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Dementia Enquirers Report

How can urban and rural transport systems help people diagnosed with dementia live independently for longer?

March 2021

Dementia Enquirers

COMMUNITY FUND

Innovations in Dementia

Key messages from Dementia Enquirers projects

1. People with dementia can lead their own research projects – both drawing on previous life skills and learning new ones to explore the questions that most interest them.

2. The research questions that people with dementia generate can be different from existing research questions. They are based on lived experience – on topics that will make a real difference in people's lives.

3. "Being in the driving seat of research" doesn't mean that you have to do everything yourself. Team work and support can really help. But controlling the research and leading the way gives people with dementia a huge boost in confidence.

4. Making the language and processes of research more accessible helps everyone!

5. Research *between* people with dementia makes communication and engagement more possible, because having something in common increases trust.

Date of publication May 2021

You can download this report here:
https://dementiaenquirers.org.uk/individual-projects/thred-in-liverpool/

You can read other Dementia Enquirers reports here:
https://dementiaenquirers.org.uk/individual-projects/

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Funding

Through funding from the Deep Dementia Enquirers grant, thredCiC was able to compile this report from various groups of People Living With Dementia (**PLWD**) and their Carers across the UK (England-Scotland-Wales-Northern Ireland) about how can urban and rural transport systems help people diagnosed with dementia live independently for longer and their Hopes and Fears about using Public Transport Pre and Post Covid.

Transport is more than just travel. It connects people; it provides access to jobs, communities and goods; it delivers vital social services.

This project and final report has been led by Tommy Dunne BEM and Paul Hitchmough, both of whom are living with Alzheimer's and are Directors of thredCiC*

Additional research, material and support was provided by Pat Broster and Louise Langham, both former Carers and current Directors of thredCiC*

Footnote
https://www.thred.org.uk/
*(Transport, Health, Research, Economy - Dementia Community interest Company 'thredCiC' is a not for profit organisation).

Abstract

For this project thredCiC set out to meet and talk to various dementia and DEEP groups around the UK. It became clear from the discussions that transport played a major part in the quality of life for People Living With Dementia (PLWD) and their Carers.

Therefore, we at thred CiC thought that it was vitally important to find out how living in a Rural area differed from living in an Urban one, and to look at how transport can promote independence or can contribute adversely to Social Isolation.

Loneliness is a killer….. People who feel lonely are 64% more likely to develop dementia than those with an active social life (Journal of Neurology, Neurosurgery and Psychiatry). It also raises the vulnerability to mental health illnesses like depression. This could also be the reason why a lack of social interaction and feelings of loneliness are predictors of suicide in old age.

This is particularly worrying for PLWD and their Carers, but loneliness is preventable by enabling people to travel when they **want** to, rather than when they **have** to.

We carried out a number of face to face meetings with DEEP groups in England, Scotland, Northern Ireland and due to the Covid-19 lockdowns, Zoom meetings with groups from North and Mid Wales.

These meetings were filmed by Tommy Dunne BEM and Paul Hitchmough using new skills they had learnt thanks to this project being funded.

All questions and surveys used in the compilation of this report were devised and administered by Tommy Dunne BEM and Paul Hitchmough. Collation, analysis and diagrammatic were compiled by Pat Broster and Louise Langham, facilitators of the project.

Dementia is not a visible disability and the condition may not be immediately apparent to those around the person that they have it, so it

could be assumed that the PLWD is just being awkward or is under the influence of drink or drugs.

Access to reliable, affordable and safe transport is important for people with dementia to maintain contact with friends and family who may live some distance away.

PLWD need good accessible safe transport to get to the shops or appointments, therefore helping to avoid loneliness and isolation which can both adversely affect wellbeing.

Getting transport ‘right’ for people with dementia brings with it many positives to wider society; including increased numbers of people that will be able to shop and spend so there is a benefit to businesses and the Economy.

Unfortunately, over the past year we have been, and at the time of writing this report (2021) are still living in unprecedented times, with the Covid-19 pandemic.(ii)

The lockdown restrictions that were placed on society were actually a taste for society of what it's like to be socially isolated; to be told **when** and **where** you could go out, to be told **whom** you could and could not meet.

Before the pandemic, many People Living with Dementia we spoke to did not have the confidence to use public transport. Now that society has failed to support people with dementia during the pandemic, many are feeling “forgotten’ and “abandoned” by the government, local authorities and NHS.

Most felt there was a lack of support for people with dementia and the onus was on them to actively seek out support, so it is going to be even harder to get people out of their homes and back using public transport after being socially isolated for so long.

Transport is more than just travel. It connects people; it provides access to jobs, communities and goods; it delivers vital social services.

Executive Summary

- Mobility is central to the whole of society. It allows people to connect with places and shapes how we live our lives.

- Even now, due to a lack of awareness and training there are still issues among passengers and transport staff that can make transport difficult for People Living with Dementia (PLWD) and Other Hidden Disabilities.

- Many people following a diagnosis of dementia have to give up driving. This is the first tangible sign to them that they are losing their independence.

- Dementia has affected people across the globe throughout the ages, which brought with it social isolation. The current pandemic has brought even more social isolation.

- PLWD were losing their confidence to travel Pre Covid, but now, even more since the pandemic began, our evidence indicates confidence is low.

- We need to instill confidence in PLWD in order to encourage them to use public transport, taxis, the ferries and the airports.

- We need to work with transport providers to ensure that their training reflects the problems that PLWD and other hidden disabilities experience when using public transport, airports etc.

- Getting it right for PLWD will benefit society, in particular the ageing population and the economy as a whole as they regain the confidence to get out into society and spend money.

- More than 920,000 people in the UK are living with dementia – a number expected to rise to over a million by 2024 (Alzheimer's Society, 2019). The vast majority of people with dementia are aged 65 and over, accounting for over 880,000 people.

- Dementia is not an inevitable part of ageing and is not a disease in its own right. It is an umbrella term. It describes the symptoms that occur when the brain is affected by certain diseases or conditions that cause the gradual death of brain cells. This leads to progressive cognitive decline.

- ***According to *Alzheimer's Disease International, the total estimated worldwide cost of dementia was US $1 trillion in 2018. If dementia care were a country, it would be the world's 18th largest economy (World Alzheimer Report 2015)***

- There is a connection between travel and quality of life; when older people are unable to travel, it is often due to illness, low income or isolation

- Transport essentially allows people to be socially active and therefore positively impacts on their health and wellbeing.

- Disabled people have the same rights as every other citizen; to equal access to employment and healthcare, and to participate in learning, social, leisure and cultural activities in order to live life to the full.

Technology

Globally, we are more connected than ever before, with advances in technology allowing us to keep in touch with people across the world in many ways and at any time.

Without a doubt, the arrival of new technologies is radically changing the ways in which we think about travel. During the pandemic lockdowns of 2020/21 we are starting to see the emergence of “mobility as a service”, bringing together functions such as customer information and payments across different transport modes.

People travelled less for business meetings and people were able to work from home, thus cutting down on the amount of journeys made. While this was good during the pandemic, it also had an impact on people’s social life and their social interaction skills.

While the use of technology was good for the above reasons, it’s left PLWD even more socially isolated than ever before. PLWD need to interact with other people, they need to have face to face contact with their family, friends and society as a whole.

If people are only interacting on Zoom, Teams etc., then part of their communication skills could be lost, given that 7% of what is communicated is via what is said, 38% is via tone of voice, and the majority, 55%, is via body language (Mehrabin and Ferris 1967) If PLWD don’t use it, they could lose it.

