

MND Matters: Episode 19: Travelling with MND

Intro:

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

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Welcome to MND Matters, brought to you by the MND Association sponsored by Toyota GB and Toyota Financial Services. I'm Steph from the care team, and today we're going to talk about travelling with MND. I'm joined by Ken Blackburn who's living with MND, and he has a vlog on YouTube called [Life After Wheels](#) about his travels in his all terrain wheelchair. I'm also joined by Antonia Lee-Bapty, the managing director of [Euan's Guide](#), the disabled access review site. Ken, can you tell us a bit more about when you were diagnosed with MND and how it affects you?

Ken

Hi, I'm Ken. I'm now 64 years of age but still feel like I'm in my 30s until I tried to do anything and then I feel about 90. I was diagnosed with PLS, a rare form of MND in October 2020 after five years of slowly worsening symptoms. The first sign was having speech problems they get first but gradually becoming a real issue. I worked as a taxi driver, but in the end, I couldn't use the radio or telephone and speaking to passengers was difficult. I left my job in 2019 after 23 years, I now have telephobia which causes me anxiety when my phone rings, so I won't answer it. After many appointments with my GP, he finally referred me to a neurologist for investigations. This in itself led to three years of appointments and tests, all of which proved to be inconclusive. I saw three different neurologists in that time. In the meantime, one day I was out for a walk with my wife, I turned around and fell. I couldn't understand why. I noticed my legs were tiring, quicker. I used to go running. But as time went by, I got noticeably slower. Then I started to have falls in and around the house. My current situation is this, I can still just about talk to people face to face. But I use a text to speech app for my vlog videos. And for speaking to you today. I can't walk without holding on to something even indoors where I rely on a rollator to get around. When I'm out and about I use my All Terrain power chair. I feel lucky to still have the use of my arms and don't have any real issues around eating and breathing yet. There's one thing that's really annoying. Any sudden loud noise makes me jump. I've lost count of the number of cups of coffee I've ended up wearing while watching TV. I don't feel like things have declined for quite a while. And I put that down to my positive attitude and determination. Long may it last!

Steph

Thank you, Ken, thank you so much for sharing. And yeah, you definitely have that positive attitudes coming across.

Ken

Yeah.

Steph

Fabulous. And yeah, it's really good to hear about you're getting out in your all terrain wheelchair. Antonia, tell us a bit more about Euan's Guide and how that works and how it may support someone like Ken who's living with MND?

Antonia

Absolutely, so Euan's guide is the award winning disabled access charity. We're best known for our disabled access review website, which is Euansguide.com. People often compare this to a TripAdvisor or a Trust Pilot but concentrating on disabled access. We also make 10s of 1000s of accessible toilet safer and run the UK's largest and longest running access serving. So today I'm going to be focusing on the website and how you can find and share disabled access information. But before I do, I want to give you a little background about Euan if that was okay, who is the founder and who had the idea for the website. So Euan is based here in Edinburgh, he loves watching live sport going to gigs socialising with pals, including the dram of whiskey. And he became a wheelchair user then a power chair user due to motor neurone disease and was constantly frustrated at not being able to find reliable, disabled access to information before he went to new places. And there's two memorable examples. The first he got invited to an outdoor music festival. And he was really pretty nervous at going thinking mud, wheelchair wheels, this is going to be a disaster. But actually he had a fantastic time and really wanted to tell other people about it. And then later that month, he got invited to a concert in Glasgow, and he had tickets for an accessible seating area. And then when he got there, they offered to carry him and his power chair upstairs. So when he said no thank you, they actually offered they actually paid him to go away. And both of these he'd really liked to have known about in advance because it would have taken anxiety out of the situation or maybe he would have decided not to go. So we came up with the idea of Euan's Guide as he wanted to share his experiences and also learn from other people. And fast forward to the present day Euan's Guide, the website is going to be 10 next year. And Euan's a pretty interesting chap anyway, and this is not the first great idea he's had. Some of the other people listening to this might know him, because he's also set up the Euan McDonald center for motor neuron disease research in conjunction with the University of Edinburgh. And he's also came up with the idea for speak unique, which is voice banking solution for different speech needs. But back to the website, Euan's Guide is very much designed as a positive place to find disabled access information written by disabled people, friends, families and carers. And we mainly feature UK content, but we love it when reviewers go on holiday and they send in reviews from their travels abroad too.

