S1E3: Helping Hands

Description: A look at the subject of carers, firstly by way of research on the issue in an Irish context and then secondly, by way of a personal story from Erica O' Driscoll and her memories of her brother Stephen.

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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'll be hearing first-hand accounts from people who use and design public transport systems and specifically the role accessibility plays in these experiences and 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

So Sarah what’s the focus for this episode hi Claire so to begin this episode we're going to look at the topic of caring for a loved one with a disability we start with Kathleen one of The Producers on this show who has done some research on this as part of her master's degree in sustainable transport at TU Dublin we then talk in depth to Erica O'Driscoll in 2018 Erica sadly lost her brother Stephen who was diagnosed with muscular dystrophy at a young age Erica talks to us about her experience as a family member of a loved one with a serious disability and looks back on Stephen's own experiences of public transport and living independently hope you enjoy it

Kathleen Jacoby sustainability portfolio coordinator with TII is joining us on the program today Kathleen welcome to all aboard thanks for having me so Kathleen you recently completed a master's degree in sustainable transport and mobility and for your dissertation you explored challenges faced by family carers and you've also did some research on family carers accompanying physically or mobility impaired loved ones on journeys involving public transport in Dublin tell us about this subject I would like to start with what an informal or family carer is so unpaid assistance to others is generally referred to as informal care or family care in Ireland there is a preference for using the term family carers when referring to informal carers or caregivers we're talking about parents looking after young children and friends or family members taking care of people who need their assistance with everyday tasks which includes getting around the Central Statistics Office census considers carers to be persons aged 15 years and over who provide regular unpaid personal help for a friend or family member with a long-term illness health problem or disability including problems due to old age okay so why do you think that the mobility needs of family carers traveling with their loved ones who in many cases are physically or mobility impaired is such an important topic well contrary to population projections across the EU the Irish population is expected to increase in the next decades and at the same time the population structure is forecast to change quite significantly the CSO forecasted by 2051 which isn't too far ahead there will be less than one and a half people of working age for every person outside this age group informal care is mostly provided by people of working age so it is obvious to me that family carers will be under increased pressure in the next decades and I think we need to understand the mobility needs of caregivers and their loved ones and make sure that public transport is a viable and attractive option for them and in terms of public transport as it is now is it up to the task and did your research reveal anything here well data is very limited research carried out in 2019 as part of TII’s traveling in a woman's shoes study found that in Dublin seven percent of the women but also six percent of the men surveyed stated that the main reason for not using public transport is that they can't travel with children or the person they need to take care of my own research was too small in scale to generate conclusive results but based on my work I do believe that both Academia and the transport sector must recognize caregivers traveling with dependents as a cohort with specific issues and needs and can you give some examples of those particular issues and needs well the issue is primarily impact the mobility impaired person but you have to keep in mind that carers often support their loved ones physically in some way while they're moving about one of the issues brought up by my interviewees are long distances to overcome so for example when getting off the Malahide Dart in Connolly to catch a Luas into town it is a bit of a walk this isn't a problem for somebody without mobility issues but for an elderly person relying on their role later or another Mobility Aid it can take quite some time to get to that Luas another issue are bumpy walking surfaces and this was brought up by somebody traveling with their elderly Mobility impaired mother but also by a young mother traveling with her baby in a buggy and a wheelie suitcase safety and anti-social behaviour are issues too and carers plan journeys with their loved ones around accessibility to and from public transport stops and also the places where they change in between Services

