

I'm not alright, Jack



**S1S4: I'm Not Alright, Jack**

**Description:** Emily Larkin tells us about how she came to set up Invisible Disability Ireland and chats about her experiences of daily life with a hidden disability. Later in the episode, Sarah chats to Emer Dennehy about her life following a car accident.

**Guests:** Emily Larkin and Emer Dennehy

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Hello and welcome to All Aboard TII's accessibility podcast this is a podcast about accessibility and sustainable public transport brought to you by Transport Infrastructure Ireland I'm Claire Scott and I'm joined by our All Aboard podcast host Sarah O'Donnell throughout the series we'd be hearing first-hand accounts from people who use and design public transport systems and specifically the role accessibility plays in these experiences who is this podcast for in the first instance we hope to connect with people with disabilities who use our services but also it's for anyone who is drawn to human interest stories and has a curiosity to learn more and of course we hope to attract listeners who are designers and decision makers for Transport Systems who through the podcast might get a better understanding of some of the problems and potential solutions that are out there so without further ado let's give this a go and get all aboard TII's accessibility podcast

Hey Sarah so what's the theme of this episode Hi Claire so the theme for this episode is hidden disabilities we talk firstly to the brilliant Emily Larkin campaigner and founder of Invisible Disability Ireland and then later in the program we have an in-depth conversation with Emer Dennehy archaeologist with TII about her life following a car accident.

So we're joined by Emily Larkin founder of Invisible Disability Ireland Emily you're very welcome to All Aboard TII's accessibility podcast so you found it Invisible Disability Ireland in 2019 so maybe if you could start by telling us about the organization itself and a little bit about how you came to set it up yeah it was actually set up when I looked up invisible disability charities in Ireland and there wasn't any and I was really shocked because you know as someone who has had invisible disabilities quite a long time it kind of clicked into place that was why there wasn't the awareness and the understanding around it was because there was no kind of organization advocating and explaining it yeah so I set it off back she's part of Gaisce the President's award as part of my voluntary and work that I was meant to do and then it just kind of blossomed from there I set it up as a page originally and then it just kept growing and growing and growing which was really great to see and to sit back and watch it expand that way and then it was all just about and it still is about just raising awareness on invisible disabilities and what it means and what it looks like and just challenging the narrative around disability in general because we have quite a one-dimensional perception that maybe we think disability is a certain way and it's actually pulling back on that taking a look opening it up and digging a bit deeper and what it actually means to live with a disability because the statistic goes eighty percent of all disabilities are invisible so that's a massive proportion of the disabled population who are underrepresented so it's all just about making sure that we're getting the message across and we're encouraging and helping people as much as possible very good.

I saw that on your website [invisibledisabilitiesireland.com](http://invisibledisabilitiesireland.com) that you have a page with testimonies and stories from people and it really kind of shows the kind of diverse range of hidden disabilities so maybe for people who wouldn't be aware like what would you know what's the kind of broad spectrum of what is hidden disabilities you

know that's exactly that it's a spectrum so you have people with mild moderate severe you know if people with visual impairments with them and intellectual disability with a physical disability with chronic illness it's so broad and diverse and I think that's one thing we really underestimate or don't see a lot of the time because a lot of those conditions are hidden and so someone with dyslexia or depression or fibromyalgia you wouldn't see that so I think it's very it's very much opening up people's eyes and showing how incredibly diverse the community is and disability looks like different things for different people two people can have the same disabilities and have completely different experiences and symptoms so I think it's always important to highlight that although we have similar experiences they're not all the same yeah and in terms of kind of feedback that you're hearing and like how from the very fact that these disabilities are hidden or you know that how is that then manifesting in kind of negative ways first of all say on public transport or in society generally yeah I think transport is one of the areas that is a massive barrier you know people have to get to hospital appointments people have to go to you know school to access education they have to go to all work to access employment so transport does kind of underpin a lot of those rights and that people with disabilities need access to and I think there's been a lot of brilliant work done over the years but I think maybe where we fell down was in hidden disabilities yeah and I commuted to college for four years so it was bus in and bus out again and it really opened up my eyes to how sometimes it's just not accessible for people with hidden conditions and there were moments where I really did struggle and accessing transport and that's kind of where I know I'll talk about it a bit later about the campaign for please offer me a seat came from yeah and was that campaign initiated through Invisible Disabilities Ireland I always say it started with one email one very simple email I emailed them off the cuff and said listen you know I work for invisible disability Ireland and I have a hidden condition and I'm really struggling with public transport because I used to commute during rush hour and as we know you know the buses are crammed you're waiting a long time you're standing for up to an hour whatever it is and so it was really difficult for me with someone with a hidden condition mine being you know rheumatoid arthritis and fibromyalgia I look perfectly healthy and normal so you know it was very awkward kind of maybe sitting in the high priority seating area and people kind of giving you funny looks and you feeling guilty and it was such a perpetual cycle of all of those things.