Steph

Fabulous thank you sounds like it definitely does quite a lot which is amazing. Ken how has MND made getting out and about more difficult for you?

Ken

Well, coinciding with the first pandemic lockdown, I found my mobility suffered a great deal. Beforehand, I could walk a reasonable distance with my rollator for support. I bought an off road one which allowed me to go on rougher ground and a standard one. I could manage about a kilometer at that time, albeit very slowly. Because we didn't go anywhere for a long time, I found that the distance I could manage dropped off badly. For that reason other than visiting other people's houses, we didn't really go anywhere. My pre MND plans to do landscape photography in retirement had been shattered. The thought of being in a wheelchair after leading such an active life was equally depressing.

Eventually, I started looking at options and found there was a confusing array of wheelchairs, I discovered the All Terrain Models and was amazed at where they could take me, maybe I could still enjoy an outdoor life. After a lot of soul searching with the support of my wife, we decided I should get one. They are very expensive. And in addition to that, we had to get a new vehicle to carry it. Luckily, I can still drive. So we needed an internal transfer vehicle so that I can go out independently since my wife still works full time.

Steph

Thank you. Thank you, Ken, I'm glad you're managing to get out now and, and enjoy some of that outside world that you like, you know, being in the outdoors. There's nothing quite like it when the weather's coming to us anyway. And Antonia, what are some of the access needs disabled people have and what can venues do to be more accessible? Obviously, Ken talking about getting out into the outdoors. But obviously, that still encompasses some venues that you may need to go within that travel as well or, you know, things like, you know, accessible toilets and so on. So yeah, what, what can venues do to be more accessible?

Antonia

That's a big question. So first of all, I suppose it's important to say that everybody's needs are different, everybody's requirements are different. That's why people sharing their own experiences is so valuable. So our users tell us that the most important thing to them are accessible loos, accessible parking, general access in terms of getting in and getting around. And then most importantly, staff. So we regularly get told you can have the most accessible venue. But if staff don't know how to use the platform lift, or they don't know where the ramp is kept, and how to deploy it, then it can all fall apart. But also that venues that maybe are not the most accessible, if they have fantastic staff, they can overcome a lot of their access challenges. So those are the things really that we asked reviewers to comment on. And I guess the beauty of Euan's Guide Is that you can talk about what's important to you. We also find that pictures do really tell 1000 words. So particularly, I suppose if it comes to, for example, toilets, or bathrooms. So with a photo, you can see the size and the layout of an accessible loo you can see what side the transfer spaces, you can and then for wet room, you can see some of the detail and get an idea whether it's going to be suitable for you. And it's really interesting, Ken, what you were saying about COVID. So we find a lot of our users telling us that things have changed since the start of the pandemic and then haven't changed back. So for example, routes in and around venues, you know where you used to be able to go in and out of any door. Now maybe one door is the entrance, one door is the exit and maybe both of them are not accessible. So things like that have changed. Signage has changed. And it's also really interesting to hear you talking about the outside as well. We've had loads more reviews of outdoor places since the start of COVID. And I think again, that people sometimes think that Euan's Guide is just about the fun stuff. So hotel hotels, bars, restaurants. But it's also really important to say that people can review anywhere, everyday essentials such as post offices, supermarkets, outdoor parks, outdoor spaces. And we've even had somebody review the, the crossing at Abbey Road where the Beatles famously walked across. So anywhere where you can put a pin in the map. Another thing that our users tell us is that they want to find information when they're out and about, so that enables people to be more spontaneous. So if you're going to visit you in York Ken, we can have a look at nearby cafes, restaurants, things to do. And yeah, we know that over 60% of our users use Euan's Guide on a smartphone. So that shows that people are using it for planning before