Our greatest fears at thredCiC are that PLWD are becoming institutionalised in their own homes during lockdown. This could well become the case, unless Transport Providers prepare **now**, to give PLWD and their Carers the confidence to travel again.

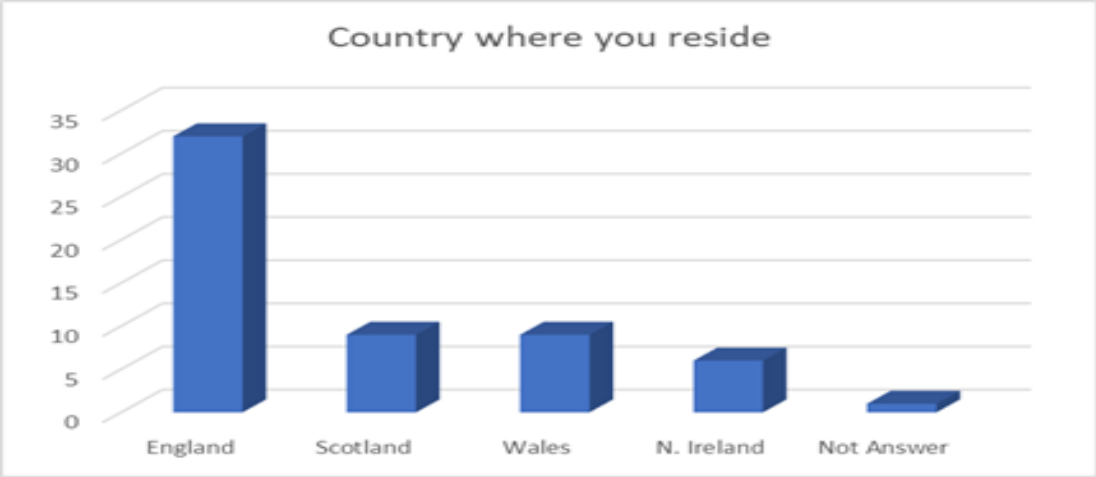
Public Transport Providers should design their services with older transport users and those with hidden disabilities in mind, using technological improvements and customer insight to improve their experiences.

We should also be preparing for any future pandemic/epidemic by making sure that People living with dementia (PLWD) and their Carers have access to technology that allows them to communicate with their loved ones.

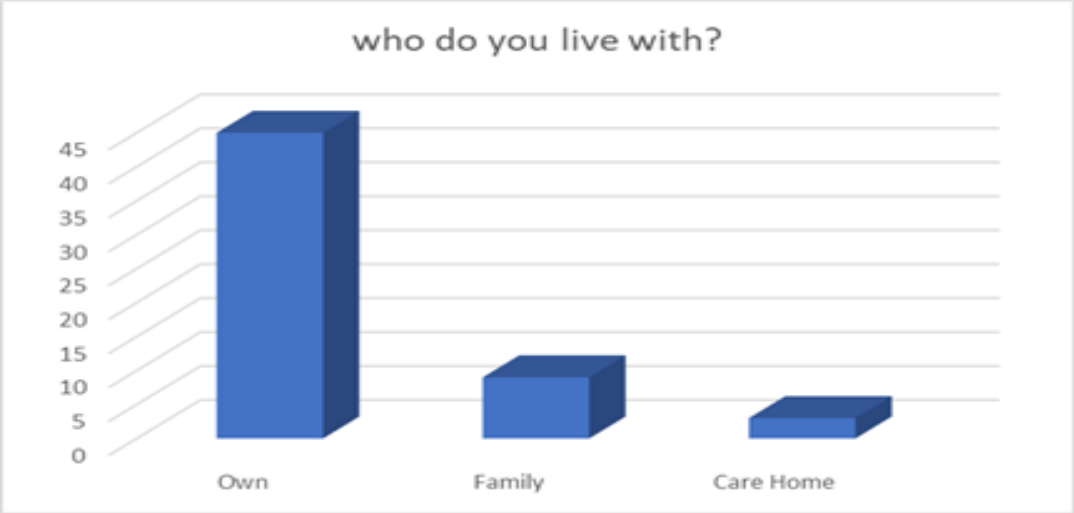
We conducted a survey (Pre Covid) on Survey Monkey and in paper format (57 completed) to gather the experiences and understanding of the type of transport, the differences between urban & rural transport and the real and perceived challenges for PLWD (The full Survey Questions are at Appendix 1)

The following graphs from our pre-Covid Survey show some of the results as %s. We have chosen 8 from the 20 Questions to highlight the most salient points.

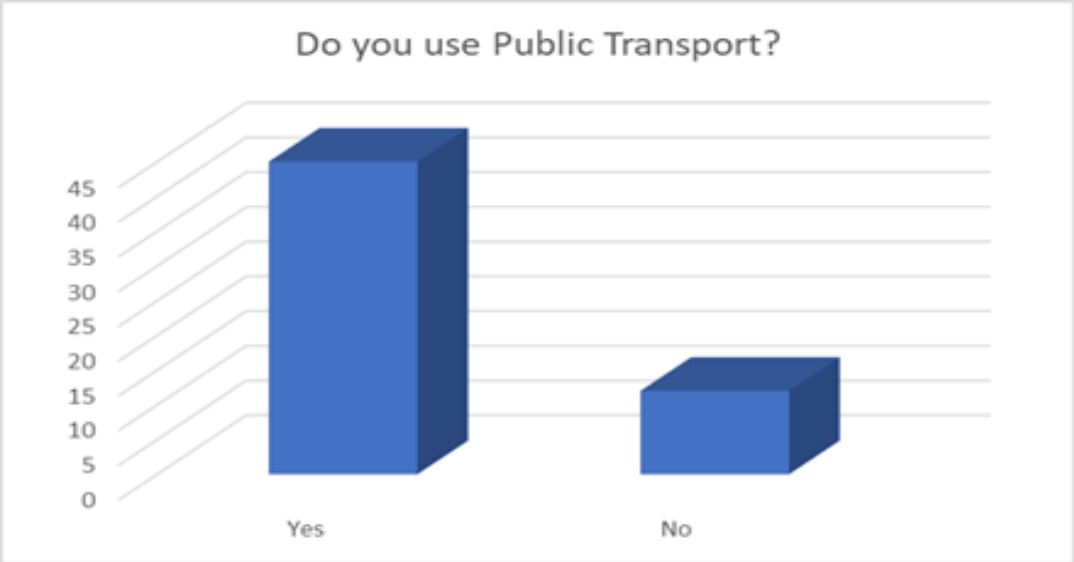
Graph 1 shows the even spread and representation per population of who took part in the 4 nations of the UK (percentage wise the level of responses co-relate to area populations)



