MND Matters: Episode 39 – Love, loss and the power of pets

Domonique
Welcome to MND Matters, an MND Association podcast today, I'm joined by Lizzie and her dog Bumblebee at Woodgreen Pet Charity centre. Thank you for your time today, Lizzie. So if you can start by introducing yourself, so maybe tell us your name, if you're happy to share your age, and can you tell me your connection to motor neurone disease.

Lizzie
So I'm Lizzie. I am 41 now everyone knows. And yeah, my husband had motor neurone disease. He passed away coming up to five years ago. So yeah, we lived through the disease, unfortunately for about four years. And yeah, come out the other side.

Domonique
Yeah, absolutely, in terms of a little bit of life before motor neurone disease kind of came in. What was Chris like? What was life like for you as a family?

Lizzie
Chris was an incredibly funny character. I don't think you'd meet anyone who knew him who couldn't tell you a funny story. He had such great personality. We met university, so yeah, we met, stayed together, bought our first house together, got married, had two kids, and then at I think, he was 34 he got his diagnosis only six months after our second child was born. So yeah, it was quite a shock, especially for someone so young and yeah, the rest is history, really. We then lived through a very, very difficult four years before we lost him sadly.

Domonique
I'm really sorry to hear that it was so close to your second child's birth as well. There's so much already happening in the home and then to be dealt with an MND diagnosis, it must have been really difficult.

Lizzie
It was, yeah, devastating, I suppose. I don't think people use that word a lot to describe, you know, very trivial things. I don't think you can ever really know what it means until you are given that sort of news. And, yeah, six month old baby and a husband with a terminal diagnosis, a five year old, yeah, it was, it was a lot, and it was, it was really, really hard. You know, your brain is amazing how it forgets those sorts of things. You know, it's, it's coming up to sort of 10 years ago, I suppose, since we received that, that awful news, but some things that burned into my memory. And, yeah, it was not a nice, a nice time of my life, not something I wish upon anyone,

Domonique

Yeah, of course. In terms of if you're happy and you're comfortable to share, what were some of Chris's kind of main symptoms, and how did you as a family adapt around those?

Lizzie
So coming up to diagnosis, the first things that he certainly noticed was that his legs were giving way. He used to play a lot of sport. He used to play football and badminton. He used to run. And he was finding that he was playing football and falling over a lot, which, you know, we were sort of like, Oh, you're so clumsy. What are you doing? But then it started to happen in the house. He'd be walking across the living room and trip and couldn't save himself. And then he had one day at work this sort of spasm down his arm, and one of his fingers bent over and never, never went back, which you know that's that's not normal. So you start, you go to the GP, and I think he must have seen about four different GPs had referrals for physio. Nobody could really tell him what it was or was overly concerned, until he took himself to a private physio who asked him lots of questions and sort of said to him, you need to go back to your GP. You need to, you know, ask them to refer you to to have some neurological tests. And that's when it all, it all came came out. So, yeah, we, you know, he got his diagnosis quite quickly once we saw the right person. But yeah, it did take, take quite some time to get to that point. And, you know, once he was diagnosed, and we knew, obviously, like, you know, your life changes completely. Never, you know, you never go back to how you were. He lost the ability to use his hands and the ability to climb the stairs, and that quite quickly. So I very quickly became sort of a single parent, really, to, you know, a baby and a five year old, and was doing all the nappy changing, you know, the bath times, the bedtimes, everything myself, because he wasn't able to so, you know, family life changed dramatically, quite quickly. And, yeah, we just continued to go downhill sadly.

Domonique
I wonder as well, with his age, obviously, being very young probably was a bit of a barrier to that diagnosis. So we know MND diagnosis, they do take a while, because you test for everything to rule out everything before you get to motor neurone disease. But when you've got someone so young, physically fit, it can be a barrier to getting to that diagnosis. So I'm pleased that he was able to get that, even though it was through private kind of systems. I'm pleased he was able to get that, because the reality is, if you don't have a name for these things, it's it can be really difficult to understand.

Lizzie
Absolutely and I think because he was also so physically fit that helped him in some ways, because it delayed his decline slightly, but yeah, it hindered the diagnosis. And yeah, as you say, you don't expect to get a diagnosis like that at 34 years old. And yeah, it, you know, really tricky, really hard time of our lives.