they go. But also really, in the moment. When people review, if they wish, they can talk about what equipment they use. So for example, a wheelchair user or power chair user can say that if they wish, and it's optional, but we regularly get told that just one review from somebody with similar access requirements can give somebody the confidence to visit somewhere new. And we also recognise the importance of providing the information in an accessible format in the first place. So we know that a lot of our users use assistive technology. Euan for example, uses a Tobii eye gaze. So the some features that are built in for users of assistive technology and Euan in particular, on when we were putting together the website for the first time, he said that he found the controls on Google Maps, very inaccessible because they were so small. So for example, we've got larger map buttons to help navigate around a map. And one of the things that's on our priority list is looking at different ways to review. And Ken, I am definitely going to be in touch with you after this to talk about video reviewing. I suppose in terms of now moving on to the venue side of it, we find it's really important that venues talk about what they have got, and also what they haven't got. So that's the most important thing. The next is to listen to your visitors, customers or guests. So every review that's submitted to Euan's Guide, we pass on to the venue. So it's a way for people to submit their feedback to venues as well. And we find that venues do make changes. So we've had venues that have changed signage, we've had venues that have stopped using their accessible loo to store 252 toilet rolls in it, or Henry the Hoover. We've had all sorts of venues that have told us that they've made changes based on feedback from Euan's Guide users, which is fantastic.

Steph

Brilliant. And yeah, I'm telling you, thank you for explaining some of the, you know the feedback that you get about venues or places that people go and the experiences that they have and things that can obviously positive ones or things that you can make better. But obviously I imagine, Ken, that when you do decide to take a trip somewhere, there's a lot of preparation involved. And can you talk us through a bit of what that planning involves?

Ken

Yeah. I try to do as much homework on where I'm going as possible, particularly parking. Having a ramp means I have to be careful where I park. I'm always worried in case someone blocks me in despite the stickers asking for space. For my vlog outings, pre planning is essential. I don't want to drive anywhere only to find out that it isn't accessible. I normally look for information online. There is some really useful stuff on the internet, particularly in places like national parks where a lot of work has been done to allow wheelchair access, for instance, the miles without styles initiative, which is invaluable. And I've now been introduced to Euan's Guide so using the reviews to see what other people have experienced is great. I'll be adding my own reviews for sure. I use Ordnance Survey maps on my phone to see exactly where I am and what 3 words is a real lifesaver, especially if you have to tell anyone where you are. Other than that it's the normal stuff to ensure you're protected from the weather etc. If I'm going on my own, I take drinks and food. I still have difficulty accessing cafes, particularly where self service is involved which most seem to be these days. It's also rare to find one which has enough room to maneuver a power chair without someone with you to help.

Steph

Thank you Ken and um, yeah, I'm sure that there'll be lots of similar reviews on Euan's Guide from from places as well but hopefully you'll find some more positive reviews for places that maybe you haven't ventured to yet and be able to go to them and obviously as the other the other side of things in terms of like the equipment that you may need, which you touched upon there, but I know you recently received a support grant from the MND Association. So can you tell us a bit more about how that's helped you to continue to get out and about.

Ken

I was so grateful to the MND Association for giving me a support grant. It was used to help fund the advance lease payment for my new vehicle. I approached a charity run by my previous employers, and they approached the MNDA on my behalf, as well as providing me with additional financial help, I will always be truly grateful. I decided to start my life after wheels vlog as a way to hopefully show others in my position that living an active outdoor life doesn't end just because you are confined to a wheelchair. I am also using it to raise awareness of MND and hopefully in turn raise funds for the Association.

Steph

Thank you, Ken, we're really grateful for your support. And I'm sure you'll have lots of followers after hearing this podcast and lots of you know, lots of people will get their own support from seeing what you've shared on there as well. And, you know, you've expressed it, you're really grateful for the grant. And that's obviously what we're there for. We're glad to be able to help in that way. But in terms of what it means to you to be able to continue to go on these days out, can you can you let us know what it means to you to be able to continue to do that.