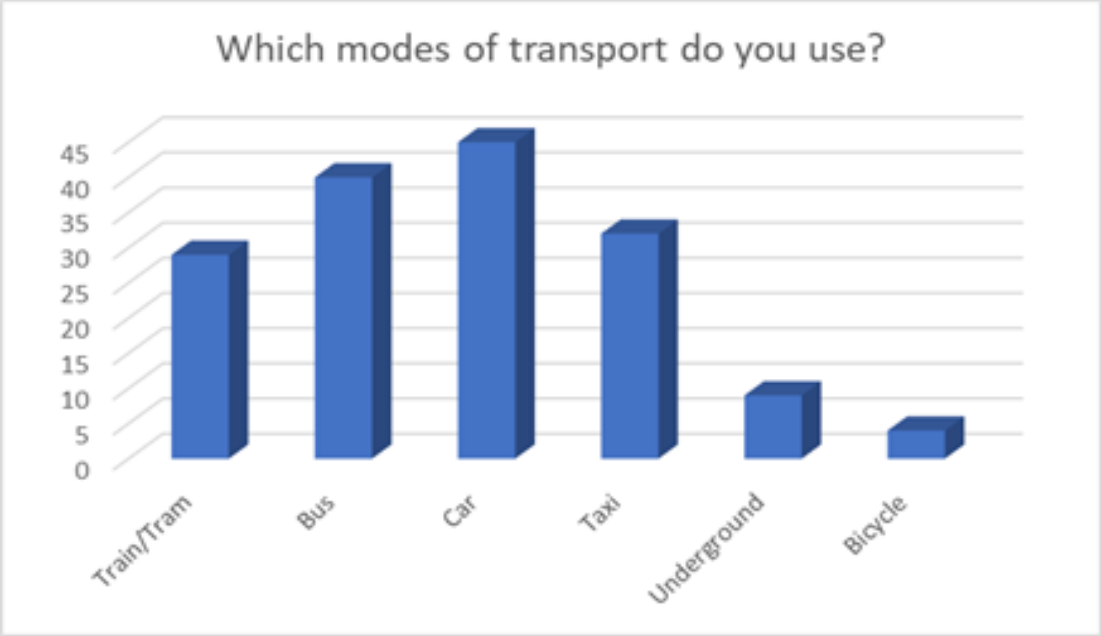
Graph 2 shows how many people with dementia live on their own. This suggests how important it is to have available and accessible public transport, especially if they have had to give up their Driving Licence and have little to no support



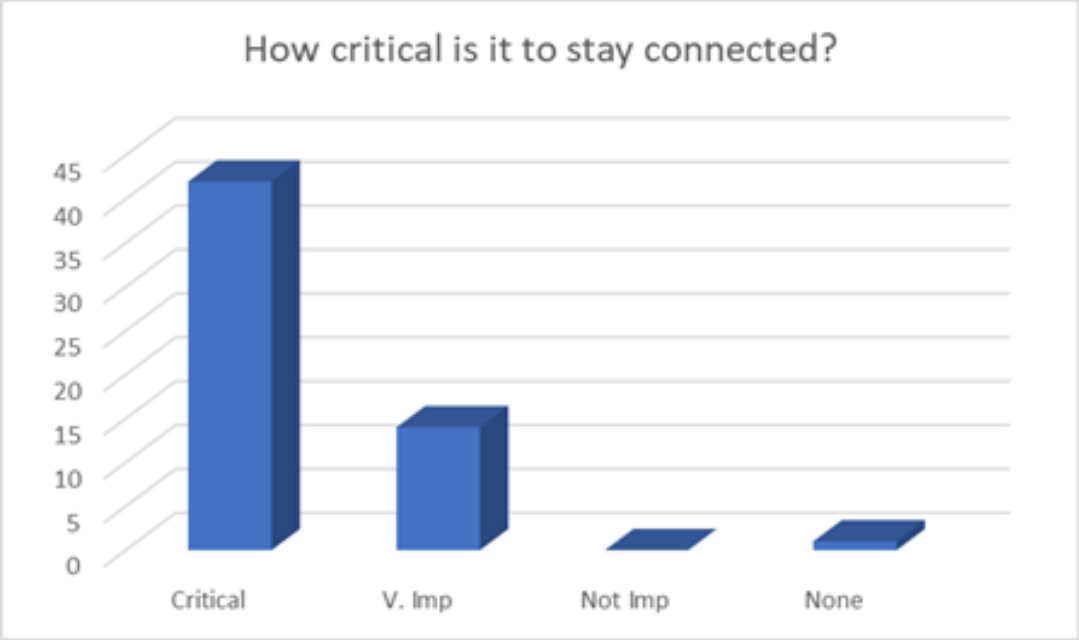
Graph 3 shows how reliant people with dementia are on public transport



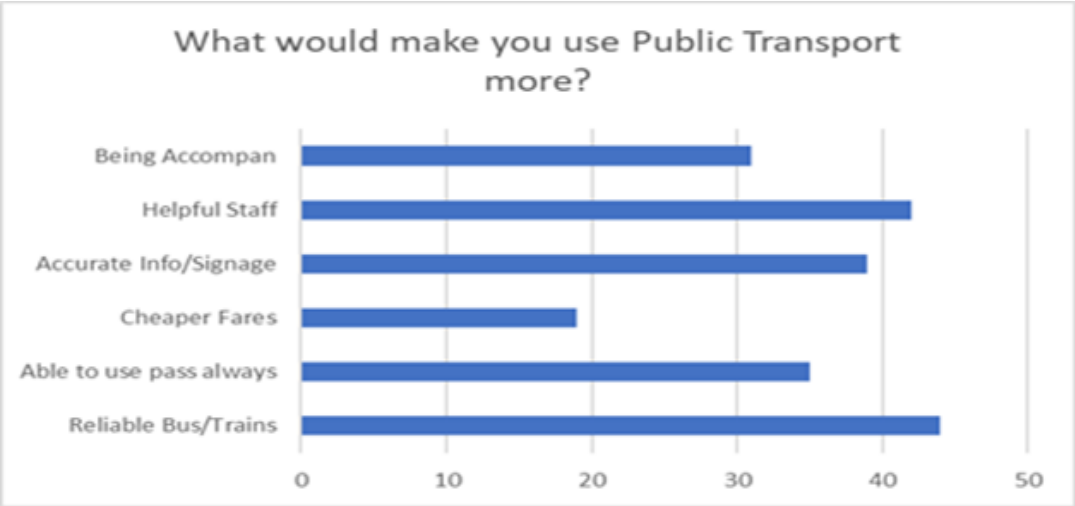
Graph 4 shows that public transport usage in various forms is high when added together, with car usage and taxis still high. As 50% completing the survey indicate they are living in rural locations i.e. villages this may account for the high percentage rate of car and taxi usage.



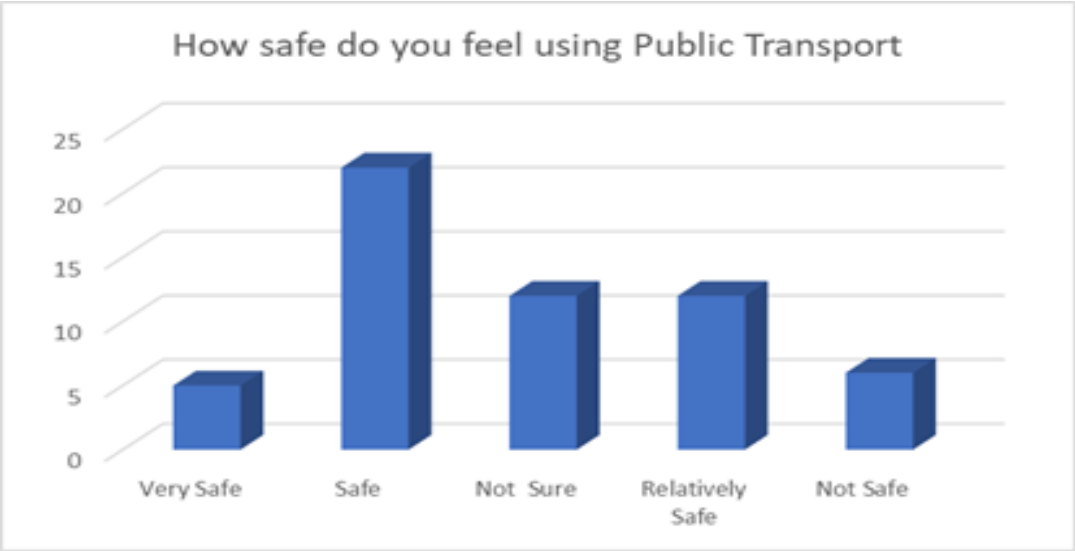
Graph 5 shows how people living with dementia consider transport as a critical service to stay connected, so regular and accessible Transport Systems are vital to wellbeing and avoiding social isolation.