That's interesting Kathleen and of course you surveyed people on the ground at those particular locations now you mentioned earlier that family carers are unpaid so what's the impact of this and what other burdens are faced by carers well caregiving responsibilities have a profound impact on the caregiver's life not only does caring take a lot of their time but it also affects their physical and mental health many caregivers either cannot work in paid employment at all or they only work part-time which not only impacts on their current financial situation but also on their old age pension entitlements additionally they may have to spend money to provide for particular needs of the person they take care of all of this can result in poverty isolation and poor health of the caregiver so when caregivers are forced to own and use cars because public transport is unsuitable for their needs not only does this add to the caregiver's burdens but it also impacts on our ability to reduce the use of private cars in favour of more sustainable modes of Transport for sure and what do you think needs to happen now in terms of public transport and carers when I worked on my dissertation in summer of 2021 I found there was virtually no research on caregivers and public transport it is a complex topic and research is needed specifically into Mobility needs of family carers accompanying their loved ones and we also need to look into how the public transport sector can engage with caregivers to make sure their voices are heard because they might not engage with public consultation processes insufficient numbers due to the burdens of their caring responsibilities absolutely and finally Kathleen where can people and in particular carers themselves find out more information about this subject so for any of our listeners who may want more information the HSE and many important voluntary organizations including Family Carers Ireland Care Alliance Ireland provide information advice and support for carers in Ireland the study I refer to Traveling In a Woman's shoes can be found on the Transport Infrastructure Ireland website thanks very much Kathleen

Many thanks to Kathleen for sharing her research and valuable insights next, we will hear first-hand carer experience from Erica who talks to us about her brother Stephen and her family supported him to live a full and independent life

Hello Erica and welcome to all aboard so how are you good Erica so you work in human resources in TII and you also sit on TII's internal accessibility committee so you're very familiar with disability from a legal and a corporate standpoint but you're here today to talk about something far more personal you're going to talk to us about your brother Stephen who lived with muscular dystrophy and who sadly passed away in 2017. so maybe tell us first of all about Stephen what was he like as a person and how did his diagnosis come about well Stephen there was just myself and Stephen he was my younger brother by two and a half years so what can I say with Stephen so he was look he was a happy-go-lucky child and your typical boy out playing all the time football running around and I suppose when he was around you know young four or five my parents noticed just a few different things you know him getting off the floor he'd run on his tippy toes little things like that so they realized maybe something's wrong and they brought him about it and he was diagnosed and he was seven with muscular dystrophy so basically what that meant was you know it's they were told it's like a wearing down of the muscle tissue and that and it was a a gradual thing and eventually he would you know have physical disability and end up in a wheelchair yeah so at that stage you know they give you time frames and they're like oh he'll be in the chair from his teens and you know and even life expectancy was very low at that stage you know I think they were saying you know 20s because he was diagnosed initially with Duchenne muscular dystrophy and Duchenne would be one of the most severe forms of muscular dystrophy and actually come to think of it at the post-mortem when he passed away there back in 2017 they actually mentioned muscular dystrophy so and we always wonder because Stephen did very well compared to other people that were diagnosed with Duchenne you know his life expectancy and even his physical disability so it when we saw Becker muscular dystrophy mentioned in the autopsy it made sense I think he was on the cusp yeah between Becker and Duchenne so just you know those little things so sorry going back to the start so you're you know you were given all these statistics and you know how he was gradually going to end up in the chairs and so you kind of think as a family you know you're planning ahead so obviously like you know the extension happened in the house you know the bedrooms brought downstairs and as he got older he did eventually go into a manual chair and he'd get tired yeah you know on long walks and that and so you'd have to bring the chair with you and he'd be in and out and in and out the house had been in the chair he hated it and then eventually you know when he was I think around 15 16 he went into a full-time you know and he's in the electric wheelchair at this stage sure yeah and so like you say it's a progressive disease yeah probably very hard for him even as a small child to come to terms with having gone from running around the garden exactly and having pals and was he able to continue in mainstream school for a while or he wasn't no because along with muscular dystrophy there's other things that come along with it every child is different and their diagnosis is different