I emailed them and said listen there was a pilot scheme done for Transport For London a few years ago and it's a blue badge and it was the please offer me a seat and I said you know would you be interested in this being replicated in Ireland and then I got the email back a few days later and they were they were all on board they were and that came from the National Transport Authority yeah that was the NTA yeah so they were brilliant yeah brilliant and do you find then in practice that people are starting to slowly become more aware of it and that it has a positive effect it actually like on the bus or yeah like my friends have seen the badges and stuff and they're like they always text me yeah and I was part of the campaign so my face was on the posters and it was really cool I was on the Dart the other day and like seeing the posters it's like wow you know that's so cool like it's something so small but you know someone's bored on the Dart and they're looking and they say hidden disability okay and you know it gets them thinking so even just 10 seconds looking

at that poster they've thought about something they maybe haven't thought about before and then the badge just brings so much help and understanding and people go oh yeah I never thought about it like that you know generally when I open up the conversation people are always very open about it and they say well actually I've never really thought of it like that before and people are very open and understanding to it which is which is brilliant so it's just a matter of providing that education and understanding and support yeah and of course it's kind of the more it's used the more people become aware of that and the you know the better it's applied yeah and then just for people who mightn't be aware how does it compare to the just a minute card the jam card and the yeah so jam card is for people maybe with maybe intellectual disabilities or you know there's lots of different reasons why people use them they might get flustered or they might need just a moment so that's what it's for it's just a minute and it gives people that time if they maybe have a language barrier or if they're feeling you know flustered or they can't find something and they need to just take a minute exactly so I think it's a brilliant initiative it gives people that that stop and gap in that breathing space to just present the cards because people are trained and knowing what it is yeah they're able to give them the time they need and then they can go about their day so I think it has a really positive knock-on effect for everyone involved very good

You're involved in other kind of Co or Associated campaigns and I saw that you know you're endorsing priority seating and all of that tell us a little bit about some of those kind of associated areas for your yeah fighting the good fight always and yeah like transport like I was saying it's such a massive part so it's letting people know that the high priority area is for people with hidden disabilities and I think it is so misleading you look at the sign it's a lady who's pregnant it's a you know maybe an old man with a walking stick and something else you know so you're looking at the sign you're going oh that doesn't really represent me and there is that guilt and I've talked to a lot of people about the guilt of sitting down and then you know the old lady or man hobbles on the bus and yeah they're kind of going oh my goodness I really need this seat I'm in so much pain today I really can't stand and it is that inherent guilt that you feel and it's trying to say to people like you are just as deserving yeah of that seat as someone else you know and that's because of the way that it's structured the seating that you know in an ideal world every everyone would have a seat but you know sometimes there isn't so it's making sure that you have enough accessible seating it's the same with them you know the prams and versus the wheelchairs that's always a really big issue it was more so on the older buses I think now there's a lot more space but its awful to pit one against another yeah they're the same but different yes they have wheels they have four wheels but completely different both deserving of the space so it's about rearranging that space and I think I've seen that a lot more with the newer fleet yeah you see that there's more space so I think we are becoming a little bit more aware and we are moving towards that which is brilliant yeah and in terms of kind of public etiquette are there other things that maybe people could learn or you know in terms of transport etiquette generally.

I think Ireland is quite good we you know we say thank you to the bus driver yeah get off the bus and I think people are good at saying oh do you want my seat no you're all right thanks very much I think people are quite good but when it's wet and it's cold and it's dark and it's winter and you've had a long day at work the last thing