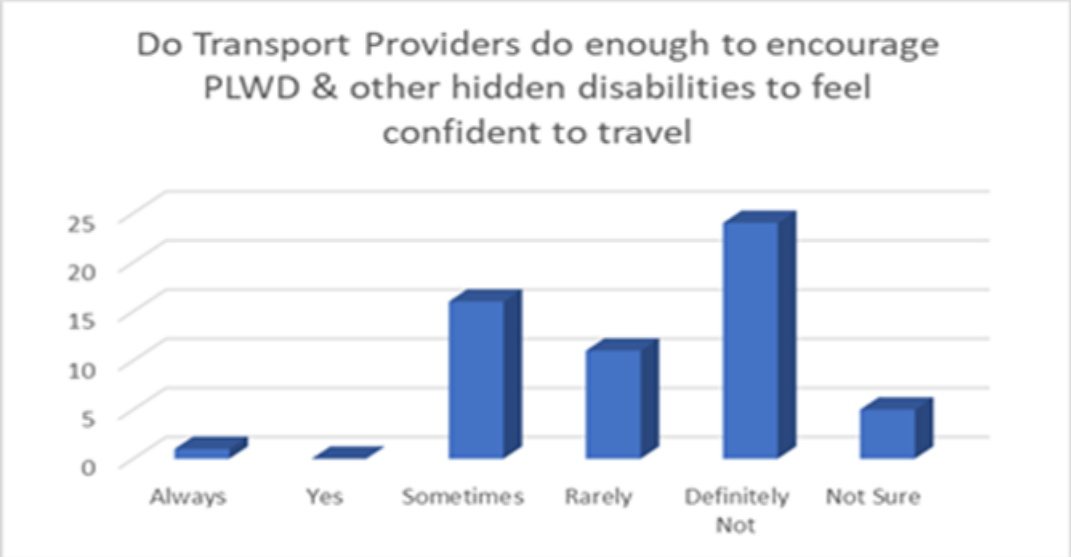
Graph 6 shows that reliability of services and helpful staff are the most important to people with dementia, highlighting that staff training is vital. Accurate information and signage is also essential to help keep people with dementia independent for as long as possible. 56% of our respondents have someone to help them plan their journey, so, for 44% at least, user friendly information formats that are accessible are important to support independent travel. For those using existing information formats there is almost an equal split between online app usage and hard copy timetables. Only 7% of people with dementia will just turn up and go without pre planning their journey.



Graph 7 highlights that people with dementia feel safe when using public transport. As this survey was conducted Pre Covid, views may have changed substantially. We are also aware of increasing concerns and lack of confidence to travel Post Covid.



Slide 8 indicates that approximately 89% of people with dementia consider that Transport Providers could do more to encourage them in building their confidence to travel. Only 2% thought they were doing enough, and 9% were not sure.



Case Study 1

Name: Teresa D.
Age: 68 years old
Location: Flintshire, North Wales.

Teresa is 68 years old and is living with mixed Alzheimer's and Vascular Dementia. Teresa lives on her own a few miles away from both her daughter and son. Teresa likes to be called Dory, a nickname her granddaughter gave her.

Dory is part of the *DEEP Deeside group

Do you use public transport?

Dory answered: "Yes, Yes I do"

What are your experiences of using public transport since your diagnosis of dementia?

Dory answered: "Well I feel more anxious, I get more anxiety, getting on transport than I did before, I just used to just get on and that was it, but I do get more anxious about travelling since".

Would you say this affects your quality of life?

Dory answered "Yes, because I have to travel wherever I go, because of where I live, this is classed as rural. I don't drive, so yes, I've cut down on my travelling really"

What would encourage you to use public transport more?

Dory answered: "Well, if they had more bus timetables up at the bus stops, probably, and what buses were stopping at that stop, and also if they had, you know like on trains, I find on the trains very good, you know like on the trains, if they had what stop was coming up, what was the next stop. I think in South Wales or Mid Wales they do, and in some places, but, in Flintshire, they don't, and I think that may help"

Are you able to travel alone?

Dory answered: “Yes, yeah, as long as I know what time the bus is coming”

How regularly/often, before Covid, did you use public transport?

Dory answered: “Well I used the trains a lot going up and down with the DEEP network, but, if I wasn’t doing that sort of work, you know, voluntary work, I’d go to Mold about three times a week, you know, to do my shopping and to see my son. So, it was a bus there and back, so about six times a week I’d be on a bus”

What difference do you find on public transport, before your diagnosis and after your diagnosis?

Dory answered: “Well I’m just more anxious because the buses, sometimes they don’t turn up, and I don’t know whether it’s late or because the bus stops are opposite each other, and I never know if I’m on the right side of the road because I’ve forgotten. And because it doesn’t say anything on the bus stop, you know, buses to Mold or buses to Chester, sometimes the buses I want have gone up the other way”

Have you had any difficulties using public transport?

Dory answered: “Yeah, I know my way to Mold, as I say, I was born in Mold, and I’ve always done that journey by bus, but since my diagnosis, I have to go to the Alzheimer’s Society offices in Mold, which are just on the outskirts of Mold. So I wasn’t sure, I got a bus to Mold, then I had to get another bus to get to the Alzheimer’s Society, but I wasn’t sure which bus stop I needed to get off at, so I got on the bus and said to the bus driver, ‘Could you let me know when we get there, what stop I needed to go to the Alzheimer’s Society’, which is a big building just off, so he said ‘Oh, well I don’t know’.

So, I said ‘Oh right’. So, he said ‘Well you should know if you're making that journey, ‘you should know what stop you want to get off at’.
I said well I don’t, because I’ve never been down this way before, I said and I have got dementia and I’m getting a bit worried I’ll end up in

Wrexham or somewhere, because that's where the bus was going, I said so I've got dementia, and he said 'oh haven't we all'

And yet, I was filmed going on the bus by ITV Wales, oh it was a couple of years ago, and there was a man from the Arriva transport, I think he came as a representative, you know for them, anyway, the bus didn't turn up. We were there with the camera, and this man was there looking at his watch and I said to him about not knowing what stop, you know, what stop to get off at, you know, if they had what stops were coming up, and he said 'all you've got to do is ask the driver, use your common sense'. So yeah, not good experiences at all".
Teresa's (Dory) Interview on Zoom: **https://bit.ly/2Qefi8F**

Conclusions:

- Dory has stated that if the bus stops had the required information, it would prevent a lot of unnecessary stress.

- These are examples of how the right information in the right place could prevent stress and anxiety. Timetables on the bus stop and a sign indicating the route would benefit not only people with hidden disabilities but would also benefit the general travelling public as a whole.

- It is also an example of the lack of knowledge of transport staff towards people with hidden disabilities. This is an example of another distressing experience for someone with hidden disabilities which could and should have been prevented by staff, had they had the appropriate training concerning their effect on the person.

Footnote
*The DEEP Network engages and empowers people living with dementia and is hosted by Innovations in Dementia – **www.innovationsindementia.org.uk**

Case Study 2

Name: Nigel H.
Age: 60+
Location: Swansea, South Wales.