So with Steven's diagnosis his came a learning difficulty as well so eventually he was in a school for that learning difficulty but it wasn't accessible yeah it was strange he went to this school for his learning disability but eventually he had to move out of us because they couldn't and facilitate the wheelchair right So eventually he went into the central remedial clinic at the school there so obviously they're fully accessible yeah and how about pals at home and in the neighbourhood and all of that yeah he like he had all his pals at home but you know yourself he couldn't keep up with them eventually and you know friends do grow a part and I suppose when he when he was diagnosed obviously you know you meet all these other children with the same condition and he would go on breaks away with these guys and he formed a really close bond with a couple of the guys in in Muscular Dystrophy Ireland great Association they do great things with kids so he kind of not last touched with his friends at home but they just were going down different paths and you know with a disability a physical disability you know the guys at home try to do their best but you know they're going off and doing their Sports and all that yeah so Stephen did but we had a great Core Group in it with the MDI and like his friend Stephen Fitzpatrick and Ed like the three of them they were like they were just inseparable the three of them yeah so and they all had muscular dystrophy too yeah fantastic and from your parents point of view and from your point of view in terms of the daily routine you said that the house was adapted you built the extension but you know there was obviously a lot of driving and trying to get for me to be exactly how was that when you couldn't like you know we grew up in the 80s and the 90s you know public transport you know been accessible was non-existent and so you did rely on the private car yeah the family car so we always had an adapted vehicle for Stephen you know the ramps going up but one state I think at one stage we actually had a car that had the lift as well so very reliant on that yeah because you couldn't rely on buses you couldn't rely on trains the Luas wasn't there exactly and of course you did go on family holidays and summer holidays and all that but presumably it took a lot of planning on your the part of your parents but tell us about your memories of some of those family holidays so we'd holiday a lot in Ireland we'd never been abroad and so our first big holiday abroad was actually Florida believe it or not I am and at that stage Stephen was I think he was seven or eight and he was in the we had to bring the manual wheelchair with us because obviously there's a lot of walking involved and we just he wouldn't have been able first so obviously the plane wasn't too much of an issue because you know you folded the manual chair like a boogie as such and you know yeah and then over in Florida we were just amazed like the buses were wheelchair accessible they had lifts I mean we got photos I mean this was like it was like a ride as well you know and this was in the late 80s early 90s this would have been in the 90s yeah you know and nothing like that back home and everything accessible everything and actually one the highlight of the holiday and it's terrible to think this but because Steven had the wheelchair you didn't have to queue for all these rides yeah go to the exit and you'd have these queues two and three hours long and there we are hopping on and off these rides you know two and three times and God loved them now he did he hated the focus on him but that was one advantage of it you know fantastic that it wasn't just getting from A to B but also the destinations were accessible as well so you know the places you wanted to go to would facilitate him everything was yeah it was they were just leaps and bounds ahead of us yeah from that point of view you know and then to go back home and then realize how bad it is you know back homes in the 90s and that you know

