on when it happens to you, the impact is just so different but the key thing for me is talking, and I don't struggle to talk. I love a good old chat so, you know, I don't hold back from having a conversation with someone and I think sometimes you don't resolve the issue, it's still there, the same problem is there, but you just feel a bit lighter for having shared it and knowing that someone sort of gets you.

**Matthew:** We've sometimes just got to put our pride to the side. There's no pride in feeling a set way or feeling sad or feeling down. I think it's really important to I guess take the time to talk and one thing that I do really strangely actually, some people probably think I'm crazy at times, but I talk to myself. It's really bizarre right but just to talk out loud, you know, even if you don't want to talk to your family, your friends, whoever it is, just talking things out loud and taking the time to go 'right, how am I feeling' and taking that time to reflect is really important. Self-reflection for me is really key to any form of progression and I just think take the time, you time, you know, 5 minutes, 10 minutes, whatever. Do it in the shower, do it when you're brushing your teeth, whatever that routine needs to be to ask yourself where you're at today, you know, what that start point looks like for you. But also have an understanding that the journey from A to B to C will have different end results for everyone, you know, where do you want to be at point B and where you do you want to be at point C. Combining that with things that make you feel better is really important. I know for me I went through a period of time whereby it was easier just to sit on the sofa and not move. Not literally, but you know, kind of just doing nothing and really isolate myself. I think it's important to embrace the things that make you feel better and I think if it's a case of, whether it's a gym routine or music or whatever it is, no-one's going to say it's going to make it get any easier but one thing it will through that repetition of doing the small things and focussing on those little small details, eventually it will build up and lead you into a position whereby, you won't even know it until it hits you square in the face, that actually, well hang on, I've gone a day without thinking about this or I've gone two days or I've gone a week. And I think that's really important just to acknowledge when you're at that point and understand that there's more than one avenue that you can take to get to that place of feeling fulfilled.

**Steph:** Thank you both. Honestly, it's been so inspiring to hear from both of you. It has honestly been amazing. I could have just sat here and listened. I didn't even want to ask any questions, I just wanted you both to carry on talking. You've both just been so open. I think that's what's been absolutely remarkable about this and just thank you for, it's so brave to be that open and you really have. I feel like you haven't held anything back either of you so it's going to be so beneficial for people who've been in similar situations because they are hearing the truth and really how this has affected you and how you've learned to deal with what you've been through and continuing. You know, it's an ongoing process and that really came across as well. I just think open conversations are so powerful and thank you so much for doing that.

**Becky:** Yeah. I completely agree. Thank you both so much for sharing your experiences with us and the MND community.

**Outro:** You've been listening to MND Matters, a podcast from the MND Association. Find more information at [MNDAssociation.org](https://mndassociation.org) and if you've been affected by any of the issues raised in this episode contact our helpline MND Connect on 0808 802 6262 or email [mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)