

What is the relationship between transport and mental health for people who are living with dementia?

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Chapter 1: Introduction

People who are living with dementia frequently highlight the importance of getting out and about in the community. They report that this enhances their wellbeing, self-confidence, independence, social contact and stimulation. However, they also describe the stress and anxiety¹– and even trauma–that they experience if arrangements are not accessible or when things go wrong.

While most transport providers make at least some reasonable adjustments for those with physical or sight impairments, accommodations for people with cognitive impairments are less mainstream. Poor signage, too much echo and noise, busy platforms, complicated timetables, poorly educated staff, bewildering floor surfaces and much more can result in people with dementia feeling frightened, de-skilled, and exhausted by their travelling experiences. Yet if they stop going out because of this, there is a wealth of evidence of the impacts on their loneliness and mental wellbeing.

Transport is an issue that has come up time and time again in the work of our organisation, Innovations in Dementia (see Appendix 3). It is often the topic of blogs, films and group discussions, and has been explored by a number of groups in DEEP, the UK Network of Dementia Voices (for more detailed information, see Context review in Appendix 4). DEEP has also co-produced a [template for personalised travel plans](#) which can and is used to help people get themselves to events and meetings. Transport is widely acknowledged as an issue which has a great effect on the day-to-day lived experience of people with dementia.

In 2022, Mental Health Foundation invited Innovations in Dementia to explore the impact of public transport on the mental health of people with dementia. This work would be linked to a wider public health agenda as part of their wider piece of work for Motability, in which two other groups would also be involved–people with a psychiatric diagnosis, and mothers with mental health issues.

The project was led by people who are living with dementia, and ran from September 2022 to February 2023.

¹ For example in [Cognitive Impairment, Mental Health and Transport](#) (International Transport Forum, OECD 2009)

Chapter 2: Context review

At the start of the project we carried out a quick context review. Our aim was to identify key evidence on the relationship between dementia, transport and mental health, in order to inform our project.

The review included any evidence, in the broadest sense, which could be helpful to the aim. This included grey literature, for example reports produced in the third sector, as well as audio and video diaries published in [Dementia Diaries](#). Most evidence was identified through search engines or personal networks.

It proved difficult to identify studies which had directly and overtly linked dementia, transport and mental health. However, when we introduced terminology *related to mental health*, the review proved much more fruitful. Negative terms included for example, 'traumatic', 'challenging', 'loneliness', 'fear', 'difficulties', 'stress', 'anxiety', 'panic', and 'confusion'. Positive terms included 'wellbeing', 'confidence', 'social relationships' and 'roles', 'socially active', 'enjoyment' and 'inclusion'. We effectively used these terms as proxies for mental health outcomes.

We found useful evidence on the following issues:

- The importance and benefits of getting out and about
- Barriers to using public transport
- Different types of transport, including:
 - Driving (and parking)
 - Train travel
 - Air travel
 - Taxis
 - Bus travel

The review also uncovered useful evidence on potential adjustments and solutions.

Conclusions

Transport is usually a means to an end to reaching an activity, a friend, an appointment etc. It can be a barrier or facilitator to achieving these ends. But it can also be a barrier or facilitator to wellbeing (i.e. good mental health) in its own right.

The evidence shows that many of the solutions are about infrastructure. However, the skills and confidence of the person themselves are also important—we need to recognise the complex cognitive skills needed to use transport.

There is a knowledge gap on public transportation and people with cognitive impairments, and closing these gaps is an important task for future research. In much of the research on problems with daily activities among cognitively impaired people, issues with local public transport use are identified but not further specified. A more in-depth assessment of causal factors and actual barriers experienced in all sections of the travel chain would yield insights and help to improve both accessibility and usability for these specific user groups. Studies based on real-world experiences are essential, and more user-centred approaches should be adopted. Moreover, there is a need for the development and evaluation of evidence-based rehabilitation. Finally, more research is needed to foster societal awareness of the problems and needs in the public transport travel chain for people with cognitive impairments.

However, from the evidence we do have it is possible to summarise 8 key factors in the relationship between dementia, transport and mental health:

1. Accessibility of information
2. Accessibility of design and environment
3. Signage and navigation
4. Skills and confidence of the traveler
5. Personalised journey plans
6. Costs (including eligibility for, and awareness of, concessions)
7. Training, presence and approachability of staff
8. Quality and reliability of assistance arrangements, especially when journeys change or go wrong

You can find the full context review in Appendix 4.

Chapter 3: Aims and methods

Using a Dementia Enquirers process

Dementia Enquirers is a programme of work around people with dementia being in the driving seat of research. It is hosted by Innovations in Dementia and has been funded by the National Lottery Community Fund (2018-2023).

Groups of people with dementia have been supported to (a) identify their own research questions; (b) learn about and carry out their own research; (c) analyse results and report on their findings.

A range of resources have been created as part of the programme including guidelines around accessibility, research methods, and ethical processes. You can read more about Dementia Enquirers at www.dementiaenquirers.org.uk

The Motability project has been a good avenue to test out some of the approaches that have been developed by Dementia Enquirers.

Recruiting a research team

The opportunity to be part of a small research team of people with dementia was advertised to the DEEP network (a UK wide network of about 80 groups of people with dementia). We also sent the invitation personally to some people with dementia who had prior interest in transport issues and dementia.

We recruited nine people with dementia to the research team: Julie, Maq, Jacqui, Gail, Paul H, Paul R, Tommy, Teresa and Wendy.

Philly Hare and Rachael Litherland from Innovations in Dementia provided support to the research team to enable them to run the project.

A reminder was given to people throughout the project that this was a short research project that we were running together. We reminded people at each meeting that we were researching the impact of public transport on people's **mental health**. We wanted to move away from the practicalities that help people with dementia to use public transport, and towards how using public transport makes people with dementia feel. We also reminded people that this was part of a big project being organised by the Mental Health Foundation.

What we did

Here is a description of what we worked on at each meeting.

Meeting 1: group discussion about the impact of travelling on public transport; supported by the artist evaluator Jolie Goodman to represent these feelings in drawings and words. People had positive as well as negative experiences to share.

Meeting 2: we thought about how to carry out this piece of research. We agreed we should keep it simple and straightforward to achieve. We should be careful not to be biased in the way we ask questions e.g. we shouldn't assume everyone has a negative experience of travelling. We discussed the type of questions we could ask other people with dementia to find out about the impact on their mental health of travelling on public transport. We created a long list of questions to think about. We also talked about the possible methods we might use in our research. We started off thinking that a questionnaire, some interviews and a 'feelings measurement' might be good.

Meeting 3: we designed an information sheet and consent form.

Meeting 4: we focused on ethics – wanting to make sure that our project was ethical in its approach. We referred to the Dementia Enquirers Gold Standards, which are designed by people with dementia. The Standards are:

- Working in real partnership (co-production)
- Respect and acknowledgement
- Safety and wellbeing
- Informed consent and capacity
- Confidentiality and anonymity
- Information that is simple, accessible and open

We agreed that a project information sheet and consent form was necessary if we were going to carry out interviews.