you want to be doing is giving nobody's making eye contact and you know keep those earphones in yeah so it's always just remembering that yeah if you can offer the seat and that's why the badge and the card is so helpful because it's that hint and yeah you know I have a hidden condition would you mind and yeah people generally are very good once they know exactly you know yeah and just in terms of other initiatives that you support your the sunflower lanyard scheme and all of that and the priority passes and seating it at stadiums and things like that do you want to chat about that sure yeah well first on the sunflower lanyard it's I always say it's just a hint it's just a little helpful hint that this person has a hidden condition and it actually started off in an airport so once again accessing transport yeah and we started off an airport in the UK and it's been kind of brought over to Ireland so we're still quite slow on the rollout of it but it is there I've seen people in Ireland use it and the feedback is always really good so it won't fix everything and you know if I forget to wear my lanyard you know what can you do I still have a hidden condition I just maybe can't outwardly show it so I think it's a great way of subtly showing to people that this is why maybe like they're accessing a stadium they're accessing different seating or things because we were in Disneyland a few years ago me and my best friend and you know I can't stand in queue's for long periods of time so we had a priority pass yeah and it is kind of funny when you would you know walk up to the queue and skip it and other people are going hang on a second you know and they're trying to piece together and getting irate yeah you're going to look and maybe having the lanyard there people might say oh absolutely so it's just that subtle hint and like people think of it as a luxury like oh you get front row seats at the stadium and you get to skip the queues in Disneyland but I I wouldn't be able to go and do these things and access these things at all if it wasn't for those so I think it's always important to highlight while they're great and it's great to skip the queues and Etc yeah I literally would not be able to go and access these things so it's nothing people know those resources are there if they need them yeah and that it's okay to need them and use it absolutely yeah and I mean it's so interesting to think of the behaviour of people in queues and crowds like people can get very unlike say maybe as we were saying on a bus or a tram or whatever people are open to helping maybe but when as soon as you put people in the queue yeah they get very cross at things yeah and so and just in terms of say I thought that you were doing a lot of other campaigning around you know say during covid delays to procedures and all of that yeah like aside from public transport what are the what other areas are you campaigning for I think health is a massive one you know I think every Health Service in in the world is struggling with post-pandemic the impacts that covid has had and then if you look at you know we all know the waiting list the trolley crises that come and go delays to surgery I've definitely been there so I think that's a massive thing because then you know if you're not accessing say a service early on when you can intervene it's going to become worse it ends up being more expensive you need more intervention more funding so it's all about that early intervention get getting people into clinics or into hospital when they need it getting their surgeries and giving them the best quality of life yeah and I think that's something Ireland really struggles with is getting people into Hospital on time giving them that care they need and going home because I've been both having arthritis and a heart condition it's kind of slow and fast you know if it's polar opposites where we're through mythology you could be waiting months for an appointment and you're kind of bottom of the wrung yeah versus being a heart patient where you're

rushed into ambulance and you're the first person they see yeah so I've experienced both ends up you know maybe pain management or maybe you know just by best intentions that that you know the kind of pain management is oh chronic pain chronic fatigue those conditions are definitely pushed in pushed and it's really interesting the research that has come out that it's young women who are predominantly affected by misdiagnoses and gaslighting so conditions like fibromyalgia so pain conditions endometriosis they predominantly affect women yeah and young women and so they often wait it's something like six to ten years is kind of the time frame they wait to get diagnosed so there's massive issues there around chronic pain conditions and in young women getting them diagnosed and getting them the help they need and is there any research to suggest as to why that might be or why I think it's a number of factors there's no x-ray or blood test for fatigue or for pain unfortunately yeah so those conditions are a little bit harder to diagnose and and therefore doctors you know when you're young and you're healthy or you're a young woman and doctors are saying there's nothing wrong with you yeah and so I think there's a lot of factors but those would be the main ones that I have seen and but I think with more awareness I think people are a lot more aware about these things and we're working towards them you look at the big you know campaign on menopause that's been really big in the last few years so I think things are slowly starting to come you know come up come up and get better so and I know that on the Luas Finglas extension that we're doing we're doing an awful lot of work on designing through a gender lens and traveling in a woman's shoes and all of that but I suppose you know looking at who's using the space and why they might be using it and why they might not be using it initially kind of from safety point of view but then you're trying to kind of get a universality out of it so a lot of what we're looking at on Finglas would be resting places you know where you're walking up hills and of course it benefits everybody and just trying to make space is usable by everybody including maybe women who wouldn't be traditionally using them yeah because I think I saw it was at South Korea they have women only carriages on their underground.

I thought that was really fascinating and they loved it so it's interesting that you say that that it's important to tailor and to change things up and to mix it around a bit and at least be thinking about it and just seeing how we can exactly and but in terms of so I suppose what we're hoping to do with this podcast is to I suppose let people know about our Light Rail and Metrolink and future projects Etc but we're also hoping that designers and decision makers within our own organization get to hear kind of a diverse range of stories and then that'll feed into yeah so from your point of view what could what could transport designers or even you know Engineers Etc learn from your group and from you yeah I think I love the phrase it's nothing about us without us I love that because like that there's no point designing a transport system and you know saying it's for people with disabilities and then suddenly you realize that the ramp isn't high enough for someone with a wheelchair to get on and then there's not enough accessible seats so I think it's so important to listen to a variety of people so it's great to be here and to share my experiences and its greatest to see people listening I think that's the most powerful thing you can do sometimes is to just listen to other people and see how you can help and so for me it's just all about it being accessible so you know when I had to get two buses it was

I was able to get off my first bus I was able to walk a relatively short distance from my joints I was able to wait you know a few minutes there was a seat there if I needed it yeah I was able to get on the second bus you know it wasn't full I could have a seat and I could put in my earphones especially for people and with ASD with autism they might find a bus very overwhelming over stimulating place so it's doing all of those things having the announcements I remember speaking to the NTA for people who are visually impaired having the yellow railings you know we've done there's so many things that are hidden in the design that you wouldn't know is accessible but it's there for people so yeah I think it's still continuing down that road because it's like we were saying earlier there's great work done but there's always more time to do yeah and like you say just good interchange you know you don't want to get off one and have to walk miles around the corner yeah it's a long wait and you know yeah because even going into St James's today I know one of the main reasons they built the National Children's Hospital was because it was the Luas and Light Rail and having access to transport so it really does underpin how we use our world how we use everything around us so it's definitely so important and I think absolutely it's come a long way it's brilliant.