Nigel is 60+ years old, Nigel lives on his own in Swansea. Nigel was diagnosed with Posterior Cortical Atrophy dementia in 2012. He is a steering group member of the 3-Nations Dementia Working Group (3NDWG*)

Have you had any difficulties using public transport?

Nigel answered: “I think everybody has a problem with very busy railway stations, although, in all fairness, that if you go to the help-desk they’re usually pretty good, but it is the general overcrowding and in fact some of the trains aren’t fit for purpose when it comes to disabled people.

When it comes to the steps, there’s always a hoohah over disabled seats, who should be sitting there and the problem is you’re asking people to move”.

Is there anything that would put you off using a particular public service?

Nigel answered: “A lack of understanding of my needs, yeah, if people don’t understand what I need, the service isn’t for me, it’s not fit for purpose”.

Is there anything you can think of that would make your travel experience better?

Nigel answered: “Boarding, hanging around waiting for the train numbers to come up on the boards, so probably some form of advanced boarding for people who have a disability card, so they could be sat comfortably and not have to deal with the rush, because it can be dangerous.

I've said to staff if you're a bit wobbly on your legs it can be difficult and there's always a danger of catching the wrong train, which I have done a couple of times".

Do you think that travel for people living with dementia should be part of social prescribing?

Nigel answered: "Absolutely, should be a national initiative, one of the main issues that people living with dementia become isolated is because, well, the main reason is because the public transport system is poor.

A lot of us have had to give up our driving licences and rely on public transport and more often than not the buses are not friendly, the trains are not friendly. The airports are getting better, but you do still have occasions when people say 'why are you standing in the disabled bit, you don't look disabled to me' ".

Are you happy with the public transport available in your area?

Nigel answered: "No, when you get on the bus and there is information telling you next stop etc. I would like that to be a talking thing, you know, you're now coming up to ……. And if you want to get off ring the bell please. Needs to be more age friendly really.

We're all getting older and as you get older you rely on public services and it would suit not only the mental issues but also physical issues too".

Conclusions:

- There is nearly always an issue when it comes to the use of the disabled seats on trains. In most cases, because dementia is a hidden disability, people look at you and are reluctant to give up the seat.

- Nigel's suggestion of some form of enhanced boarding for people who have a disability card so they could be sat comfortable and not have to deal with the rush, because it can be dangerous is a

great example of what could be done to encourage people living with dementia and other hidden disabilities to travel.

- Yet again, because dementia is a hidden disability, PLWD are being questioned and embarrassed about sitting in disabled seats that they are fully entitled to.

- Nigel quite rightly points out that a lot of people when they are diagnosed with dementia, have to give up their driving licences. They may be the only person who drove in the household, or they may, like Nigel, live on their own.

- Another good point that Nigel makes is “We’re all getting older and as you get older you rely on public services and greater accessibility would address not only the mental issues but also physical issues too”. People are living longer nowadays so public transport needs to meet the needs of everyone, with a focus on accessibility for all.

Footnote
*The 3NDWG is a working group of people living with dementia across England, Northern Ireland and Wales. Members are based across the three nations, creating a network of voices on dementia who can lead on regional projects. A steering group of 12 people with dementia drawn from the membership lead the 3NDWG

Case Study 3

Name: Joan B.
Age: 70+
Location: Brecon, Mid Wales.

Joan is 72 years old, Joan lives on her own in the Brecon Beacons area. Joan is the Chair of the Brecon Area Dementia Friendly Community Group.

Do you use public transport?

Joan answered: “I do not use public transport and neither does any of the people living with dementia, that I know use it. The main reason is it’s very Rural. The bus services are, I mean, I live closer than most people that I know with dementia, but even I’d have 1½ miles to get into the town.

To get a train, you have to travel 20 miles, well, in excess of 20 miles to the nearest railway station, and lots of people, particularly in the surrounding villages…

“Frances, for example, Frances, she would have to travel a couple of miles or more, before, maybe more, to get to a bus. So, I think it’s almost impossible.

Everyone that I know that’s living with dementia either has somebody to drive them where they want to go, which can be a pain, I know, or spend some of their allowance on taxis.

A couple I’m very friendly with, just around the corner, the wife takes him everywhere, you know, the husband has dementia, and they spend a chunk of their allowance on taxis so they can go.

But really, people are restricted down here, so I don’t know anyone with dementia that uses public transport, it’s just not accessible to people because of where we live”.

Does this affect quality of life?

Joan answered: “Definitely! It’s an issue, obviously before lockdown if people wanted to get involved in activities and groups and they didn’t have somebody to take them from A to B, they couldn’t get involved, you know, because they really wouldn’t be able to travel, so I’m sure it affects quality of life, and takes away autonomy.

People down here would not be able to go out on their own time because of where we’re situated. People living in the little villages would find it particularly difficult.

People are having to use most of their allowance on taxis to get around. So, there could be people that are socially isolated because they haven’t got access to public transport, if they haven’t got a family member to drive, yeah, people living alone have no choice”.

Do you think that car sharing/pooling might be a way to help these people?

Joan answered: “Certainly, before lockdown one of the things we used to do was, we used to have accessible sessions in the Leisure Centre. So I’d pick up the couple from around the corner and somebody else, so yeah, a bit like car sharing but people giving lifts, otherwise people would not be able to get there unless they were using their allowance to get taxis”

Was that voluntarily, that you organised yourselves and is there any community transport in your area?

Joan answered: “There is Dial and Ride yeah, I think some people use it, but it’s not something you can walk out and use, you have to book it in advance, so for someone living alone with dementia* may find it difficult because it has to be booked and paid for. So, I think it’s very difficult, it’s not like living in Liverpool, I’m not saying life is easier for people in Liverpool, but transport is much easier”.

Do you think Social Prescribing is a way forward for people in rural areas?

Joan answered: “Yeah, I think it probably could, social prescribing is good in any situation, but people in rural areas have different needs to people in the cities.

Everyone is realising what it’s like to be stuck in, this is the time to capitalise and understand the effect it’s having on people’s mental health and cognitive ability, because without stimulation, you know, everybody deteriorates a little, so yeah.

I’m not living with dementia, but, I’ve lost my confidence over the, well, it’s nearly a year, I can feel that in myself, so for PLWD it must be exasperating”

Joan’s interview on Zoom:
https://bit.ly/3vlgXSQ

Conclusions:

- If people are having to rely on lifts from friends and neighbours, then it is taking away the fact that people living with dementia and their carers can travel when they want to and replacing it with when they have to.
- Social Prescribing would benefit the well-being of both the person living with dementia and their carer. It could also have an impact on the health budget as less people would be socially isolated, which could lead to more socialising, which in turn could lead to people feeling less lonely, depressed and anxious.
- There would be the added benefit to the local economy as PLWD and their Carers would be able to use the local businesses, cafes, pubs etc.

*Footnote**A lonely future:120,000 people with dementia living alone, set to double in the next 20 years. Alzheimer’s Society May 2019

Case Study 4

Name: Paul H.
Age: 68
Location: Liverpool

Paul is 68 years old, and lives on his own in his own home. Paul was diagnosed with Alzheimer's 6 years ago.

Do you drive, have you got a driving licence?

Paul answered: "No, I had to give up my driving licence when I was diagnosed with early on-set Dementia, Alzheimer's, which was a blow as I ran my own taxi firm".

Do you use public transport?

Paul answered: "Yes, it's the only way I can get around, taxis are too expensive".

How regularly/often, before Covid, did you use public transport?

Paul answered: "I'd be out every day, I hate staying in the house on my own. If I stay in my dementia gets worse and I feel depressed. It's been terrible during this lockdown; I feel as if I'm in solitary confinement".