We refined our survey questions based on discussion.

Meeting 5: we looked at the answers to the questions pertaining to dementia in the Public Opinion Survey, and we talked about how we could encourage more people with dementia to complete our survey. We became more realistic about what we could do in the given time – and choose a questionnaire as our research method. We finalised the survey and Rachael launched it on SurveyMonkey on behalf of the group.

Meeting 6: we looked at the results so far from our survey and thought about what these results might mean. We discussed how it seems there are many issues underlying the psychology of asking for help, maybe location, stigma and life experience for example.

Meeting 7: we looked at the final results from our survey. We were surprised at some, less so at others. Some made us feel sad. We discussed the best ways of presenting the results so they are accessible to people with dementia (bar charts and pie charts are good, word clouds are bad!).

Our research method

Although the group had initially wanted to use a lot of different research methods to gather data, we changed our minds as the project progressed, based on the amount of time available and how able people felt to manage the processes.

A questionnaire was created and circulated via SurveyMonkey. We advertised the link through the DEEP network, and also through Twitter (via Innovations in Dementia), with purposeful tagging of organisations like Alzheimer's Society, Dementia UK, TIDE and Age UK, asking for these organisations to send the link on to people with dementia.

We asked that other people might support the person with dementia to complete the survey. But we were clear that we only wanted the views of people with dementia to be reflected in the survey answers.

The survey was open for 8 weeks.

Rachael collated the results from the survey, and we analysed them together at Meetings 5 and 6.

Chapter 4: Findings

Who filled in the survey?

40 people with dementia completed the survey

- 5% were aged between 45-54
- 25% were aged between 55-64
- 42% were aged between 65-74
- 23% were aged between 75-84
- 5% were aged between 85-94

What does this mean? These results may be a limitation of our SurveyMonkey approach to collecting data, in that older people are less likely to have access to the internet. However, 28% of respondents were over the age of 75. It may also reflect the age of people with dementia who are most likely to be using public transport.

How often did people travel by public transport?

- 15% travelled less than once a month
- 5% travelled once a month
- 17% travelled a few times a month
- 2% travelled every day
- 22% travelled once a week
- 39% travelled a few times a week

What does this mean? 63% of people with dementia who filled in our survey are frequent users of public transport, using it weekly, sometimes more than once. Other people travel less frequently.

How did people travel?

People reported the kinds of public transport they used. People could choose up to two examples. The results are reported here in descending order.

- Bus (74%)
- Train (64%)
- Taxi (21%)
- Aeroplane (12%)
- Tram (7%)
- Tube (7%)
- Ferry/boat (2%)

60% of respondents travelled alone on public transport; 40% travelled with someone else.

What does this mean? There are some common modes of transport that people with dementia are using – train and bus. This might focus any future initiatives that aim to improve travel experiences for people with dementia. It should be noted that a lot of people with dementia in the survey travelled alone (60%). This has implications for things like the use of the sunflower lanyard, the willingness to ask for help (and for other passengers to offer help) and more organised travel assistance.



How do you generally feel about travelling on public transport?

The answer options for this question had been generated by the research group in Meeting 1 and had arisen from their own feelings when using public transport. You will notice that there are positive responses included as well as negative. Respondents were asked to tick their top four answers. Results are reported here in descending order.

- Anxious (74%)
- Worried (60%)
- Uncomfortable (45%)
- Fearful (29%)
- Safe (21%)
- Happy (19%)
- Free (19%)
- Lost (16%)
- Cared about (14%)
- Stupid (9%)
- Lonely (9%)
- Stimulated (7%)
- Equal (5%)
- Included (2%)
- Unwelcome (2%)

What does this mean? There were four times as many negative responses as positive responses. Although travelling by public transport with dementia can sometimes engender positive feelings, it is more likely to be a negative experience.

How does it feel when travelling goes well?

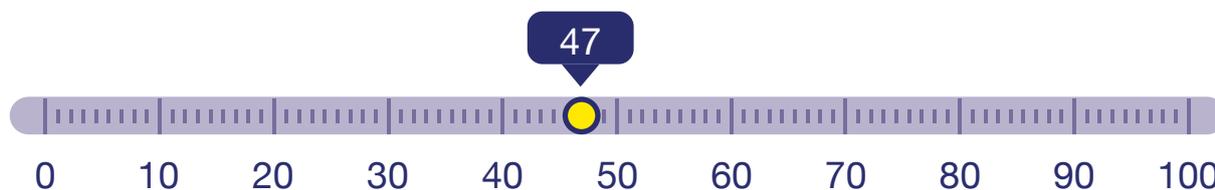
A successful trip using public transport provokes a lot of positive feelings. These results are reported in descending order and were a freestyle answer. Some people used more than one word to describe their feelings.

- Happy (12 mentions)
- Relieved (9 mentions)
- Proud (5 mentions)
- Satisfied (4 mentions)
- Elated (4 mentions)
- Normal (3 mentions)
- Pleased (3 mentions)
- Encouraged (2 mentions)
- Comfortable (2 mentions)
- Confident (2 mentions)
- Grateful (1 mention)
- Safe (1 mention)
- Excited (1 mention)
- Independent (1 mention)
- Content (1 mention)
- Empowered (1 mention)
- Accomplished (1 mention)
- Included (1 mention)

What does this mean? A successful trip on public transport tends to give people with dementia a sense of happiness – but also relief. This suggests that people are prepared for their experience to be negative – and pleasantly surprised when it goes well.

How confident do people feel before they set off on their journey?

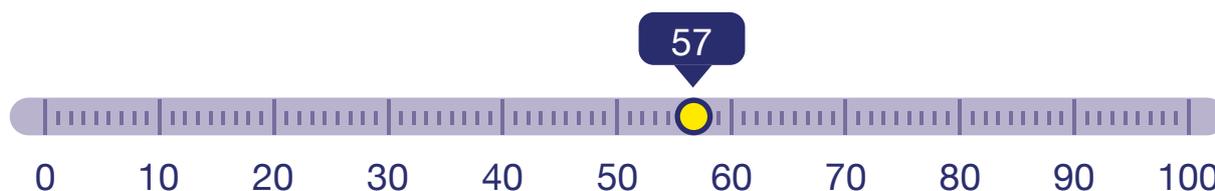
This question used a sliding scale between 1 and 100. People could move a dot to a place on the scale that reflected how confident they feel before they set off. The mean result was 47 (ranging from 5-97).



What does this mean? People with dementia are, on average, in the middle range of confidence before they set out on a journey, although some people are very confident, and others are very unconfident. In the future we could carry out qualitative interviews with these two subgroups to find out more about why this difference in confidence might occur.

How likely would you be to ask for help on your journey?

A sliding scale between 1 and 100 was used again. The mean result was 57 (ranging from 0-100).