And of course like as Stephen got older he moved out of home and was living with a personal assistant unfortunately his friend Ed had independent living and Stephen got a taste of that and then unfortunately Ed passed away and I think Stephen kind of saw his life flashing before him thinking God I have to go back home now and he had the best about worlds he'd be at home and get his home comforts and then he had his escapism down to his friends Independent Living and I think he panicked and at that stage I think he realized what he wanted and he wanted an independent living situation for himself so yeah he moved out and he got a lovely apartment down in the Irish wheelchair Association and he got some lovely pas he was so lucky you know they were more than personal assistants to him they became very close friends so again though at this stage this was in in the like the noughties and I suppose even though there was you know public transport was getting better he still he hated the focus been put on himself so there was a bus stop right outside the Irish wheelchair Association and I remember him getting on the bus the first time because I kept saying look the ramps are on the bus now yeah you can do this but it was the beeping he got on and there the bus driver obviously has to press this button on his beep beep everybody looking out the window everybody looking at the boy in the wheelchair yeah he hated that and he said I am not doing that again yeah so again he relied on the family car so you know he'd ring us up and he'd be like I need to go here there and everywhere and you know obviously I had to drop off a house my parents would and it were a vicod I'd be dropping him everywhere yeah couldn't really rely on the trains because train stations you know the lifts could be broken yeah you had to plan ahead you had to ring them ahead of time and let them know he couldn't do anything on a whim basically everything had to be planned out and of course even you were saying in his friendship groups Etc like it's very difficult from more than one person to travel Often by public transport because there just isn't the space there just isn't the space there at all I mean it never like it wasn't it never even contemplated gone abroad on planes once he was in the electric wheelchair you know you hear a horror story of his friend going away and his electric chair go and get missing for two days and what do you do if you've no wheelchair for two days you know it's not like a missing case yeah and just like my wedding you know he planned he had to ring ahead for taxis you know he couldn't leave when he wanted to leave he had to give them a time to pick him up so everything had to be planned well out in advance you couldn't do anything on a whim basically yeah for a big day like that where you're going from the church to the venue and you know there's and that's why we did what we did we stayed in the city centre do you know that way so that there wasn't much traveling literally we were only around the corner we went from City Hall to the restaurant and the bars and we had to make sure everything was you know accessible lifts and ramps and everything so yeah like a lot of planning but it just become second nature as a family you know you've done this for 30 years yeah you know and it's just secondness you're there for him and he's there for you exactly you just know however everything works and well I suppose the Luas has made a difference in that it's easier for designers of the light rail because it's new system so we could start from scratch and we could kind of take lessons from other cities but how did how did that system how did the Luas change life for Stephen well I suppose it was when he got into town you know I mean it's a it's great that it is extending out you know but when we were in town one day and I said come on we have to go on this Luas and had you started working for Luas at that time well I was in we were NRA at that stage so we had merged so this this was even new to me yeah you know so I said come on we have to get on this list well he couldn't believe he didn't need a ramp yeah he didn't need to ring ahead he didn't need to plan anything there was loads of space he couldn't believe like all the space for numerous wheelchairs on us so this was a great experience and he was like why has it taken so long yeah so we were on it and it was it was quiet enough and we were on it and it was brilliant and then I think it was a few months later we were in town and we were gone somewhere but it was peak times yeah so we were getting on it again and it was busy and he was very conscious of the size of his wheelchair he was in a very bulky chair so he was always conscious of people around him he didn't want to go over anyone's toes but he just couldn't believe how many people literally would just be ploughing on and he was just a bit nervous so he could take his time and obviously a few people would always stand back you know and it was a different experience as such but we look it was still busy when it's busy but the funny thing was we were we were on it and whatever way was it was very busy the people right beside us and this woman fell on his lap in the chair and our God loved the woman like she was mortified but he couldn't stop laughing he said well if any advantage to this travel you know I have women falling on me a lady falling right into his lap yeah I hope she was beautiful oh well I don't think he cared

Yeah and I suppose it's interesting probably most people don't mean to be inconsiderate but just in the crush and in the busyness and we all have headphones on or earphones in in our own worlds but yeah and like there's loads of people that are considerate you know but there's just those few I as look they could be having a bad day you just never know what's going on in people's lives so I've never you know been hard on anybody but it's just when you see I mean I see it today you know all over I even see it on the Luas you know there's people with chairs and they're trying to get on and they're waiting and waiting and the Luas that just goes do you know that way yeah then they wait for the next one they're only 10 minutes I know it was they could be waiting there for the third one before somebody actually it took someone the last time to physically hold people back and say let this person on you know because the people in the chair they don't want to put people out so they're the last people to actually voice their opinions yeah and like a perfect example I was on a bus a few years ago and like that there was a woman on with her buggy and the bus stopped on a man in a wheelchair was getting on but the woman with the Boogie all her shopping was underneath so she couldn't close the buggy up yeah now look she wasn't really killing herself trying to do anything and the bus driver I mean I know they are kind of caught in the middle but he had to go like he couldn't let the man on yeah you know he would he was at he really should have asked the lady to get off and the man to get on the chair but again the man and stuff was just going no go go go he didn't want a fuss to be made and yeah so it's just little things like that yeah you know definitely I think the buses are struggling but trying to find a solution to that aren't they whether it's an additional space that you have you know designated space for both buggies and wheelchair rather than pitting the two that’s it and realistically the spots the space is on the bus you can really only fit one chair you know I know they say you know maybe you can get two you can especially if you had someone with a bulky electric wheelchair getting on you're only going to get one person yeah on it you know and then at peak times when people are standing there's no way somebody could be getting on and off easily there as well so yeah going forward now I'm not sure how they're going to get with that now hopefully frequency of service will help as well the people aren't waiting for you know that there's a you'll have plenty more busses and choice of services and that ultimately if you are a stock that you won't have to practice