Domonique
Obviously, we're joined by the lovely Bumblebee today, who is a fantastic extra guest on the podcast, and we're at Woodgreen Pet Charity centre. Can you tell me a little bit about your role here at Woodgreen Pet Charity centre?

Lizzie
Yeah so I am a pet matching officer. So my role really is to match the dogs that we we get in for rehoming to their their new forever homes, and help, you know, people to find those, those dogs that they're looking for. So I spend my days, you know, talking to people and seeing what they they need and what they're after in a dog, and hopefully, you know, finding them that forever companion.

Domonique

Amazing. Have you yourself always been a pet family, kind of I understand that you you rehomed a dog yourself, brought dog into your home during Chris's MND. Have you always had dogs around the home? Or was that a conscious decision you made to kind of get a bit of companionship for Chris and give you something to kind of, you know, focus on as well as Chris and your children.

Lizzie
Yeah. I mean, no, I have always been a dog lover. I am one of the lucky people who can say that I work in an area that I've always wanted to work in. So growing up, I always had dogs and pets and all sorts of animals. But yeah, as a family, me and Chris got a dog when we first got our first house. That was the first thing we did, I think, was get a dog together. So, yeah, we'd always had dogs. The dogs that we had were actually very elderly by the time Chris was diagnosed and we lost we lost them. But getting Betty, my other dog, she came at a really important point, I think I was in quite a quite a dark place. You know, it was sort of a year on from diagnosis. Things had gone downhill. I was caring for Chris and caring for two children, and I needed something to help me. I needed, you know, an escape from the realities of life, I suppose. And so took on Betty. She was only a puppy, so some people probably thought it was a crazy idea, but she made such a difference, not just for me, but also for my children and for Chris, it was an opportunity for him to have that companionship, to have, you know, someone who was there all the time. Obviously, I was very busy, still working as well. I wasn't around all the time, and MND, if nothing else, is so isolating, so lonely. So to have that companionship of the dog in the home that was always there, always there to listen, always there to chat to, I think really helped him as well. She became my running buddy. She's what sort of got me into running. I really wanted to start running. Chris loved running, and he couldn't do it anymore, so I sort of said, well, I'll do it. If you can't do it, I'll do it for you. And, yeah, we ran together. She took part in all of my training for my marathon I ran. So, yeah, she was a real, real sort of asset to us during some really difficult times.

Domonique
Yeah, definitely. I think as. Well, like you said, MND can be really isolating for the person who's living with the disease, but also for their family, their spouse, their carer. It can feel like your world all of a sudden gets really small. But having that companion there in Betty, knowing there was that unconditional love you know you as well when you're away from home, knowing that Chris had company, it must have been a very reassuring kind of comforting feeling. Would you say that was right?

Lizzie
Absolutely. Yeah, I think it's incredibly comforting to to have that companionship and know that there is always someone there, you know, and sometimes the companionship of a dog is better than human company. They don't judge you. They you don't, you know, they don't have to sort of speak. They're just there. And sometimes that's all you want, because it's hard. It's hard keeping up that you know, that that smile and like, Oh yeah, I'm okay. Sometimes you just want to say, I'm really not okay. And you can say that to a dog. It's easier to say that to a dog than a human. So, yeah, very, very important.

Domonique
Good. I'm glad that Chris had that and that you had that as a family when you were going through such a difficult time. So as Chris' symptoms progressed, as his MND kind of got worse. What would you say some of the challenges were for you as his partner and his carer, kind of managing those changes and also managing, you know, Betty being brought to the home?

Lizzie
So as Chris's mobility sort of decreased and his need for adaptations like wheelchairs and walkers increased, that that can be really difficult. If you have a dog in the home, they get under your feet. They, you know, they want to be there where you are, and that makes life quite tricky. We've also had carers

starting to come in and out, which poses, you know, another issue, the dog running out the front door, the dog, you know, causing making things more difficult is not, is not what you want. So using things like baby gates and making sure the dog has a safe space to be when people were in and out of the home, a dog crate as well, so we could shut her away if the carers came in the morning and to help him sort of get to the shower, you know, we put her in there and then she wasn't getting herself in sort of any danger as well. Because, you know, there's a lot of heavy, big heavy equipment, big hoist that we're moving around the living room. Want the dog to be safe and also not be frightened by any of these things. They're not normal items that you expect to have in a in a household, I guess, luckily for Betty, she she grew up with those things because she was a puppy when we got her. But yeah, it was just about creating something that was safe for everyone.