What does this mean? People vary in how likely they would be to ask for help on their journey, with some people being very likely to ask for help and others not. In the future we could carry out qualitative interviews with these two subgroups to find out more about this difference. From the Public Opinion survey we know that a high percentage of the general public feel that they would offer help to people using public transport if they looked confused. People with dementia in our research group responded very positively to this result. If more people with dementia knew that the general public were, on the whole, helpful, this might encourage them to ask for help.

How do people with dementia reduce stress when travelling?

This was a freestyle answer, with a range of ideas, sometimes replicated across people.

The results are presented in descending order:

- Plan and rehearse the journey (10 mentions)
- Chat to other people (9 mentions)
- Read (5 mentions)
- Play a game (5 mentions)
- Look out of the window (4 mentions)
- Listen to music (3 mentions)
- Book assisted travel (2 mentions)
- Have a destination to show someone (1 mention)
- Have a map to act as a reminder (1 mention)
- Walk (1 mention)
- Take photos (1 mention)
- Wear a sunflower lanyard (1 mention)
- Travel off-peak (1 mention)
- Hide (1 mention)

What does this mean? People with dementia have lots of different stress-reducing strategies which support them when using public transport. It could be helpful to remind people to identify their personal strategies before they embark on their journey, so that they can draw on them consciously rather than as a stress reaction.

What do people do when travelling doesn't go according to plan?

1. If I miss my stop, I sit on the bus, wait for it to go round
2. Let my husband/carer sort things out. I would only worry if I saw he was worried
3. Before I travel I make sure I have a contact number for me to ring if I need help
4. I have been known to ask for help, but sometimes I rethink whether to do the journey again
5. I might not travel for a few days till I feel confident again
6. Panic and get upset
7. Cry and call husband or daughter
8. Adapt. Go with the flow as much as possible. Listen and really pay attention to details
9. Try not to panic attack. Ask for help
10. Make tea when I get home
11. Become agitated and confused
12. Try to sit and work out what's wrong and get help to put it right
13. Get annoyed and trusted and have a word with the driver to complain
14. I get anxious

15. Ask for help and advice
16. There's nothing I can do apart from get frustrated
17. Try to work it out if possible. Otherwise ask. Always got my phone to call someone
18. If no bus call cab to avoid lateness. If bus not fit then get off and walk or cab
19. Phone my family and ask for help
20. Always have a Plan B or ask for help from (a) my daughters if not at work or (b) social media
21. I try to start my travel earlier than I need, in case something doesn't go according to plan.
22. Give up and go home
23. May need to get a taxi or phone a friend for a lift
24. Get anxious and turn my music up louder
25. I withdraw. I have a period of time when I say to myself "never again". But my willpower kicks in

What does this mean? People with dementia have lots of practical and emotional solutions when things don't go according to plan on their journey. It could reduce stress to plan ahead with an answer to the question "*What will I do if things go wrong on this journey.*"

What things stop you travelling?

We know that a difficult journey can mean that people retreat, and don't want to try again, at least for a while. We have already seen responses about "giving up" and "hiding".

These are the things that people said stop them travelling. Results are shown in descending order.

- Confusion around aspects of travel such as reading timetables, or planning a journey (11 mentions)
- Crowded transport or the worry about crowded transport (7 mentions)
- Infrequent public transport – including cancellations (7 mentions)
- General fear and anxiety (5 mentions)
- Unhelpful or unfriendly staff (3 mentions)
- The weather (3 mentions)
- Additional costs because of disability (2 mentions)
- Noise (1 mention)
- Having to use a ticket machine (1 mention)

What does this mean?

The symptoms of dementia can exacerbate the experiences of travelling on public transport, for example, planning a journey or interpreting travel information during a journey. More practical things, that other people may also experience, also apply to people with dementia, and may compound existing issues that stop people travelling.



Experiences of using travel assistance

In our sample, we found that:

- 44% of people had never used travel assistance
- 22% of people had used it once
- 27% of people had used it sometimes
- 7% of people had used it often

Of those people who had used it at least once:

- 79% said it was usually helpful
- 13% said it was sometimes helpful
- 4% said it was rarely helpful
- 4% said it was never helpful

What does this mean? A lot of people with dementia have never used travel assistance, but those who have, on the whole, are positive about it. It is possible that travel assistance is most strongly associated with train or aeroplane travel (rather than e.g. bus) but also that many people with dementia are not aware of it, and how to access it. This could be explored in further research.

Chapter 5: What next?

As the project progressed, those involved came up with a number of ideas for future research questions. These included:

Help-seeking

We would like to know more about:

- the psychology of asking for help – maybe looking at location, stigma, life experience etc. When do people ask for help and why (or why they don't)
- what response they have when they do ask for help
- the sunflower lanyard—how well do the public recognise it, and, if they do, how do they respond? How do people feel about wearing it? What about other identification cards stating that the wearer has dementia?
- experiences of Assisted Travel in the various transport sectors – and how these could be improved or made more consistent

Travelling alone

We would like to understand more about the experiences of travelling alone versus those of travelling with someone else.

- Do some people with dementia prefer to travel alone – and if so, why?
- How do the feelings people have about travelling correlate to whether they are alone or not?
- How can they feel less lonely while travelling?

To drive or not to drive?

Thirdly, it would be interesting to explore how many of those living with dementia who can still drive a car actually choose to use public transport instead—and why?

A more general suggestion is for more 'action research', through which potential solutions and adjustments to public transport issues could co-produced with, and tested out by, people with dementia. This might also usefully involve real-time observation to complement retrospective reporting.

Appendix 1: Project Information Sheet

Project Information Sheet (October 2022)

This short research project is being led by people with dementia, with support from Innovations in Dementia and funding from Motability. This is part of a bigger project being organised by the Mental Health Foundation.

We want to find out about the impact of public transport on people's mental health.

If YOU are living with dementia AND use public transport (sometimes or often) we'd love you to be involved.

You may contribute through our online survey <https://www.surveymonkey.co.uk/r/transportdementia> and/or through an interview or group discussion.

Our commitment to you is that:

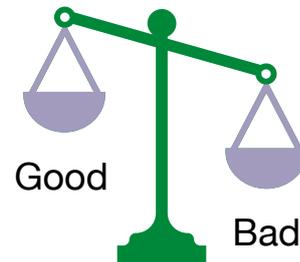
- We treat you with respect and make the process as easy as possible
- We keep and store your name, identity and responses safely and securely
- You can withdraw at any point, without giving any reason
- We give you feedback on our findings if you wish (you will need to share your contact details for this)
- If you become upset when contributing your views or experiences, we will do our best to support you.

If you have any questions please contact Philly Hare philly@myid.org.uk

Appendix 2: Consent Form

I have been told the potential benefits and risks of the study.

(tick if agree)



I understand that I am able to leave the project at any time without giving a reason.

(tick if agree)



I know my personal information will be anonymous and stored securely.

(tick if agree)



I know who to ask for help if I have any questions.

(tick if agree)



Name: _____

Signature: _____ Date: _____

If you are unable to sign your name, you can ask someone else to do it for you.
Or we can record you saying that you give your consent.