I can't wait to go and have a holiday abroad with my mate in the sunshine again. The airports only up the road and I look at the planes going out through my window, and I think they are flying off towards sunnier climates. I loved my holidays in the sun".

Are you able to travel alone, or do you need to be accompanied?

Paul answered: "Yes, I've got no choice as I live on my own".

Are you happy with the public transport available in your area?

Paul answered: "Yes and No. You never know when the bus is going to turn up, and where I get the bus along Speke boulevard there's bushes

and lorries that block the view of which bus is coming, so you have to take your life in your own hands and step out onto the busy road to stop the bus. Sometimes I've put my hand out and stopped the wrong bus, then you get an earful off the driver".

Have you had any difficult experiences of using transport since your diagnosis of dementia?

Paul answered: "Yes, I've got a Disabled Persons Railcard, I used to travel to London a lot by myself, but as the disease was kicking in, I used to find it a bit more difficult.

I particularly remember one day, which is engraved in my memory. I was travelling home to Liverpool, I was on a Virgin train and the rules changed for some reason, which I never knew about, and I got on the wrong train, the earlier train, and sat down.

When the ticket collector came round, she really kicked off on me and was shouting all these horrible things out to me 'People like you are ruining the railway, People like you should know better and this and that and the other', a full rant.

I carry one of the Alzheimer's blue cards, which stated my illness and the problems I have, it's like a help card, so people can read it and calm me down, So I passed that to her and said I'm sorry I've got dementia, I didn't realise.

Anyway, she took it and just slammed it down and said 'I'm not interested in that card'

I'll always remember that, by now I'm at the end of my tether and I'm not sure where the next stop was, Rugby or Stafford, or one of those places. I'd had enough, I just got up, everyone was looking at me, and I said I'm getting off at the next stop anyway and I'll wait for the proper train.

She than start shouting 'You don't have to do that, you don't have to do that'

Anyway, I was so upset and embarrassed, I felt like crying, so I got off at the next station to wait for the next train. I've never felt so low or lonely, waiting on a strange station, wondering if I'm going to be embarrassed on the next train.

I sat there thinking, why didn't the staff understand? We don't do things out of our own volition; I didn't deliberately set out to do something wrong. To make matters worse, the next train was cancelled".

Would you say this affected your quality of life?

Paul answered: "100%, It knocked my confidence about travelling on my own, in fact I've not been to London since, I don't know why staff don't know about these things".

What would encourage you to use public transport more?

Paul answered: "That's easy, If I knew that transport staff had training on how to deal with people like myself, and I knew I wasn't going to be embarrassed, I'd definitely use public transport more".

You said that you have been abroad before Covid, which airport did you use and what was your experience there like ?

Paul answered: "Yeah, I went to Spain with my girlfriend Paula, we flew out of Speke John Lennon airport, you can walk to it from my house. The experience was fantastic from the minute we got there.

Liverpool airport introduced the Butterfly Voucher to assist passengers with conditions such as autism and dementia. The system allows passengers with hidden disabilities, who may need support in passing through the airport to wear a discreet butterfly lanyard.

The staff, from cleaning staff, security staff, retailers etc., have received training on dementia and hidden disabilities, so when they see the lanyard they know that the person has a hidden disability and could need some assistance.

They don’t ask what your disability is, you are fast tracked through check in and they even have a quiet space to go to if you prefer.

It was totally stress free, and if it came to travelling, I would rather go through the airport than get on a train or a bus”.

Conclusions

- Paul’s experience on the Virgin train has affected his confidence about travelling on trains. It’s another example of how a situation could and should have been handled differently.

- The embarrassment that Paul experienced has affected his confidence about travelling on trains. This sort of experience can contribute towards social isolation.

- Prior to this experience, Paul was a confident, independent traveller.

- The worrying thing about this case was the possible outcomes and consequences that could very well have happened. We had the situation where a very distressed Person living with dementia, gets off a train alone at night onto a strange station.

- Sometimes because of their spatial awareness and cognitive abilities, a person living with dementia might not recognise that there are running rails between opposite platforms, so they could just walk towards the opposite platform.

- There was also the possibility that Paul could have tried to walk home along the track, which could have resulted in trains being stopped while the railway line was searched, which could also have resulted in the police helicopter being sent up.

DEEP -THRED Post Covid Transport Survey - Hopes and Fears for people with dementia

We received a further amount of funding from DEEP Dementia Enquirers for a smaller project, as we wanted to find out if the fears of people living with dementia about using public transport have increased because of Covid and what hopes for improvement and fears do they have for using transport Post Covid. It will enable us to compare the findings from our Pre Covid DEEP THRED National Transport Survey and assess if the issues are similar in terms of fears for PLWD.

Tommy Dunne and Paul Hitchmough both living with dementia developed a short snapshot survey to gather the hopes and fears of travelling now and post Covid. There were 8 people living with dementia engaged in the snapshot survey. They also dedicated an hour twitter chat to this subject to gather further feedback. In addition to this there was an in depth interview with Ronald Amanze who travelled from London to Liverpool (when we were out of lockdown but under strict Covid restrictions) for a recording session with Paul Hitchmough last year.

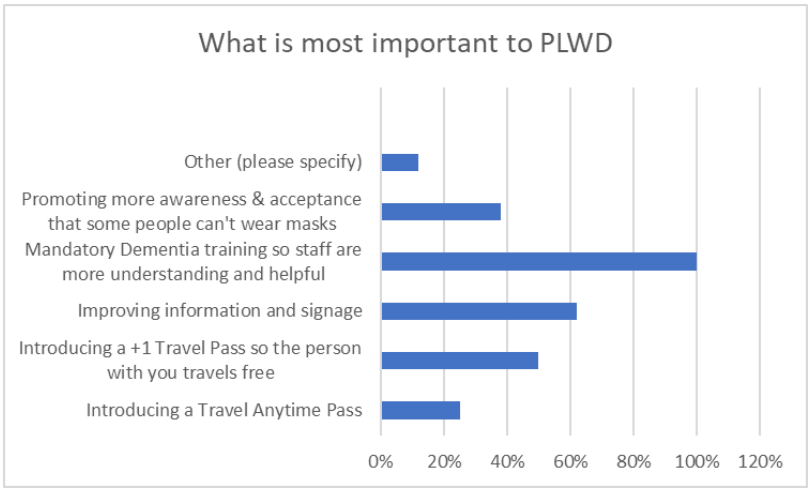
We interviewed and recorded Ronald Amanze on Zoom, discussing his experience of travelling under greater Covid restrictions. Please see the link to his interview below:

https://bit.ly/3tlYjOX

Questions and results from the snapshot

Question 1

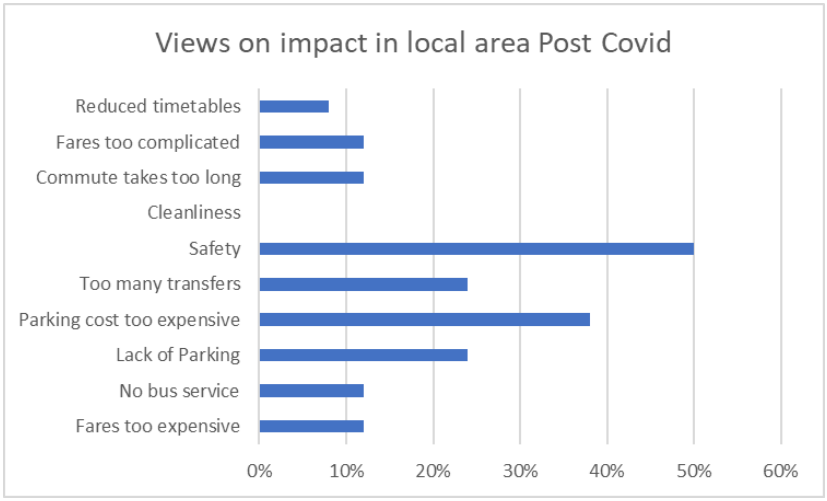
What would you like to see transport providers doing now and post Covid that would encourage you to use their mode of transport? Please tick up to 3 boxes that are most important to you (you can also add your own suggestion in the 'other' box)



The 'Other' in the graph is accompanied by the following comment: "better connections with buses – ever tried getting to hospital appointment by bus?"