So, you were saying earlier Emily that she started the campaign basically you put it together as part of a Gaisce thing so you were still at school I was while I was in college I was 19. okay the Gold Gaisce so there was the bronze the silver and then the gold very good yeah and I see that from your website as well you've done an awful lot of interviews around the International Day of Persons with Disabilities and is there a Hidden Disabilities Week did I see that sure yeah that's in October yeah so it's great to have the separate week as well as the Day celebrating it together for all people with disabilities and it's nice to have the two just to raise awareness especially when maybe it's currently so unknown or you know that you're really just beginning to and how did that go was that something that you established yourself the week or is it an international so we have that week from America that was where that stems from so they set the date every year and I just follow along yeah with it so it's January I think it was the 18th and 24th or something this year so it's great to have kind of a global week set aside for us to campaign on yeah and the messaging is always so clear because it's invisible disability week and it was really special having people share their stories on our social media this year and the theme was believe me see me yeah I think that's really important like we're talking about earlier where young women in particular are very vulnerable and doctors believing them in their pain and it can be very hard for people to look at someone when they say they're in chronic pain and to say well you look fine yeah you know you look healthy you look well so it's all about seeing beyond that and believing them yeah I thought that was something that was really good very good

So Emily you were chatting about the organization itself maybe if you'd like to just go into a little bit about your own background and how that led you to set up Invisible Disability Ireland yeah so I was originally diagnosed with rheumatoid arthritis when I was 13 years old so it happened quite quickly and I became quite unwell and then developed kind of aches and pains and then the journey to a diagnosis began and then over the years you know I developed complications



naturally I developed fibromyalgia augmentation of my muscles I've a connective tissue disease and I have a stomach condition and then I have three heart conditions and for good measure so obviously over the years I've kind of gotten sicker and so that's kind of led me to set up the organization because there was Charities that represented my heart condition and you know arthritis and stuff like that but there was nothing that represented everything yeah and what it actually meant to live with multiple chronic illnesses and disabilities and especially ones that were hidden so that's kind of where I felt the need for the organization in society and that was why I set it up and you were saying when we were chatting earlier that initially you were reluctant nearly yeah oh yeah I think anyone's reluctant to open up by such a vulnerable part of your life and especially when I was so young and but I think over the years I grew more confident in myself and my abilities and who I was as a person and so I understood like I was saying how important it was to advocate and to share my stories because it it was so important for other people to learn and understand about it so now I'm very open about it but I wasn't always and people prefer different things some people don't like to talk about it and some people do and that's okay so yeah very good and you're now a primary school teacher yeah and just in terms of the kind of the work that you're doing both as a teacher and with Invisible Disability Ireland is there an overlap are you seeing with some of the kids that you're teaching is there kind of a crossover relevance I'm sure there is yeah I mean every class has disability and I think it's so common like I was saying earlier one in seven so that's at least three children in your class minimum will have a disability and I'm very lucky to have children with disabilities and to learn from them and to watch them and to encourage them so it's been a great learning experience for me to see disability in a different perspective in an educational context so it's been it's been really great yeah I know you finding that the kind of school supports are just gradually improving over the years that people again through awareness maybe that the kind of teaching culture is just much more supportive maybe of diverse kids I think that's the two biggest things awareness and funding yeah you know and but I think yeah it's like anything it's massively improved and it still has some way to go but I think kids definitely are in a much better position than they were even 10 years ago so I think it's constantly improving and changing which is brilliant thanks to people like yourselves Emily it's been an absolute pleasure and thank you so much for your time and it's been great to talk to you and keep up the Fantastic work thank you thank you