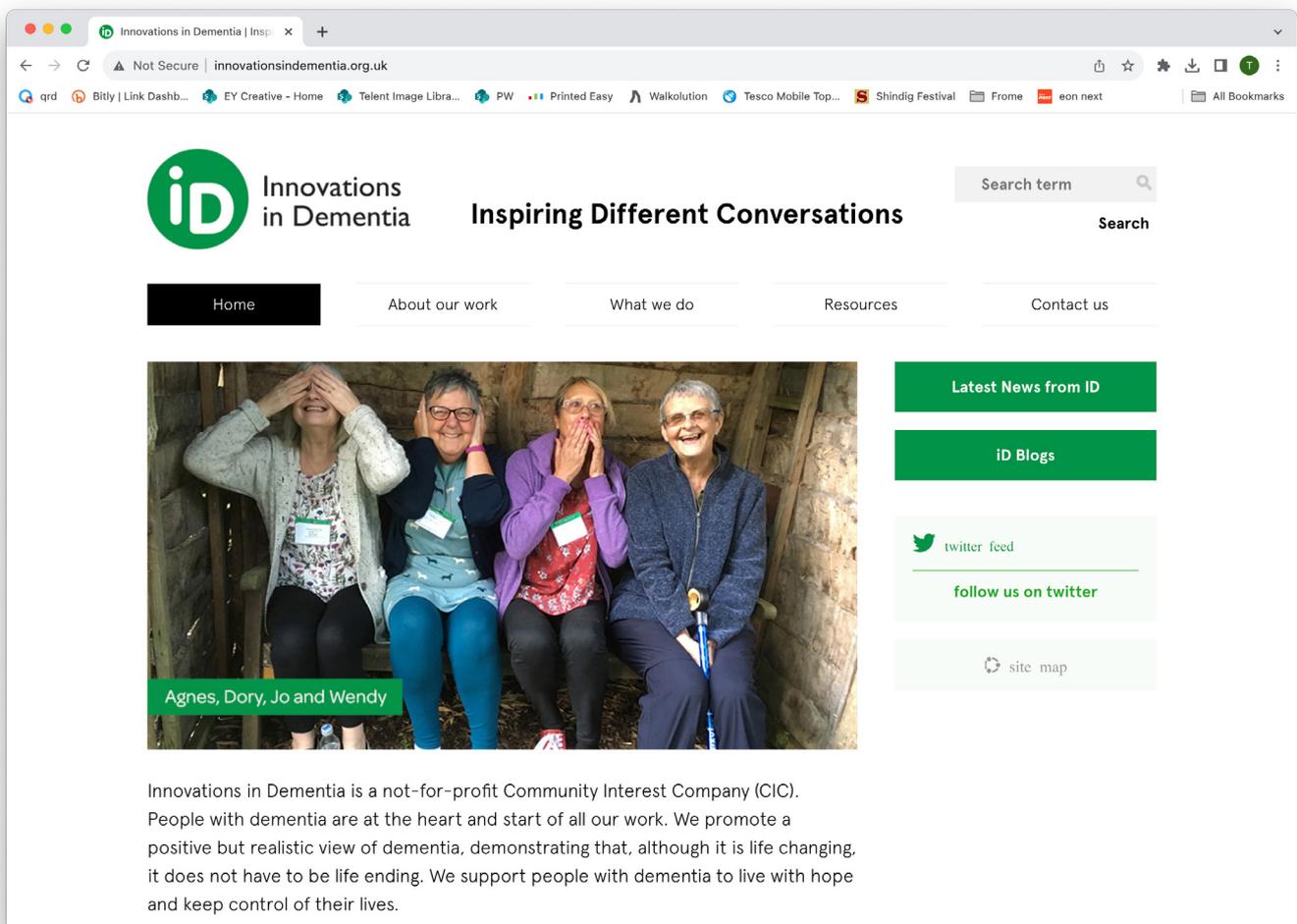
Appendix 3: Innovations in Dementia

Innovations in Dementia is a well-established not-for-profit Community Interest Company (CIC).

We support people with dementia to live with hope and keep control of their lives.

We want to influence how others engage with people with dementia, and we provide training and consultancy. We run many innovative projects, often in partnership with universities, public bodies or charitable funders.

We promote a positive but realistic view of dementia, demonstrating that, although dementia is life changing, it does not have to be life ending. People with dementia are at the heart and start of all our work.



The screenshot shows the homepage of the Innovations in Dementia website. The browser address bar displays 'innovationsindementia.org.uk'. The website header features the 'id' logo, the text 'Innovations in Dementia', and the tagline 'Inspiring Different Conversations'. A search bar is located in the top right corner. A navigation menu includes 'Home', 'About our work', 'What we do', 'Resources', and 'Contact us'. The main content area features a photograph of four women sitting on a wooden bench, with a caption below reading 'Agnes, Dory, Jo and Wendy'. To the right of the photo are several green buttons for 'Latest News from ID', 'iD Blogs', and 'follow us on twitter', along with a 'site map' link.

Innovations in Dementia is a not-for-profit Community Interest Company (CIC). People with dementia are at the heart and start of all our work. We promote a positive but realistic view of dementia, demonstrating that, although it is life changing, it does not have to be life ending. We support people with dementia to live with hope and keep control of their lives.

Appendix 4: Context review

The aim of our quick context review was to identify key evidence on the relationship between dementia, transport and mental health, in order to inform our project.

It proved difficult to identify studies which have directly and overtly linked dementia, transport and mental health. However, when we introduced terminology *related* to mental health, the review proved much more fruitful. Negative terms included for example, 'traumatic', 'challenging', 'loneliness', 'fear', 'difficulties', 'stress', 'anxiety', 'panic', and 'confusion'. Positive terms included 'wellbeing', 'confidence', 'social relationships' and 'roles', 'socially active', 'enjoyment' and 'inclusion'. We effectively used these terms as proxies for mental health outcomes.

The review included any evidence, in the broadest sense, which could be helpful to the aim. This included grey literature, for example reports produced in the third sector, as well as audio and video diaries published in [Dementia Diaries](#). Most was identified through search engines or personal networks.

1. The importance and benefits of getting out and about

People who are living with dementia frequently highlight the importance of getting out and about in the community – to the shops, to the cinema, to the doctor's surgery, to visit friends, to attend a peer support group. They report that this enhances their wellbeing, self-confidence, independence, contact and stimulation. Transport can either sustain or undermine social activity, relationships and roles.

The right to accessible transport for disabled people (which includes people with dementia) is enshrined in Article 5 of the UNCRPD (United Nations Convention on the Rights of Persons with Disabilities). Other Articles that are relevant include:

Article 2: Freedom of expression and opinion, and access to information

Article 9: Equality and non-discrimination

Article 19: Living independently and being included in the community

Article 20: Personal mobility

Article 23: Respect for home and the family

Article 28: Adequate standard of living and social protection

The Equality Act (passed in 2010) states that a person has a disability if he or she has a physical or mental impairment that has a substantial and long-term effect on the ability to carry out everyday activities including travelling. The accompanying guidance² confirms that this includes dementia.