Domonique
Yeah, I think that's really important. Like you said, with motor neurone disease, you have carers coming in and out, you have occupational therapists coming in and out. You've got extra visitors. You know, neighbours might be popping in to drop things off or pick things up. So you do see an increase in strangers, essentially coming in and out of the home. So those tips are really helpful for people who might have a nervous dog. Might be wanting to minimise any stress that they put onto their dog and onto the family as well. You know, you need to be focusing on the visit itself, and not worrying about where's the dog. Is the dog? Okay? So baby gates, crates and things like that are really useful kind of pieces of guidance for people. So there may be a lot of people who are listening or watching this podcast today, and they have motor neurone disease, and they also have dogs at home, or other pets as their MND progresses and their symptoms get worse, are there any ways that they can adapt to having their dog? Perhaps special harnesses for walking, or making sure you've got a neighbour or a friend on hand, or perhaps even inquiring about a dog walker to come and make sure your dog is exercised well?

Lizzie
Yeah, absolutely, yeah. I mean, your dog is part of your family, and you, you know, you have to consider how they're going to fit into, you know, what, effectively, is a very new sort of part of your life. I think the most important thing is, is making sure that you're, you're considering the dog's needs and feelings, along with everything that's changing. Obviously, dogs, you know, they're not all used to high powered electric wheelchairs and big hoists and things. So introducing, you know, those things carefully try and make experiences as positive as you can with with lots of treat treats and encouragement. Again, we spoke before about making sure the dog has a safe place to retreat to if as and when they need to. You know, dogs can walk alongside mobility scooters and wheelchairs and things. It's something you can do. You can train your dog to walk alongside your wheelchair. It just takes a little bit of time, and you probably will need some some help to do that. So if you've got friends and family who can, you know, help you and come, come in and do a little bit of training with you, then that's that's going to help a lot. But reaching out, yeah, as you said things, there are so many dogs, it's important to make sure you've got friends, family, neighbours, who are who on hand to either help walk and exercise your dog or help you do some training with your dog. There's no reason why your dog can't come out with you and your and your wheelchair. It's just all in the training and making everything sort of positive for them. But there are times, obviously, when you're really busy, you know, there is not time to walk your dog, and that's when, you know, dog walking services can come in. There are plenty of people out there now who who do dog walking, and that will take some of the pressure off as well. You know, it's just one less thing to worry about. If you know, you've got someone else who can take your dog out for you. So there are plenty of people who can help you. It's just making sure you reach out to them definitely.

Domonique

And, like you said, making sure that your dog's needs are looked after as well, and maybe taking some of that pressure off by, you know, using external support and the Association, we have financial support grants that can help towards behavioural training, to teach people, to teach dogs how to walk with a wheelchair, to help with dog walkers, costs of that, and also to help with travel for family and friends, if they are coming to walk your dog for you, or help you train your dog with a new piece of equipment. So that's really helpful advice. Thank you. So say your MND is progressing very rapidly, and you've you're starting to have trouble managing your dog or your pet at home. What kind of support might be out there for people who are looking to potentially rehome their dog?

Lizzie
So here at Wood Green, we have something we call the pet promise. So that is a scheme that you can sign up for whereby, if you become sort of terminally ill, if you go into care, if you pass away, we will take your dog and care for them, and, you know, potentially re home them. So if you sign up for that scheme, you've got that peace of mind that if something the worst happens, Wood Green will step in and care for your dog for you. So that's a really good scheme. And just again is that little bit of takes that little bit of pressure off and gives you that peace of mind that your dog will be okay.

Domonique
Yeah, it's really important. Dogs are part of the family, aren't they, so it's good to know that if anything were to happen to you, you do have that support from Wood Green as well. So yeah, thank you. Looking back now, do you think Betty had an understanding of Chris's condition?