We're joined now by Emer Dennehy archaeologist with TII so Emma you're very welcome to All Aboard TII's accessibility podcast now Emer when the podcast team put out a call out to staff to participate in this podcast you responded to say that you'd like to talk about your experiences following a car accident and I initially thought that that would make an interesting item on temporary disability but as I've discovered from talking to you since the fallout from your accident has been much more long-lasting really and it's probably more accurate to say that you're or even to look at your experience in the light of hidden disability so maybe if you just start by telling us about the circumstances of your accident when it happened how it happened Etc yeah well thanks million for having me and thanks for organizing this because I think it's quite a useful podcast and I hope this disability would I classify it you know maybe some people look or she's just a long suffering you know human

but I suppose what happened was well at the Christmas party if we go way back at the Christmas party in 2008 I actually broke my foot and it snapped dancing and I thought oh my god I thought this is the worst thing I genuinely thought that was the worst thing ever that could possibly happen to me and two days before the cast was due to come off we were driving on the M50 and there's been recent road works and they were constructing doing the new Red Cow roundabout construction works and as we came up along the Luas and a gantry collapsed on top of the car and tore the car in half yeah it was very traumatic yeah and then walked out of it got up dust my while I was on my crutches and I got out of the car and then the road was blocked and they made me sit in the car for two over two hours which was mentally not the best thing that could you ever do to someone and initially just thought I was fine and then the pains just started and my legs started swelling and obviously I was due to get my cast off the next day in the hospital anyway as it was and it couldn't find out what was being wheeled around from room to room and it turned out that I had the cast the impact of it had crushed my heel crushed my ankle I had horrendous whiplash like you know which just got worse and worse.

It turns out that the whiplash had and you know people say oh whiplash and see people going around on their collars but whiplash is actually quite serious if you have it like you know and I know a lot of people take advantage of it but it caused quite a lot of damage for me it damaged all my spine damage down into my hips it damaged my hips bone growths on my vertebrae now I've lost all feeling in my fingers well not all feeling like 70% of the feeling and some of my fingers lost feeling in my toes and that was like how that was 17th of January 2009 and we're now what are we now 2022 and still in physio still in treatments like you know so a long and painful recovery which is still ongoing yeah and so how does that affect your day-to-day living you know in terms of you mentioned you have a dog for example yeah just three dogs way too many dogs yeah well initially was extremely difficult as I was saying to you earlier initially I couldn't live by myself couldn't wash myself couldn't walk properly couldn't take care of the dog I didn't see my dog for months couldn't drive couldn't travel couldn't do anything like and you're just going around in this daze of not knowing what's wrong with you when is it and you think as well oh my god just a few physio sessions now I'll be fine like this pain will get better but for the it was three years of really intense really bad pain like you know like it was three years before I could sleep in the bed without a pillow to prop my foot up I used to pray for my leg to be amputated I just could not bear with the pain it's just and that was just the pain in my leg yeah then I had all the back pain and the chest pain and the pain just the pain is just I suppose now or just left for chronic pain which as I said isn't bad the chronic is just means it's long term but I have not known a day without pain since it happened and then as I said you get like you think it's all going well and then I break another bone and because I don't have very much muscle in my feet left I have a lot of muscle wastage a lot of muscle damage and my toes break all the time so I'm constantly breaking my toes and I'm actually breaking my fingers as well there's a problem with that because I don't feel my fingers very well anytime I do damage I have to go and get it checked out because I actually don't know how much damage I've really done like you know and so yeah so constantly in physio like what they say is now it's a maintenance phase like you know people are surprised you'd see people walking but they might see you then limp in

particularly on a cold day if I've done too much walking or sat in the wrong kind of a chair and they don't realize that I'm still kind of living in in this and compared to what it was like the pain is nothing I think you know it genuinely isn't but I've never known a day without pain and that's that can be quite tough at times like and particularly then when you do break something and you're just like oh my god I thought it was getting better and then I'm back but you know but they I've kind of come to learn now like you know this happened before you've had your setback just sit down take a break and then tomorrow I'll get up again and move forward and you will move forward and it will recover and you'll get back to where you were but I suppose for me walking can be quite difficult and when it's taken away from you even just for a month or two it's like oh I'm here again I'm and you might as well be back sitting in the car sometimes inside the wreck of the car like thinking god at the spot ahead of me again and as you were saying just I mean even the fact of the kind of violence of the accident almost that you were in counselling and still are yeah just to try and come to terms with the injuries but also the experience yeah and the mental I think as well like you know people think oh you know it's the hidden illness it's a mental health illness it's people always say oh god you know your health is your health