Probably the most robust review of research regarding public transport for people with cognitive impairments is by Risser et al (2015)³. This qualitative systematic literature review made a comprehensive synthesis of previously published information. Research articles accessible to web-based literature search were collected and based on agreed criteria, each article was screened for inclusion or exclusion. The final set of included articles were then analysed according to a chosen theoretical framework.

Thirty-four articles were included and analysed according to which part of the travel chain they covered in the used model. The results showed that the articles were unevenly allocated to the different parts of the model.

In a recent study⁴ by Rohr (2021), participants living with dementia emphasised that mobility—be it through walking, cycling or using public transport—was a pivotal aspect of their brain health. Transportation is also one of the eight domains that define age-friendly-cities in the WHO Age-friendly Cities Framework (2007)⁵. Importantly, the themes imply that the design and function of the urban environment is a prerequisite to being able to engage in and practice lifestyle behaviours that enhance brain health.

2 <https://www.gov.uk/guidance/equality-act-2010-guidance>

3 Use of local public transport among people with cognitive impairments – A literature review . R. Risser et al (2015) Elsevier Transportation Research <https://www.sciencedirect.com/science/article/abs/pii/S136984781500008X>

4 How can urban environments support dementia risk reduction? A qualitative study (2021) Susanne Röhr S et al <https://doi.org/10.1002/gps.5626> Accessed August 8, 2022

5 World Health Organization. Age-friendly cities framework (2007) <https://extranet.who.int/agefriendlyworld/age-friendly-cities-framework/> Accessed August 8, 2022

A new cross-disciplinary paper from Edith Cowan University (2022)⁶ proposes we change the way we view tourism, seeing it not just as a recreational experience but as an industry that can provide real health benefits. The study found that many aspects of going on holiday could have a positive impact on those with mental health issues or conditions. This research is among the first to conceptually discuss how these tourism experiences could potentially work as dementia-interventions. More evidence is probably needed – but if traveling is found to be beneficial to mental health, then public transport will undoubtedly contribute to that.

Another important review⁷ by Roger Mackett (2017) was produced for the Disabled Persons Transport Advisory Committee (DPTAC) which advises the UK Department for Transport (DfT) on accessibility issues relating to disabled people. While this found some evidence in the academic literature, most of it was in reports produced by various stakeholders, published or unpublished, on websites and within the knowledge of various experts.

An older study, by the intergovernmental International Transport Forum for the OECD (2009)⁸, found that: *“for people both with cognitive impairment and those with mental health problems, using public transport can be a traumatic and challenging experience, and for many, simply impossible. While much is being done to improve vehicles and infrastructure to meet the needs of people with physical or sensory impairments, the issues of cognitive impairment and mental health are largely neglected.”* The study is clear that *“what is important is not whether a person has Alzheimer’s disease or schizophrenia, but that they share a common difficulty with perception and memory.”* It also makes the point that *“that difficulty – and many others highlighted in this report – is also shared to a greater or lesser extent by the vast majority of the travelling public at some time and in some conditions.”*

The same study found that the transport challenges faced by people with cognitive impairment or mental health problems are not yet well recognised or understood either at political or executive levels in the transport field.

6 Jun Wen, Danni Zheng, Haifeng Hou, Ian Phau, Wei Wang. Tourism as a dementia treatment based on positive psychology. *Tourism Management*, 2022; 92: 104556
DOI: [10.1016/j.tourman.2022.104556](https://doi.org/10.1016/j.tourman.2022.104556)

7 Building Confidence – Improving travel for people with mental impairments.
Mackett, R (2017) UCL

8 Cognitive Impairment, Mental Health and Transport (2009) OECD.
<https://www.itf-oecd.org/sites/default/files/docs/09cognitive.pdf>

Moreover, examples of good practice are not routinely or systematically evaluated to measure their effectiveness. It did find however that transport providers and planners can make a significant difference simply by applying principles of universal design and by addressing the functional needs of public transport users as a whole rather than the specific and therefore “special” or “minority” needs of particular disability or impairment groups.

The study concludes that the steps that can be taken to alleviate the difficulties specific to people with cognitive impairment and mental health problems are generally simple, low-cost and will benefit the travelling public as a whole. These include:

- training of transport staff
- familiarisation of people with cognitive impairment or mental health problems with the transport system to help build or restore their confidence
- clear presentation of information and signage, in both audible and visual form
- physical design features
- the presence of staff

2. Barriers to using public transport

Mackett⁹ (2017) found that people with mental impairments (not necessarily dementia) make **fewer journeys** than the rest of the population. This is because some have difficulties going out at all, for example because of their lack of confidence to travel, concerns about the attitudes of other people, both staff and fellow passengers.

People with dementia describe the stress and anxiety¹⁰ (OECD 2009)– and even trauma–that they experience if transport arrangements are **not accessible or when things go wrong**. If they (and their carers) find using transport difficult, this can cause them to withdraw and impact upon their well-being¹¹ (Crampton et al 2013).

9 Building Confidence – Improving travel for people with mental impairments. Mackett, R (2017) UCL

10 For example in [Cognitive Impairment, Mental Health and Transport](#) (International Transport Forum, OECD 2009) Accessed August 8, 2022

11 J. Crampton, R. Eley Dementia-friendly communities: what the project “creating a dementia-friendly York” can tell us [Working with Older People](#) ISSN: 1366-3666 9 (31 May 2013) 17 (2) (2013), pp. 49-57. Accessed August 8, 2022

This is very much linked to **reliability**. Assisted rail travel enables many people to travel around the UK every year. But sometimes the service doesn't work so well¹² (ORR 2017). Delays and cancellations can disrupt Passenger Assist, potentially turning a journey into an anxious situation for passengers and staff alike. A lack of information or poor understanding of a person's needs can prevent staff from offering the service they want to provide.

For many there is a real **fear of getting lost**. Although research suggests¹³ (Bantry 2014) that this is a low-frequency event for people with dementia, for a small minority, the risks are considerable.

[Wendy Mitchell] "In many areas of daily living, people with dementia will need to make plans, and will often struggle most when plans go awry. This is particularly acute when travelling, as people are often alone and can feel very vulnerable."

Cost is also another factor¹⁴ (Mackett 2017). Taxis can be an option for those who cannot drive (or find it difficult), but they are expensive and not always reliable. Other forms of transport can also be expensive (especially for those on benefits) and the many different companies (and local authorities or even countries) have different rules for concessionary travel.

Information is a common barrier. Different companies have different ways of providing and presenting information. Both bus and train travel are often hindered by inaccessible information. The Risser review¹⁵ (Risser 2015) found evidence that reliable information before/during the trip is essential.