Question 2

Which of these do you think will impact the most on your experience of public transport in your local area Post Covid? Please tick up to 3 boxes that are most important to you (you can also add your own suggestion in the 'other' box)



Question 3

Has the current pandemic affected your confidence in using public transport, if yes, in what way?

Comments

“No”
“No, there has been a lot less people on them”
“Yes”
“Cleanliness and I work from home”
“yes, ...Not sure if it's safe to travel on public transport, being challenged for not wearing a
mask, other people not wearing masks”
“I feel socially isolated. Worried about safety and how public will use masks”

Question 4

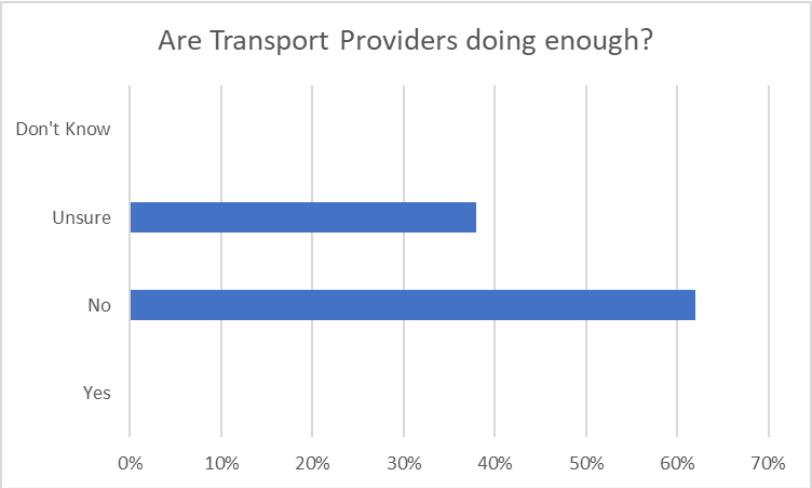
What are your Hopes and Fears for travelling Post Covid?

Comments

“I would take my old relative by car instead to save time”
“I want to remain independent, and fear losing my driving license”
“Ease of movement”
“Clean safer transport”
“Hopes, more services”
“Hope that travelling on public transport can return to normal, Fears, that this may never happen
unless managed safely and there are people in place with the right information, training to
manage very different operating environment”
“Staff are aware of hidden disabilities. Safety biggest fear”

Question 5

Do you think that Transport Providers are doing enough now during this current 3rd lockdown to encourage people to use public transport safely Post Covid?



We will share our findings with transport groups with the intention of influencing positive change for a post Covid world, essential for restoring confidence to get out and about, allay fears and reduce further social isolation.

Conclusions

Safety is the number one priority for people living with dementia. There are also concerns over how wearing of masks (if still required) will be managed and enforced. Currently in Liverpool British Transport Police are assisting local police forces to manage confrontational behaviour linked to travelling during Covid and to enforce safe travel during Covid, including the wearing of masks.

It is clear from this survey that those taking part believe that mandatory Dementia training of staff is a priority, as people with dementia will need additional re assurance and support to build their confidence to keep travelling independently. The fear is that transport providers are not doing enough now to encourage people to use public transport safely Post Covid.

The snapshot survey also reinforces the same concerns from the Transport Enquirers project, better information and signage, fully trained transport staff and additional carer passes will help increase confidence

for people living with dementia to get back our and about connecting with local services, families and in their communities.

PLWD still have fears that public transport may never return to normal, and one of the biggest fears is that safety will not be managed properly.

Quotes

What if staff make a scene and embarrass me?

How will I cope if I have to stop driving?

"Am I eligible for home/hospital transport?"

I'm frightened to approach staff for help in case they think I'm stupid

"Can I get public transport discounts?"

Sometimes I can't get the words out to ask for what I want, staff look at me as if I'm drunk

I would feel more comfortable approaching staff if I knew they had an understanding of hidden disabilities

It would be nice if staff were trained to recognise that someone may need help without them having to ask. 'A more proactive approach'.

England - Scotland - Wales - Northern Ireland

According to the Office for National Statistics, in 2019 the population of the United Kingdom was estimated to have been over 66.8 million

England: the population was estimated to have been 56.29 million. There are 11 million disabled people in Britain (Source: Prime Minister's Strategy Unit). Over 7 million people or 18% of the working-age population in Britain are disabled as defined as by the Equality Act 2010 (Source: Employers' Forum on Disability).

There were vast differences in the transport services, depending upon which region and area you lived in. There was evidence from those we spoke to that people were being socially isolated because they did not have access to a regular, reliable transport system.

Scotland: the population was estimated to have been 5.46 million. There are 1 million people that are defined as disabled. (Scottish disability awareness)

Again, there were vast differences in the transport services, depending upon which region and area you lived in. Again, there was evidence from those we spoke to that people were being socially isolated because they did not have access to a regular, reliable transport system.

Travelling to and around certain regions of Scotland, particularly rural areas, can be difficult and costly. This can deter people from travelling to rural areas of Scotland, and those who do, often travel by car rather than public transport.

Wales: the population was estimated to have been 3.15 million. With 21% being classed as having a disability (*People living in Wales (26%) are more likely to have a limiting long-standing illness or disability than other regions of Great Britain)

In some areas of Wales, the people we spoke to said that transport was so bad, they had to rely on neighbours and friends giving them lifts in their cars. The alternative was to walk a mile or 2 to get to a bus stop. This is not practical if you are living alone and have dementia.

Again, depending upon what part of Wales you live in, transport services can be as little as a bus an hour.

Northern Ireland: the population was estimated to have been 1.8 million. (Recently published statistics show that almost one in five persons of working age (18 per cent) in NI have a disability. Disability Right in Northern Ireland - Equality and Human Rights Commission)

In some rural areas of Northern Ireland, there is only one bus service a day, One person stated that the only bus that runs at the bottom of his lane is the school bus, and that only runs during school term. (Heaven knows how he has coped during this pandemic with the schools closed).

In Northern Ireland they use the JAM Card. JAM stands for Just A Minute – it's a special card created by NOW Group service users for when they need more time and patience while using shops and public transport.

JAM Cards allow people with hidden disabilities and people with a learning difficulty, autism or communication barriers to tell others they need 'Just A Minute' discreetly and easily.

Those with a communication barrier are often reluctant or unable to tell others about their condition. The JAM Card allows this to happen in a simple, effective non-verbal manner.

JAM Card was originally developed for those with learning disabilities and difficulties. However, it can be used by anyone with a communication barrier.

Issues raised during our conversations with the UK groups (see Acknowledgments)

1. The need for staff to have training and awareness of the problems people with dementia and their carers have when using transport.

2. The need for the carer to be able to accompany the person with dementia at all times without them incurring additional costs.