I'm like well your mental health is an absolute fortune because when that goes yeah it's gone so I did I did unfortunately because I was left sitting in the car they took my crutches off me and then if we sit there and the wind was still blowing and I thought oh my god going to die here you know and so I did develop and post-traumatic stress disorder and I've been dealing with that constantly and with the post-traumatic stress disorder and with the injuries you're never recovered you're in what they call these main a maintenance phase so you're as good as they're going to get you you'll never be perfect we'll have a good quality of life now most of the days you know 95% of the time is a good quality of life despite everything else but just then you just have to be always kind of watching the signs of your physical you know or if I walk a bit further now I'm going to actually do damage stop don't push yourself take a day off tomorrow yeah and then the same for your mental health just you know you're getting a bit stressed out just go and talk to your professional and get a bit of help and get a big perspective and honest to god sometimes you go in and you think god that how am I going to do and the way to the world comes off your shoulders when you've talked talking to someone talk to anybody will help you yeah cope with what you have to do with you know yeah and just in terms of your I mean your role in TII is as an archaeologist and plenty of experience and that involves a lot of site work a lot of chiming into cellars and old buildings and up and down stairs yeah and across a lot of uneven surfaces and god knows when you we didn't have the Luas you know Luas Cross City you're going out building it and it was the same one you'd be working on a road you're like god this place really needs a Luas this place really needs a road because they're hard to get just there's a lot of walking the steel toe caps are incredibly uncomfortable that's the steel toe caps of your PPE your site gear yeah and even like on a bad day like on a bad day now the hard hat weighs a lot because my neck is sore and even the tags from hanging you know your ID tags they can actually cause quite a lot of discomfort and pain and people don't realize that but walking on site and on uneven surfaces and going across fields and hopping ditches and I remember doing a job here and like thank god for the for the guys I work with are so understanding and they could get one leg over

the gate but I couldn't get the other leg over the gate it and the lad's trying to push me over down in Carrickmines Park and ride trying to get me onto site like you know and like yeah it has it does cause me a lot of worry and a little bit of stress oh my god I have to walk all that way will my foot be good will my foot be bad would I be able to make it would I get a taxi what will I do like you know plenty of planning.

You were saying that you have had a fair bit of support from TII but say for other people in a similar situation what kind of support do you think employers or colleagues could give well you know I'm going to say this because I also suffer quite about from migraines as well like you know people don't realize how debilitating migraines can be too like you know so you kind of have a double whammy so I do think like and I'm very blessed I have a really great colleagues really understand and support from colleagues and from my manager but I do think you kind of need to take a bit of cognizance to the fact that you know and sometimes you're asking someone to do something and what you're actually asking them to do is way more way more than you'd ever anticipate and I've said it to my manager and he said god I never thought I said you don't have to live in my head you don't have to realize that what you're asking me to go down and look at that site like I actually have to build myself up quite a bit now some days I take no notice but if I'm having a bad day and I'm hurting I have to build myself up to going out on site and I do think you kind of need to maybe like sit down when you're asking someone to do something and just say are you able to do that today yeah would you like to do it tomorrow you know because when you can't do your job like and a job that I'm very passionate about like I love working on construction sites I love everyone I work with and I love building the Luas or the Metros as they go on but I don't want to I don't want to be put under so much pressure that's going to come to the point where I actually won't be able to do my job like you know and I don't think this that will happen here but I do think that you people and your own employers need to be a bit conscious of how much stress something simple is actually putting under some putting pressure on yourself particularly maybe where it's more hidden it's not an obvious disability or not an obvious yes there'd be a day when I could run down the road like you know and you'd be like what's her problem like yeah and then there'll be a wet day and a cold day and it's gone into my hip and it's gone into my leg and I'm like oh I just can barely make it to the office you know and sit in here and just this is just the pain is getting worse so and sometimes as well like that's why I think the advantage of covid and working from home is that you know maybe be that person can do a full day's work if you don't ask them to come into the office yeah but if you ask them to come into the office and do that commute you're actually putting so much pressure on them it's going to be the point where they're actually going to have to phone out sick which makes them feel like a lesser person like you know because it's not that you I don't have anything to contribute to society it's not that I can't do my job but put me under pressure to commute yeah if I don't need to commute if I'm having a bad day I think things like that will actually help people an awful lot I think good communication and a little bit of understanding and maybe not too to be able to kind of see past the kind of yeah obvious and I think to be fair as well like I don't want to take advantage of it I don't want to use it as an excuse not to come in yeah because when I'm able to come in I should come in like you know yeah and just on that you saying that you generally for getting around I mean you would use public transport

and like what kind of barriers do you encounter when you're traveling day to day yeah well like at the minute I am suffering I'm on a bit of a setback at the minute so my hip isn't working very well so the stairs are extremely difficult for me at the minute sorry yeah really struggling with stairs and first off