12 Research into passenger experiences of Passenger Assist (2017) Office of Rail and Road <https://www.orr.gov.uk/media/10755>

13 Dementia, walking outdoors and getting lost: incidence, risk factors and consequences from dementia-related police missing-person reports. Bantry White E 2014 **Aging & Mental Health** Volume 19, 2015 - **Issue 3** <https://www.tandfonline.com/doi/abs/10.1080/13607863.2014.924091>

14 Building Confidence – Improving travel for people with mental impairments. Mackett, R (2017) UCL

15 Use of local public transport among people with cognitive impairments – A literature review . R. Risser et al (2015) Elsevier Transportation Research <https://www.sciencedirect.com/science/article/abs/pii/S136984781500008X>

People with cognitive impairments often have problems related to **orientation and navigation**. Further, there is a lack of both assistive devices and trained personnel helping and assisting with orientation to achieve a stress-free navigation¹⁶ (Risser 2015).

Inexperience of public transport is another issue. In the Risser review¹⁷ evidence was found that public transport was not judged or experienced as an option when people had to give up driving. Instead, individuals rather wanted to go by car driven by informal caregivers (friends or family members).

Quite apart from the transport infrastructure and systems, Mackett¹⁸ (2017) points out that many **mental skills** are required to make a journey. These include: the ability to remember information obtained previously; comprehension of information received from outside sources; the ability to take decisions based on this information; interpersonal communication skills; confidence in travelling alone; and the ability to behave in line with contemporary social norms. Cognitive impairments such as dementia can affect all these skills. But by considering all tasks, adopting a user perspective and including all used modes of transport necessary for a certain route, all potential barriers and facilitators along the whole travel chain can be identified¹⁹ (Stahl 1997).

Travelling with public transport comprises many different tasks e.g. planning the trip, getting to and from the bus stop/train station, and buying the ticket. All tasks along a travel route need to be considered as essential aspects to safely and comfortably participate in public transport²⁰ (Carmien 2005).

16 Use of local public transport among people with cognitive impairments – A literature review . R. Risser et al (2015) Elsevier Transportation Research

<https://www.sciencedirect.com/science/article/abs/pii/S136984781500008X>

17 Use of local public transport among people with cognitive impairments – A literature review . R. Risser et al (2015) Elsevier Transportation Research

<https://www.sciencedirect.com/science/article/abs/pii/S136984781500008X>

18 Building Confidence – Improving travel for people with mental impairments. Mackett, R (2017) UCL

19 Ståhl, A. (1997). Elderly and functionally impaired persons' needs of public transport: problem inventory and present situation. Bulletin 148. Lund: Lund University.

20 Carmien, C. et al (2005). Socio-technical environments supporting people with cognitive disabilities using public transportation. ACM Transactions on Computer-Human Interaction (TOCHI), 12(2).

There may be a difference in the mental skills required between making a **familiar journey and an unfamiliar** one. Carmien and colleagues²¹ say that regular travellers use personally meaningful landmarks and local experience for navigating while travelling, whereas infrequent travellers have to rely on ‘abstract navigation artefacts’ such as maps and timetables and general knowledge about how systems function.

‘The Right to a Grand Day Out’²² (Innovations in Dementia 2018) was a project based on the recognition by people with dementia themselves that they have a right to get out and about. During this piece of co-produced action research numerous barriers were identified e.g.:

- Transport websites can be difficult to use
- Timetables are often complicated and different e.g. a bus timetable will be presented differently by different bus companies
- It can be difficult to decide between the array of transport options
- Tickets are often cheaper online, but some people prefer face to face interaction
- People make a difference – small things like a smiling driver
- It could be good to have a pass that shows you might need assistance (but not everyone likes this idea)
- Information boards change too quickly in stations. The main destination is displayed in large print, but others en route are very small.

If people stop going out because of these barriers, there is a wealth of evidence of the impacts on their loneliness and mental wellbeing. But the literature suggests that there are some changes that could be made to transport to make it easier for people with dementia to use.

21 Carmien S et al (2005) Socio-Technical Environments supporting people with cognitive disabilities using public transportation, Transactions on Computer-Human Interaction, 12 (2005), 233–262, available from <http://l3d.cs.colorado.edu/clever/projects/maps/papers/TOCHI-submitted-2-26-04.pdf>

22 The Right to a Grand Day Out The DEEP Network (2018) https://dementiaenquirers.org.uk/wp-content/uploads/2020/12/9527a_deep-and-de-the-right-to-a-grand-day-out_v6.pdf

3. Different types of transport

Driving

Although driving is of course not public transport as such, it does have relevance to this review, not least because giving up driving can be an emotional and practical blow, and because public transport, with all its complexity, is often the only alternative available. This fact places a great demand on the public transport system to be accessible for all.

Driving is often a lifeline for people, especially those living in rural areas (of which there are many in the UK). One in three people with dementia still drive²³, but many feel the loss of their license very keenly, and feel that the procedure for assessing ability to drive should be better communicated and more sensitively administered. Most people with mild dementia can continue to drive at least for a while, although they may find navigation and parking increasingly difficult (see below). But dementia is progressive and the evidence suggests that most people with dementia cease driving within three years of the first signs of the disease. Many patients and clinicians will be faced with questions about driving safety in the course of their illness. Decisions must take into account not only cognitive abilities, but any physical comorbidity, vision, mobility, insight and history of driving errors and accidents. Deciding to stop driving, or being required to stop driving is often difficult for patients to accept and can be a particularly problematic consequence of a dementia diagnosis. Not only is it an emotional wrench, but it often means they will have to rely on others for a lift, and/or use public transport (sometimes for the first time.) This is hardest for those who live alone and/or for those whose spouse has never driven. And for those who may have never or rarely used public transport before.

23 'Driving and dementia' information on Alzheimer's Society website

<https://www.alzheimers.org.uk/get-support/staying-independent/driving-dementia>

Dr James McKillop, who has been living with dementia for over 20 years, has published a booklet ‘Driving and Dementia: my experiences’²⁴. In this he cites one contributor who drives and owns her own car. This is what she has to say about the cost of being retested every 6 months:

“I think it is most unfair to be charged £50 for the review assessment. It is a discrimination for drivers affected with dementia. It was not our decision to be given a diagnosis of dementia so we are being penalised for this condition. On assessment day, which is every six months, I have to make arrangements for someone who is a car driver to accompany me to the centre, as you cannot use your own car. This is an added cost to the nominated person that accompanies you.”

Many people have also recently lost the right to a government-funded Motability car:

“Without the Motability car [that was taken away] I am unable to make the bus journey (with 3 changes) to get to hospital in town.”

The Shindig group in Sheffield looked into the practical and psychological impact of having to [give up driving because of dementia](#) (journal paper forthcoming).