Ken

Hmm. Before having MND, I love being outdoors going for long country walks. I used to take my camera and follow my passion for landscape photography. I soon realised that I wasn't going to be able to carry on. In April 2019 Kay and I did our last big walk together climbing Goat Fell on the Isle of Aaron. It was tough. After my diagnosis, although I didn't admit it, my mental health suffered. I often woke up in the middle of the night in a state of panic. I needed to get out and breathe fresh air. Of course, lockdown didn't help. Once I had my power chair and vehicle, things started to change. I started looking to the future, making plans for outings, my mental health became much better. And although I rarely sleep well, I don't suffer panic attacks like I did before. I've been to quite a lot of the places I love the coast Rosedale in the North York Moors, and only this weekend, we visited Bremen rocks, an interesting area owned by the National Trust. With the right equipment, I've really found a renewed zest for life. I never really thought about how going out can provide such a boost to wellbeing. As long as I'm physically able, I'll be getting out and making my short videos. I really do hope that other sufferers of this awful disease can find a way to enjoy getting mobile again and live life to the full.

Steph

Thank you, Ken, thank you for being so open and sharing. And I'm really glad you're getting to enjoy some of your passions again, by getting out there and enjoying the outside and exploring countryside and coast and yeah, just is wonderful thing to do. So glad you're able to do that again. You've talked a bit about other people live with MND as well and hoping that your vlog inspires them to do the things

that help with their well being. But what sort of advice would you give to other people living with MND, who are wanting to plan a trip themselves?

Ken

My only advice would be whatever your individual needs may be to check out the accessibility at your destination, be it parking, toilets, hotel rooms, etc. I have found out just how many variables there can be the weather claims of accessibility, which can hide a multitude of differences. Be prepared to ask for details which are important to you as an individual. We are all different. So there is no such thing as one size fits all. If you don't have a suitable wheelchair for rougher ground, or don't have the vehicle to carry one, check out whether there is a mobility scooter available to borrow or hire. A lot of places now have such equipment. Booking is normally required. So check before you go. Above all, if at all possible, keep doing the things that give you pleasure. Never give up.

Steph

Thank you can really inspirational as well. And really good advice for people wanting to plan their own trips. And obviously now that you're aware of Euan's Guide, then presumably that's somewhere that you take a look before you plan your next one. And I think there'd be lots of valuable information on there in terms of people using that website, Antonia, do you have any tips for people living with MND, when they're going on there? What sort of things that you should be looking for what they should be searching?

Antonia

First of all, I just like to echo everything that Ken said about preparation and about finding as much information before you go as you can. We run an access survey every year. And I can't remember the exact percentage off the top of my head. But it's a vast majority of people won't actually go somewhere unless they can find out access information in advance because they presume it's not accessible. And there's another good stat about people not traveling to places when they don't know there's an accessible toilet there that's going to be suitable. for them as well, they just won't go. So. So yeah, in terms of tips for people, when using Euan's Guide website, as Ken said, again, everybody's different. So everybody uses it slightly differently. But I chatted Euan about how he in particular uses Euan's uGuide. And, and he gave me an example of traveling to London for a sports fixture. And now you in loves his sport loves his life music, love socializing loves the odd dram of whiskey. So he was talking about how, before he bought tickets, at this venue, he checked out what people had said about the venue where the accessible viewing area was and whether you could actually see the game on what was going on from there. He then looked for accommodation. And we all know how rare accommodation is with the hoist and a decent wet room. So once he found accommodation that is going to be suitable, he booked the tickets, and he booked that accommodation. And then near the time of his trip, he started planning other activities. So on Euan's Guide, he found a theater that had been reviewed by a changing places user. So he was confident that that would meet his needs. He also looked at reviews of pubs and restaurants that had been written by other power chair users, and ended up booking somewhere after he'd read a review that said that somebody visited a venue with three power chair users in their group, and that they'd had a great time. So he figured that would work well. After he visits he then reviews the places that he thinks are great, and sometimes asks his PA to do that too, because often they have slightly different ideas on that access and have different insights.