I don't like people then judging me when I'm getting the lift like a lift is there for a reason I'm having a bad day don't judge people just because they're getting a lift for a flight of stairs you don't know what's going on or why they need it with me like then as I've said to you and I've discussed with you those ramps in this train station because I commute by train I drive halfway to the train station and walk a little bit and then trying to get over the platforms you know it can be quite like oh the flight of stairs just feels so big yeah but then the ramps are so long like you know and if the ramps are anyway uneven if there's any imperfection because my foot has been so damaged that they've advised me that my brain actually doesn't recognize fully where my foot is yeah so I have a tendency to trip and the bottom of my foot would drag on the footpath you'll see oh my god what's wrong with this one she's not walking but it's because my brain just cannot judge the distance between the foot and the ground so I hit it the ground quite a bit so if there's any unevenness in ramps it becomes quite like it's a quite a trip hazard like you know and I remember when I was on crutches and I was just I was living in an apartment block and again there was another ramp and just falling because I just it just wasn't even it was just that little bit of unevenness and just couldn't keep your balance going so things like that and the ramps are just so long and I don't know how much physical strength I think you have but like when I was really bad at the start like and my back was so bad I was on crutches for my foot and I could I was trying to get myself around on crutches and my back was so bad and then the ramps were so long

You're just like god has anyone who designed this sat in a wheelchair and seen how much energy or put on your crutches that it actually takes to get up this long distance of a ramp and when I first started as well my train station in Kildare when I was able to move home and take care of myself again didn't even have that it was just a flight of stairs and you'd have to get taxis because I couldn't drive over I had to get a taxi up and then the station Master would have to come and open a special gate for me and I'd have to book it or phone him on the way and say I'm in the taxi now can you please come and open the gate because it was the only way I could get onto the right side of the platform to access work and then you get on the train and I'm going to say as well like the one thing I have realized is there's always someone worse off there's always someone with a worse case and the train that I take going up to Kildare is actually the train that a lot of cancer patients take coming up and down to their Hospital in James's yeah and you'll be standing and I remember one day saying to lady and now I was in agony standing and she was on her way of chemotherapy like you know and again nobody noticed nobody saw that us two women were down the back nearly in tears she going for chemo and me just like an absolute agony with my foot like you know and people just don't realize that like and I said to you before there was a day and the disabled chair was free do you know the you know the designated space like a I sat in it and like we were in between stations so nobody was coming and a woman actually gave out to me and

I was like you have no idea how bad a day I have just had I'm really in pain here I just want to sit down for five minutes and you're having to go with me yeah and like I'm sure there's people who take advantage of those chairs I'm sure there is but you know I've had people on the Luas trying to take the Luas you know and not getting up off their seats kids just taking you know with their feet on the chairs and you're like I could really do with that seat like I really so a bit of consideration and not jumping to conclusions I suppose when you see somebody who looks able bodied yeah whatever yeah and you just you just don't know like how much physical pain and you'll see me sometimes I might like I'd be middle of walking and then I actually have to stop and I have to rearrange my whole posture to try and get myself walking again like you know what like people are going through and that's just me and like I'm mild now in comparison when I'm nothing in comparison to what I was yeah and then we were talking about trying to get around even on crutches and the kind of difficulties which then you know yeah the day yes I did have to cross from again I wasn't living in my own house I was living in an apartment in Dublin and I got in on the platform at Houston and I had to cross over and my crutch got stuck in the track of the Luas was coming and I said of all the people to get a crutch stuck as an employee now who works on the Luas I could not wiggle my crutch out of the track yeah like you know this is it this is so embarrassing but it really happened like you know and like the other thing is when you're on crutches and you're trying to manage everything on your bag and you need to have hoods because you can't carry umbrellas you and then you're trying to push the buttons you're trying to manoeuvre and push the buttons to get the doors open so I got into the habit of saying to people would you mind opening the door or pushing the button for me there yeah you know simple things like that and I think don't be afraid to ask you know you know would you just like little things like push the button makes a huge difference because it means you don't have to rearrange yourself and things like that like you know and maybe if you're standing at the door as well just automatically I would try now just automatically open the doors because you never know what else someone else is going through like you know yeah and even for you know women with prams and not even people in wheelchairs I've seen people in wheelchairs I've been in a wheelchair myself trying to reach things it's really difficult like you know so just like look around press the buttons like you know it takes two seconds like so yeah and what about other what have you found in terms of re-recovery what have you found that has helped physically mentally Etc

That would that maybe might be of use to people well great physiotherapies I used to have two hours people I don't think realized that I used to be in two hours of physio a week it was quite tough so a great physiotherapist a really strong physiotherapist because god they earn their money when they're dealing with someone like me Pilates now everyone sees me here running after Pilates and think oh god that one must be so into health I hate it with an absolute passion I absolutely hate it but Pilates is a great you asked me before about pain management Pilates is a huge pain management technique for me and when I initially was bad it when we give me maybe one or two days of relief now I could get maybe a week a week and a half of relief out of Pilates so that's huge and it was actually a former manager got me into counselling as well like you know and if that person would I be here today I don't know if that person hadn't gotten me into