An American study, published in 2001²⁵, (but drawing on data from a 1996 survey of households in California) explored how giving up driving affects households, and focused particularly focus on those where an elderly driver has had his or her license revoked due to Alzheimer’s disease or a related dementia. It found that, after losing their license, the vast majority of people surveyed depended on informal support systems for transportation, such as rides from family and friends. Although such arrangements were not reported to be a problem for the majority of households, certain groups of non-drivers reported difficulty accessing services, particularly social and recreational destinations. The most commonly reported problem was a lack of available licensed drivers to chauffeur non-drivers. Importantly, no

24 <https://www.ageuk.org.uk/globalassets/age-scotland/documents/dementia/general-dementia-documents/driving-with-dementia.pdf>

25 The effects of driving cessation on the elderly with dementia and their caregivers. Taylor B and Tripodes, S in [Accident Analysis & Prevention Volume 33, Issue 4](#), July 2001, Pages 519-528

increase was observed in the number of people walking, using public transit, taxis, or van services following license revocation. People who did not live with at least one licensed driver and those who were younger and healthier reported the greatest mismatch between their need and desire to travel and the availability of transportation. In addition, some caregivers reported that they frequently missed work or stopped working entirely in order to care for and chauffeur people in the former drivers' household.

Overall, these findings reinforce the importance of both developing transportation policies to support the functioning of informal transportation structures, and in improving the range of alternative transportation options for those individuals with particular disabilities — like dementia — who are not well served by either informal arrangements or by formal transportation services for disabled people.

Parking

Whether you drive or are driven, you need to park. Like other disabled people, those with dementia often need to park very close to where there are going. In the UK, the Disabled Persons Parking Badge Scheme, often referred to as the Blue Badge scheme, allows people who have disabilities various concessions and privileges relating to parking. The eligibility rules vary depending on whether you live in England, Wales, Scotland or Northern Ireland.

Many people with dementia felt (at least perhaps until recently) they are discriminated against in terms of eligibility for the Blue Badge (apart from in Wales). The Scarborough group, DEEP Vibes, **identified a number of problems** this unsatisfactory situation caused for people with dementia. These included risks to the person left on the pavement while their carer parked—risks of abduction, getting lost, or getting panicky. If the person with dementia was the driver, they may have to park far away and have more difficulty navigating to where they need to go – as well as forgetting later on where they parked. In addition, the application forms are very complex, you have to supply a range of documents, and the cost is prohibitive to some. Other issues raised included:

- Some people are able to apply for Blue Badges, and others are not
- Some find it hard to apply in the way required.
- Even if you have a badge, there are different rules in different places – sometimes you can park anywhere (e.g. in metered carparks), other times you can only park in allocated spaces

- There are often not enough disabled spaces
- Spaces are not wide enough

The group set up a petition in May 2017. Here are some of the comments of the signatories:

“My father had Lewy Body dementia and Parkinson’s... he was 84...we were refused a disabled parking space as he was not the driver... red tape and rules and [regulations] in this country are archaic and need a massive overhaul.”

“My husband has no road sense now due to his dementia and just steps out without looking, we have had a few near misses!!!! “

“Dementia is not all about memory, there is also spatial awareness.”

“The forms are too complicated. I gave up.”

One woman, who did have a Blue Badge, found that having to park in a bay marked with a wheelchair symbol caused her problems. She said that people looked at her as if she shouldn’t have a Blue Badge when she walked away from her parked car, and even questioned her need of the space.

On a positive note, the national criteria for Blue Badges have changed since (and possibly partly because of) this project. The new rules, introduced in August 2019, widened the eligibility criteria to ensure that people with ‘invisible’ disabilities are not disadvantaged. Now people are eligible if they cannot undertake a journey without there being a risk of serious harm to their health or safety or that of any other person; cannot undertake a journey without it causing them very considerable psychological distress; and/or have very considerable difficulty when walking (both the physical act and experience of walking).

Train travel

Mackett's study (2017)²⁶ found that, for rail travel, cost is the most critical factor for people with mental impairments (not specifically dementia), because of their low incomes. Anxiety and lack of confidence are also major deterrents. When a person's condition fluctuates from day to day (as dementia can), this prevents them from committing to a journey in advance and so they cannot take advantage of some cheaper fares. Positive aspects of rail travel for some people with mental impairments are the amount of space offered and the availability of toilets on some trains which reduces one aspect of anxiety. However, aspects of the modern design of trains cause problems for some people with mental health conditions, for example, sealed windows in air-conditioned carriages, and electronic doors which cannot be opened manually including toilet doors

Many people struggle with poorly designed systems:

“The complexity of multi changes is difficult for anyone, but is more confusing when you can't remember the last thing you clicked.”

“Finding the right seat on the train can be very stressful, depending how they display the reservations. Cross Country are particularly stressful.”

“I got off one train and had no idea where the exit was, so spent the next half an hour or so wandering up and down the platform and over the bridge to the platform on the other side and back again. The railway staff just ignored me until the person meant to be picking me up came looking for me!”

Assisted rail travel enables many people to travel around the UK every year. Research into passenger experiences of Passenger Assist (2017)²⁷ tells us that Passenger Assist was booked 1.4 million times in 2016-17 and 63% of passengers said they could not have completed their journeys without it.

26 Building Confidence – Improving travel for people with mental impairments.
Mackett, R (2017) UCL

27 Research into passenger experiences of Passenger Assist (2017) for ORR
(Office of Rail and Road) <https://www.orr.gov.uk/media/10755>

But sometimes the service doesn't work so well. Wendy Mitchell explains in her blog that it is very much oriented towards those with physical disabilities, and has yet to grasp the problems faced by people with cognitive impairments (and not necessarily needing a wheelchair).

“I was on a through train (carefully chosen!), having been put on into a reserved seat. I was due to be collected by someone from the numbered seat at my destination (they had the number), when there was a crisis on the line and an announcement was made for us to get off (I did not understand the message) and to find our own way to our destination! Only when the blind man in the seat in front started shouting for help and he was just told to 'be quiet and 'shut up' by the staff member who was going through the carriages told us to get off... When my daughter wrote to them later we were told as I had not registered for help in an emergency none would be provided. The consequence of this was I now NEVER travel alone! [Wendy Mitchell]

Mackett's research²⁸ (2017) found that bus drivers are sometimes unhelpful, rude, unable to communicate well, and lacking in knowledge about bus routes and timetables; they occasionally take advantage of people with mental impairments; the behaviour of other passengers can cause difficulties by smoking, drug taking, playing loud music and bullying, and schoolchildren can be noisy and bang on the side of the bus; overcrowding can cause problems for some people.

When a bus service is disrupted, the lack of an explanation may cause distress; people with mental impairments may lack the ability to generalise about what to do in a novel situation, such as a disrupted journey or a bus terminating short of the advertised destination; when bus routes are revised a person who has had travel training will need to learn about the new routes and this may interfere with knowledge about previously learned routes.

28 Building Confidence – Improving travel for people with mental impairments.
Mackett, R (2017) UCL

A blog by Dr Wendy Mitchell²⁹ illustrates the importance of training and staff attitudes:

“I got on the wrong bus at the weekend...however, sometimes I get confused by numbers and I think one number is another. Some of our buses don't stop at every stop. I rang the bell as usual, got up and went to the front of the bus, and it went sailing past my stop. I panicked and rang the bell again and said to the driver that I needed to get off...I said I'd got confused with the numbers and would he mind stopping on this occasion. He was downright rude and no way was he going to stop the bus until he got to his destination two miles further on. He was even rude when I got off and said I should take more notice next time...York is aiming to be a 'dementia friendly' community. Most bus drivers are brilliant in York but the driver was obviously off work the day he was supposed to have training... I may have been someone who hadn't ventured out for weeks. After that experience I may not have ventured out for many more weeks.”