Lizzie
She's always been Yeah, Betty has always been incredibly intuitive. She always seems to go to the person who needs her most. So she would on his on bad day, she would go to him, and she would, you know, climb up and sit on him, and he couldn't stroke her or do anything, really, but she would, you know, happily lie on his lap and just accept that, you know, he couldn't stroke her, but that was okay, and I think she did. She for a long time. You know, she sort of took care of him, and when he passed, she slept on my daughter's bed for about a year, every night she would go and sleep with my daughter and with me. Then the night that we lost him, she never slept on my bed, but she knew that I needed her, and she, yeah, she came and stayed with me. And dogs do have an amazing ability to. To know what you need and to recognise who needs them the most they are. You know, such a fantastic kind of outlet for for those people who are really struggling mentally, they give you companionship. And just having something there to stroke, something there to sort of release some endorphins, can be so, so important in tough times.

Domonique
Yeah, I think that's so true. They are so intuitive, aren't they almost emotionally intelligent, if someone was watching or listening to this podcast today and they have motor neuron disease, or they care for someone with MND, what considerations would you encourage them to think about if they were wanting to adopt a dog, you know, if they had limited mobility and things like that. Is there anything in particular you would encourage them to think about or particular dog breeds that would be best for those kinds of conditions.

Lizzie
I think if you're considering getting a dog and you do have someone in your home with mobility issues or or MND, specifically, it's important to get a dog with the right temperament. You don't want a dog who's going to be bouncing off the walls and causing more trouble for you. You know a dog that is calm and relaxed, breeds like your retrievers, for example, who you know, we see being used as guide dogs and assistance dogs. They're great because they have a really lovely temperament, they're intelligent

and they're really trainable. So they, you know, they have all the qualities that you're you're looking for. Getting a dog who is not going to be tiny and under your feet is probably quite a key, a key consideration, but you don't want to give yourself more more work than is necessary. So, you know, make sure you're getting a dog that's actually going to enhance your life and the MND sufferers life. A dog that's going to give you what you're looking for is really, really key.

Domonique
Obviously you We're here today because you recently or last year, you helped re home a dog to David Lawrence and his family. Can you tell me a little bit about some of the kind of adjustments and adaptations you made to that rehoming process? Did you have to do things a little bit differently taking into consideration David's condition?

Lizzie
Yeah, so with the Lawrence family, David sadly wasn't able to travel to us, for, you know, obvious reasons, so we used fantastic technology and did a rehoming chat over zoom, and that gave me the ability to talk to all of them, and including David, and get you know his thoughts and his opinions on on what he wanted for his family. It was very important to him that the dog was not just for him, but also for Gaynor. He wanted her to have that, that companionship when he was no longer there. And yes, so we, we did the the initial chat over zoom Gaynor came up and did the important meeting of the dog and the vetting to make sure it was the right dog for them. And then we took the dog to them, and them. It's something that was quite important to me, to you know, to see Dave, meet the dog for the first time. And yeah, we went on a little day trip down to their house, introduced them. It went amazingly well. I think Bailey, the dog, was snuggled on the bed with Dave within sort of 10 minutes of us being there. And yeah, they they really, really appreciated, you know, that that kind of adaptations we made to help them get what they needed. And it was a brilliant success.

Domonique
I'm so pleased to hear that. And I think there's for you personally with that connection to MND. Did you find that you were, you know, even more invested than normal to try and make sure, you know, considerations were put into place in terms of how the dog's temperament was and things like that, how the dog might feel around the home with with, obviously motor neurone disease equipment and things like that, delivering the dog and seeing the bond between David and the dog straight away. Bailey, how did that feel for you?

Lizzie
Yeah, it was really important to me to do this rehoming for Gaynor and David, having been through what they were going through. I think I had that understanding, you know, with MND, I think a lot you get a lot of sympathy from from everyone you meet, but nobody truly understands. And I did understand, and I felt that that was really important to them, as well as to me, that we were on the same page, we were on the same wavelength, then they could trust that I knew what they needed. And it helped obviously, as you say, knowing how difficult it was for me and everything, all the equipment and everything that you went through, I wasn't going to match them with a dog that wouldn't cope with that, so it helped me to find them that right dog. And they, you know, they put their trust in me to do that. And that was really special. And it's such a it's such an awful disease. There is so little anyone can do so to be able to give them just that little bit of sort of ray of sunshine, I suppose, in a very dark place. Then you know that was really, really important. And yeah, I felt very privileged to be able to do that.