counselling because I didn't know what was going on I didn't know why I was waking up screaming you know I had no idea you see these things people always say to me you know you're having flashbacks to the accident and I said no I have horrendous nightmares absolutely but I never ever not once have had a dream about my about my accident it's been other issues I have an awful lot of fear of being trapped I've a desperate fear of being trapped because I was trapped in the car and they took my crutches off me which I'm really bitter about yeah like you know because then I couldn't get out of the car even though I've the doors would open and I just couldn't get out of the car so I just think like these small things like you know maybe as well you know sometimes you might see someone panicking in an elevator I know what's happened to me in the past panicking in a small space like you know there might be something underlying that and I do think like I talk quite openly about my mental health because somebody took the time to sit me down and get me into help and maybe me just talking about it might actually help somebody else because when you're going around and you're in this blur and this Haze and you don't know what's wrong with you and you're in so much pain it gives you a life coaching technique of how and the best one I ever got was to change the channel it was a it was a technique my counsellors helped me like every time you're having a flashback just pretend you're pressing a remote control changing the channel think about something else and it'll get your mind off it so it is and even if it's down to pain management again it was my counsellor who said it to me how would you expect to get through your day if you're not actually taking the painkillers you know if you're not doing what the doctors have told you to do so I do think everybody in any walk of life and any issue needs to talk to someone and be open and because just relieving that pressure gives you those coping methods I was just going to say it gives you the strength to find the other coping mechanisms gives you the strength like the last thing I was giving out in my last counselling and his final words were do your Pilates yeah you know I hate it but it will help you like yeah so that's and I think you know having a job you love and like you know we all I know we're old RPA and but our pay was the time that things were bad for me and my colleagues really stood by me and really helped and there'd be days when you just be doom and gloom they put a smile on your face and I like they've been good to me there's been days I haven't been able to tie my shoes yeah and my colleagues have actually been down and tied my shoes for me carried my books for me yeah and helped me and that's what's and going out on site and just construction sites are great to for a laugh at a great for a mental health break as well like you know and the guys just really helped me in that regard like you know yeah which is fantastic to hear that and I'm sure they'll be glad to hear yeah I know yeah really have helped me you know so I mean when we were chatting earlier you said that your old life banished on the day of the accident and that you had to come to terms with an entirely new life which is kind of a pretty profound readjustment so I mean I know you feel that difficult and all as it has been that it's been an incredible learning experience it's opened your eyes to other things and yeah like what I say is that somebody got out of the car it just wasn't me anymore yeah and even actually on the day I got out of the car someone ran over and a man and he helped me and he said it's all right now love it's all right now and I will never forget that man I don't know who he is or who he was but I've always said it has been the absolute kindness of strangers and I used to cry and I used to say where's my life back I just want my life back and I had to come to terms and say it's never coming back but it

has been great as much as it's been bad it has been great like going to physio twice a week every night I actually started meeting people I would say to my friend I would say would you meet me after physio and I started actually becoming a lot more social if you kind of say to me now oh you can't do that I'm like is that a challenge yeah you know and like there's many things like I've said to you I know I have a list of things.

I actually it was another constant thing this don't list of all the things you've achieved and when you sat down and like I still have that list it was like god the day I was able to dress the bed by myself the day I was able to get dressed myself the day I was able to wash myself yeah the day I was able to move home all these targets and it's not like I was in hospital I just physically could not take care of myself like you know so all these little targets that were set for yourself and I still do that I still say all these targets and like I've climbed Machu Picchu I would love to do the Camino and I just have to do it in a different way you know and just don't let it stop you but if you don't get the help that you need you're the only person you're stopping is you're stopping yourself yeah I'm not like Pollyanna I don't see the good in everything I still get quite bitter yep you know but there is good in life and in the past and I have gotten a lot of positives out I could I go back and say and I supposed the big message really for people is just you know there are hidden disabilities out there and just give people a break if you even think of us you know yeah you just really do not know what is going on inside someone's head that day or how like their little genuinely days when just putting one foot in front of the other is so hard and you just want to give up I can't give up no and I won't give up good for you Emer thank you so much for coming along and talking to us so candidly about your accident and all of the fallout from it and I hope it'll be of help to people who are listening all right thanks a million for having me and thanks for organizing this really appreciate it.

So that's it for this episode we hope you enjoyed hearing from Emily and Emer and their experiences of living and traveling with a hidden disability you can find out more about Emily's work at [invisibledisabilityireland.com](http://invisibledisabilityireland.com) we will link to the website in our episode notes thank you to our host Sarah O'Donnell to Trevor Cuddin on sound to the production team Kathleen Jacoby Rachel Cahill and Claire Scott to Sinead Foley from TU Dublin who designed our fantastic graphics and to everyone else who helped make this podcast please send us your comments and feedback to [AllAboard@tii.ie](mailto:AllAboard@tii.ie) and for more episodes from All Aboard please go to Spotify iTunes or wherever you get your podcasts until next time...