I mean look that's really the only way forward isn't it and so is there anything that you think that planners or designers or managers of public transport systems could do to improve life I think the main thing really is just to speak to the people that are affected and get their point of view you know I mean these are the people they need a voice they're the one using the transport they're the ones that know the issues so there's no point in the likes of us sitting down here and talking about what we could do when it does it doesn't affect us yeah we can get up and go wherever we want yeah but I suppose another aspect is you know all disabilities are different and one disability will affect another disability because for example Stephen was constantly given out about the raised bumps at pedestrian crossings obviously there for blind people but it was really it affected him and his chair his chair was unbalanced and it'd be really bumpy going over which affected his back and you know because of the sometimes he could be in a lot of pain and you know from his muscles and his you know bones and that so going over those bumpy surfaces affected them yeah so he was always giving out about them and I said what state we need these here you know this is people with other disabilities so you know it's getting perspectives from all disabilities yeah do you know and just I suppose everything to link up as well yeah you know and but yeah I think the people that are affected the most important thing is for them to have a voice yeah and to hear their stories you know and Erica so obviously there are a lot of barriers when it comes to public transport and improvements it has to be said but in other areas of life you know what kind of obstacles did Stephen come across you know in terms of go to restaurants yeah I mean look the main thing is you know wheelchair accessibility and you know some restaurants say they are accessible but when you go up there's a little dip and fair enough if you were in a manual wheelchair somebody could help you up if you're in an electric wheelchair you can't cut up those little dips you know the weight of the chair you just can't yeah so and then obviously the toilet situation you know I mean you need a lot of space so it needs to be a properly you know accessible you know for you to turn around I mean we've gone into many toilets and you couldn’t close the door behind you know yeah and then um obviously you could never go to the beach with Stephen because she can't go into the sand yeah we went a few times and obviously he would have to stay up on the grass area but he could never go down like when I had you know my son Jake we used to go down the beach lot and you know we just couldn't go down and enjoy the water with them and all that yeah so we really only got to go to the park with his nephews you know yeah and then like there was one year God it's years ago we went to this Festival I can't even remember which one it was and you know no toilets I mean yeah they’re bad enough anyway probably very simple changes could really make you know open that whole world up you know that and if yeah a little bit of advanced planning maybe would no In fairness like I mean I know the stadiums are great they they've you know all the three Arena all of them you know they've specially the special areas for the Wheelchairs and like he's gone to you know football matches with his dad and so he's gone to a few and they do have designated areas and that's great and they have the wheelchair accessible toilets and it's brilliant yeah but I suppose yeah just little things I mean like at the beach I mean I know lately there's things coming out and they have these boardwalks now yeah but it's terrible like it's just one area they just go down and what if 10 wheelchairs wanted to go out the same day yeah they're using the same boardwalk they have to line up behind each other you know it's a good idea on paper but you have to look at these things practically yeah you know like don't just think there's one person in Ireland in a wheelchair yeah you know like there's thousands of people yeah do you know and what if 100 people go to the beach on the same day and so it's just about thinking outside the box and just don't be so close-minded when it comes to people with disabilities like you might know someone with a disability but they are out there and there's more than one yeah you know so it's just taking that into account absolutely yeah thank you okay well thanks so much Erica for coming in and talking so candidly and openly Stephen sounds like a really lovely guy and yeah he was he was a gentle giant as I called him yeah so we missed him dearly but look if this highlights you know issues that can be sorted and help future generations you know to be more independent because that was that was his main thing you know independent Living yeah and if one step Gone towards that it'll be a great help for everybody absolutely yeah thank you very much thanks Sarah

So that's it for this episode we hope you enjoyed our conversations on disability and design and gained some insight into the role we can all play in ensuring public transport is truly for everyone thank you to our host Sarah O'Donnell to Trevor Cuddin on sound to the production team Catherine 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 All Aboard at tii.ie and for more episodes from All Aboard please go to Spotify iTunes or wherever you get your podcasts until next time...