When I was talking about this earlier, another colleague who is power chair user wanted me to share that they went to Amsterdam based on the strength of a collection of reviews on Euan's Guide. So that was definitely one of our success stories. And he said to say if the reviewer was listening to say a big thank you. And I know there'll be some people listening today, that may go on to have a look at Euan's Guide. And maybe disappointed that there's not enough content in that area. So hopefully, I would say to people that are disappointed with the amount of content in the area, please go and review a couple of places tell people about a couple of your favorites. If somebody comes to your area, they know a couple of great places they can go. And we find that once somebody starts reviewing in their area, people tend to start submitting more content and it becomes a really rich source of knowledge. I mean, Euan's Guide really works best if people if more people use it and the more content is submitted, the more useful it becomes.

Steph

Absolutely, that makes complete sense. I'm sure we'll have lots of listeners who are who are happy to contribute and share their experiences as well. We also spoke to some of our MND community and we ask them their top tips for travel as well. So hopefully, there'll be adding those to Euan's Guide. But we had Di who sent us a couple of links to websites where you can find toilets and accessible countryside locations. And we also had Ian who mentioned booking assistance ahead of a journey on public transport particularly. So I think what this shows is that preparation is absolutely key before going on a trip or a day out for somebody living with MND. And I know obviously Ken has echoed that in what you've been saying, Antonia, you've been saying exactly the same for people that contribute to you Euan's Guide. But would you agree? Is there anything to anything that you'd want to add or? or sort of suggest to people when they're planning a trip or anything you don't think that we've already covered that people may be wanting to know?

Ken

Um yeah, toilets. Yeah, I'll just say that I tried to look for changing places facilities, because they provide much more room and tend to be laid out better. Sadly, most disabled toilets just don't have enough room for my power chair. And the layout is often bizarre. Changing places.org is a great site.

Steph

Yeah, thank you can I know some of the MND community have also mentioned changing places and I know that on Euan's Guide, there's people that have reviewed changing places toilets. Yeah, I think that is definitely something that's really important to mention for people who are going and planning the trip. I guess Antonia did you have anything that you wanted to to add?

Antonia

Em, I was just going to second , or third, the importance of toilets. You know, as a team, our phones tend to be full of pictures of toilets, we snap pictures of good ones, we snap pictures of bad ones. Toilets can really again, make or break somebody's visit. So if you if you have a venue, it might sound strange, but please just put a picture of your accessible loo up if you're talking about you're accessible or your access information.

Steph

Absolutely. Thank you. Yeah, and I think what you said about having the photo so people can really visualise and be able to see whether that is going to work from them from before them before they travel somewhere. Think the photos any photos of of any accessible venues are useful so you can really visualise where you're going and whether it's going to work for for your needs. So Perfect. So yeah, thank you both so much for for sharing your experiences, you know the information and for really just helping others to make plans when they want to travel. Think with additional support and planning, travel and going on holiday can still be made possible when you've when you're living with MND. And I think you've both shown that today. And of course, you can use the Association support as well can download our free [Getting around guide](#), you can apply for grant as Ken did, you can call the MND Connect helpline for guidance. You could also check out Ken's blogs for some more inspiration, just search for life after wheels on YouTube. You can also check out sites like Euan's Guide for access reviews of places around the UK. Just look for Euansguide.com Thank you again, both of you for coming to talk to us today. And for being so open and for sharing so much to the MND community who hopefully be planning their travels.

Ken

Then you from me.

Antonia

Thanks very much for having us too. And Ken It's been fantastic to meet you. I'm really looking forward to keeping in touch.

Ken

Yeah, me too.

Steph

Thank you both.

Outtro

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