Domonique
Thank you for sharing that. And you're right, it is such a beautiful gift to be able to help someone bring to life, isn't it, to have that dog come home and, like you said, be a ray of sunshine in some really

difficult and dark times. We've mentioned about kind of the various equipment that people with MND need in the home, and all the additional visits that you have as well, and also how it can be a very isolating experience. Can you tell me a bit about some of the support that you received from the MND Association during Chris's Motor Neurone Disease.

Lizzie
Yeah, the MND Association were fantastic during during Chris's time with the disease. There is so much information on their website and support available. We sadly went through motor neurone disease during lockdown. So two lockdowns make something that's already incredibly isolating, so so much worse, and that was really hard. But our local sort of MND worker, I suppose, she was always in touch. She kept in touch. She really helped me with looking for things for the children as well, sort of trying to explain and support the children what was going on and also support the children. And just having someone there in the background who rings you up every few months just to check you're okay. Was, you know, invaluable, really, I think again, there is with a terminal diagnosis, there is not that much that you can do, but the MND helped fund various things for us. You know, they were really, really sort of key to us getting through what was it really terrible, terrible time of our lives? So, yeah, wouldn't, wouldn't have been the same without you guys.

Domonique
Of course. Thank you. When you care for someone with MND, as you'll know, your life essentially revolves around them, their medication, their appointments, their general care, their wellbeing. When you lose that person, there's, you know, a massive hole in your routine and your structure to your day. However, having someone like Betty around or Bumblebee around, did you find that helped fill some of those, those kind of moments of of missing Chris?

Lizzie
Absolutely dogs. Yeah, the dogs didn't just provide help during Chris's time with MND, but after even more so having them around, you know, it gives you purpose. Obviously, I have my two daughters as well. So, you know, you have to keep going for them, but to have that daily routine of, you know, I have to get up, have to feed the dogs, have to walk the dogs, I have to do these things. And the distraction as well. The process of losing someone is, I don't think, and led to you've been through it. You can't believe or understand how, how awful it is. And with MND, I think you saw grieving from the day you get the diagnosis, so almost losing him. Then I guess there was an element of relief there that, you know it was over for him, and we, you know, we were out the other side, but so, so difficult. It's a whole other set of emotions and feelings that you you're now being flooded with. And the dogs for me are, you know, they're my world. They are my life, and I love them. You know, just like my children, they are my family. And, yeah, it's really, really important that they were there for me.

Domonique
Yeah, it sounds like they really, like you said, kind of filled that, filled that hole on those, those big moments of grief by just giving you that unconditional love and you knowing that they were there, basically, you know, tails wagging ready to sit on your lap at a moment's notice. Obviously you understand that we've updated our branding this year. One of our core values is kind of everyday matters when you're living with something like Motor Neurone Disease, every day matters. In your own way. Can you tell me how every day matters? What that means to you?

Lizzie
Every day definitely does matter. Your time with someone can be incredibly short. From the point of getting a diagnosis, you realise that life is, you know, one day it's here and the next, you know, it can be taken away with from you. So for me, now, I am definitely a different person. I do live every day, you

know, as as it comes, but I also am very, very aware that I'm very lucky to to have the life I do, and I think we need to just embrace life and enjoy life and do the things that make us happy. There's so many things that just aren't important when you're faced with a terminal illness. And yeah, I live a different life now, but it's a good life.

Domonique
Yeah, brilliant. I'm so happy for you. And just to round us up today, for anyone watching or listening to this podcast, if they're at the start of their kind of MND journey, if you will, what advice would you give to them?

Lizzie
Reach out if you are starting a journey and you feel completely lost and isolated. That is normal, but please reach out to the MND Association. Reach out to your friends, your family support groups. There are people out there, like myself who have been through it. You're not alone. It's really, really hard. Don't be too hard on yourself for having bad days caring for someone who you love, it completely changes your relationship. And that, in itself, is, is a very difficult thing to navigate. So give yourself a break. You know you are you can't care for someone if you're not caring for yourself. So looking after yourself is is so important, and if that means getting yourself a little doggy companion, then I can't recommend it any more. Yeah, it you know, dogs are amazing.