3. Bus drivers need to be more patient with people who are using passes especially when there is a problem with the pass.

4. Bus drivers should wait until passengers are seated before starting away.

5. It would be nice to be able to ask the driver to remind you where you get off the bus.

6. Audio and Visual display of what bus stop is next, also would be helpful if it could include landmarks.

7. Emblem on pass to indicate that person has dementia or national card.

8. Taxis hit and miss space wise, told the person in the wheelchair "Oh we'll make do" and the person tipped back in chair.

9. Bigger space required for wheelchair users to get on/off buses and for those with cases.

10. Bigger lifts, easy access, ramps, not all stations have lifts or ramps on both sides of the platform.

11. Clear pathways, Better Signage, Clear Announcements.

Facts

- There are over 12 million people 65 and over in the UK (*Source: age concern).
- Britain's disabled people are estimated to spend £80 billion per year (*Department for Work and Pensions. DWP).
- The 'purple pound' is a term used to describe the spending power of disabled people and their families across the retail and leisure industries.
- The purple pound is worth an estimated £212 billion to the British economy.
- Only 17% of disabled people were born with their disabilities (*Source: Institute for Public Policy Research article: Work for disabled people).
- One in four people will be affected by mental Health illness during the course of their life (*Source: Mind).
- Good active travel facilities provide opportunities for recreation, for people walking, wheeling, running or cycling, whether together or individually to enhance their health and wellbeing.
- People with dementia would still like to go out and spend money, but they need good safe, reliable public transport to get there.
- Transport providers spend £millions on vehicles and infrastructure and hope that it's suitable for everyone, **but** their most valuable asset, their staff are trained on everything but dementia and hidden disabilities, and they expect their staff to be able to deal with the many situations they may come across, if and when they have to deal with a Person with a hidden disability.
- There may come a time when travelling is too disorienting or stressful for the person with dementia.

Barriers to travel

Barriers to travel can create considerable problems for disabled people.

Key challenges that the transport system must address include:

- being able to access easily understandable, accurate and relevant travel information both before and during the journey
- being able to access public transport interchanges
- being able to interchange between all modes
- being able to access public transport vehicles
- concerns regarding safety and comfort on the public transport network

Conclusions

- Mobility is central to the whole of society. It allows people to connect with places, and shapes how we live our lives.

- We need to work together with transport providers to help them understand the needs of People living with Dementia and other Hidden Disabilities, to ensure that people are not forgotten and left socially isolated.

- We need to build up confidence in People living with Dementia and their Carers and other People with Hidden Disabilities to enable them to use Public Transport.

- Getting transport right for PLWD will benefit society and the economy as a whole, as they regain the confidence to get out into society and spend money.

- There is a connection between travel and quality of life; when older people are unable to travel, it is often due to illness, low income or isolation.

- Evidence also shows that the journey itself, rather than the end result can be beneficial to wellbeing.

- Many disabled people feel trapped due to the lack of accessible transport, particularly in rural areas.

- Transport can play a crucial role in keeping people connected, allowing them to socialise, access services and meet with friends and family face-to-face.

- Reliance on community transport schemes will not satisfy the needs of all sectors of the rural population.

Recommendations

1. People have different needs and capabilities. A transport system should recognise these and work to ensure that everyone can use the system with as little effort as possible.

2. Good transport is important for everyone, and as the proportion of older people in our population continues to increase, we have to ensure that this transport should not be exclusive to the young or the able-bodied.

3. Rural areas require a flexible approach to ensure the mix of schemes and approaches in each area takes into account specific population needs and context.

4. We have got to get away from the one-size-fits-all solution when it comes to disabilities. It is time that transport providers and manufacturers worked hand in hand with people with disabilities, from the planning stage right through to the deliverables.

5. Social inclusion goals will require a different approach than an intervention designed to meet the needs of economic development.

Disability Compliance

Disability awareness training is a legal requirement in the transport industries as elsewhere, but in many cases it focusses on the needs of wheelchair users and others with disabilities that are easy to identify.

Whilst there has been training in these areas in recent years that has enormously improved the travel experience and confidence of many people with visible disabilities, the needs of those with other disabilities has been left behind.

There needs to be training in the much broader and less well defined area of hidden disabilities so that staff in direct contact with the travelling public do not make assumptions that can cause anxiety and distress.

The training of staff on hidden disabilities can help prevent social isolation.

Rights of Disabled Passengers on Transport:
https://www.gov.uk/guidance/rights-of-disabled-passengers-on-transport

Facilitators' Notes - Pat Broster & Louise Langham

This project was set up for people living with dementia to do their own research and to lead the development of the work from the perspective of a person living with dementia.

Our Project – both Pre and Post Covid - has been led by Tommy Dunne, a professional manager working across the transport sector during his career, prior to being diagnosed with dementia, and his peer, Paul Hitchmough a businessman who established and managed a local transport company in Merseyside prior to being diagnosed with dementia.

Tommy and Paul are directors of thred CIC together with Pat Broster and Louise Langham, former carers for parents who had dementia.

Pat and Louise were facilitators for this project and supported the organisation, management, marketing, delivery and analysis of the project.

Tommy and Paul developed relevant questions for surveys, met and engaged with DEEP groups and others; interviewed and filmed discussions they had with different groups across the UK. Additionally, they followed up their research to highlight emerging issues through thred's weekly twitter chat.

During this project Tommy and Paul have increased their skills in recording, interviewing and analysing the outcomes of this project. Tommy has used his professional reporting skills and with Paul drawn conclusions on the information and feedback people living with dementia have given, to highlight issues raised and proposed potential solutions.

It became clear early on in the project that Tommy and Paul had the credibility with their peers to open up trusted conversations and understanding of the transport issues raised which provided a platform to dig deeper as a researcher. The additional element that really helped this project was the creative and diverse approach that both Tommy and Paul used when engaging their peers. They engaged creatively with different groups using original music, humour and role play to gather feedback, views and information on transport issues that affect both rural and urban communities.

The Covid restrictions impacted this project at an early stage. Travel to different groups across the UK was halted, so we replanned engagement via Zoom meetings. It was also anticipated that we would organise an event in May ’20 between transport providers and people living with dementia to share the findings of this report. Unfortunately, this too was shelved and the facilitators are organising how we share the findings of this report via email, twitter and other social media platforms. We will also directly engage with transport providers to keep the conversation open as to how transport can be improved across the network ensuring accessibility, information and support.

Acknowledgements

DEEP (Dementia Engagement and Empowerment Project)

Rachel Niblock for helping us set up DEEP thred (national transport DEEP group)

Philly Hare (for pointing us in the right direction and encouragement at the start)

The National Lottery Communities Fund, for providing funding via the Dementia Enquirers project

Teresa ‘Dory’ - DEEP Deeside Group

Joan B - Brecon Area Dementia Friendly Community Group.

Nigel H. - 3 Nations Dementia Working Group

George Rook and the Shropshire and Telford Health Economy Steering Group

Ron Amanze - London

All the respondents to our surveys

Northern Accessibility User Group - Northern Trains

Merseytravel for their continued support, information

Dr Catherine Talbot, Bournemouth University

DEEP Groups in England, Scotland, Northern Ireland and Wales

Information points

*Alzheimer’s Society

*Alzheimer’s Disease International

*Employers' Forum on Disability.

*Scottish Disability Awareness

*Statswales.gov.Wales

*Disability Right in Northern Ireland - Equality and Human Rights Commission

*Department for Words and Pensions. DWP

*Institute for Public Policy Research article Work for disabled people

*Mind (Medical Investigation of Neurodevelopmental Disorders)