The evaluation of the York Dementia Friendly Communities Programme³⁰ (Dean et al 2015) described the ground-breaking work pioneered by British Transport Police to raise awareness of dementia, which was then replicated at stations on the East Coast Main Line. This involved training colleagues to become Dementia Friends and Dementia Champions, and building travel confidence in people with dementia and their carers through accompanied trips.

Air travel

Air travel can pose major challenges for people living with dementia and their companions, and airlines are not always well prepared to meet their specific needs. Dr Katharine Turner explored the core components of dementia-friendly flying³¹ (Turner 2022), with a view to maintaining and/or increasing participation in air travel for people living with dementia and those who

29 <https://whichmeamitoday.wordpress.com/2014/11/05/wrong-bus-wrong-bus-driver/> (2014) Accessed August 8, 2022

30 Evaluation of the York Dementia Friendly Communities Programme, Dean, J et al, (2015) JRF

31 Dementia friendly flying: investigating the accessibility of air travel for people living with Dementia Turner, K. (2022) <http://hdl.handle.net/10026.1/18973>

normally travel with them. Her literature review found a knowledge gap in the barriers and facilitators to air travel and also found (limited) evidence that staff within the aviation sector did not always know how to support people living with dementia and their travel companions.

Although evidence-based research into air travel and dementia is extremely limited, Turner found anecdotal evidence and critical incident reporting that suggested that air travel is not meeting the needs of people with dementia. While there has been a study on air travel and people with dementia in Australia, Turner's own research represents the first known study within the UK to explore the phenomenon of air travel from the perspectives of people living with dementia and their companions in any depth. She explored the experiences of air travel of 10 people living with dementia and 10 travel companions of people living with dementia through a series of in-depth phenomenological interviews. Her findings identified the importance of a positive social environment, airport special assistance as both a barrier and a facilitator, challenges within the general airport environment and the need for continuity of support at transit points and upon arrival at the destination.

Turner's recommendations for removing barriers to participation in air travel focused on addressing:

- Inadequate policies and standards within aviation
- Negative attitudes to people living with dementia
- Lack of provision of services within aviation
- Problems with service delivery within aviation
- Lack of accessibility
- The need for more consultation and involvement of people with lived experience

Anne Scott from Northern Ireland used [her audio diary](#) to describe her experience using airports. Although some of it was positive, she says:

“Apparently not all airports supply wooden walking sticks. Once again I did not pass security and was not allowed my own stick. I asked if I could lean against the wall while being searched and was told no. I was shocked at this and I had a hard time trying not to collapse. I was given my stick back halfway through the search by another attendant and received an apology, but for me my stress level had now reached a high level, and by the time I got to the plane I was panicking and exhausted. This all could have been avoided, and my journey made much more pleasurable, if the London airport had taken the notification they received about my travel requirements.”

Alzheimer Scotland’s Positive Dementia Group in Aberdeen (members of the DEEP network) have recently been working with Aberdeen Airport to improve access issues.

Taxis

Mackett³² (2017) points out that taxis are a very suitable mode of travel for some people with mental impairments because they convey the traveller from door to door. If another person makes the booking, gives the driver the location of the destination and makes the payment, no interaction is required with any other person.

Those who cannot drive often have to depend on taxis. Taxi issues were discussed in detail recently at the Scottish DEEP Gatherings:

“Taking taxis means you have to be able to trust the driver, to feel safe. In Liverpool they have the “Pink Ladies Taxis” just for women. Can’t we? “

32 Building Confidence – Improving travel for people with mental impairments.
Mackett, R (2017) UCL

A few members of the Lewisham DEEP group said their transport costs have increased because they can't drive and have to get taxis. Many use the bus, but some people don't feel confident to do that, so pay for taxis. They acknowledged they are lucky to be able to afford this—and that, if they couldn't, their lives would be very limited.

The evaluation of the York Dementia Friendly Communities Programme³³ (Dean 2015) described the commitment shown by local taxi company Fleetways to dementia awareness training for all their drivers.

Bus travel

One of the commonest forms of travel by disabled people is the bus. Buses offer the opportunity to travel further than walking and may be the only mode available for some people with mental impairments to make longer trips.

Cost is also a factor. Some people with mental impairments with low incomes may find bus travel expensive because they have been assessed as ineligible for a concessionary bus pass; others may not realise that they are entitled to have one; and some of those who do have a concessionary bus pass may have difficulty understanding the rules.

But while buses are often cheaper than trains, (and in Scotland carers can travel free), services are in short supply and have been cut in many areas. Buses are usually staffed by a single person, and so there is a lot that can be done to make sure that staff awareness and attitudes do not present barriers.

The Risser review³⁴ found evidence that accessible/barrier-free pedestrian environment and good design for bus stops is important. Public transport design needs to consider issues of familiarity, legibility, distinctiveness, comfort, and safety in order to meet the needs of, for example, people with dementia. Terminals, bus stops and walkways must have appropriate seating, lighting and shelter. The pedestrian environment must also be well-maintained, be even in level and constructed in a material that give a flat paving in order to facilitate outdoor mobility.

33 Evaluation of the York Dementia Friendly Communities Programme, Dean, J et al (2015) JRF

34 Use of local public transport among people with cognitive impairments – A literature review . R. Risser et al (2015) Elsevier Transportation Research
<https://www.sciencedirect.com/science/article/abs/pii/S136984781500008X>

There are a number of tasks involved in making a bus journey which Hunter-Zaworski and Hron³⁵ (1993) have identified including:

- The ability to evaluate what is needed to make the journey including route and fare information;
- Understanding the system, including learning routes, stops and transfer points, understanding the timetable and fare system;
- Accessing the correct vehicle which requires recognising it and processing information about the route number and destination;
- Entering the vehicle including paying the fare;
- Travelling on the vehicle;
- Leaving the vehicle including knowing where to alight and when the vehicle is approaching the stop;
- Leaving the stop or station.

The York event described in The Right to a Grand Day Out project report³⁶ (Innovations in Dementia 2018) identified that bus travel is difficult because different providers and route changes make it very confusing. Some display information screens and some do not. Some use colour coding, but this is often not followed through to the colours of bus stops or buses – it would be helpful if it was comprehensive and consistent. The Bradford FIT group made a short iPhone film about bus information, calling for clear route maps and colour coding at every bus stop, as well as personalised timetables. One member feels that, as a bus user, his right to go further than his immediate locality is denied:

“If you don’t limit yourself to your immediate area, then you don’t understand the bus rules of that area. You don’t know whether to put your hand out, how to use the timetables etc. This limits my freedom.”
[Bradford FIT member]

35 Hunter-Zaworski K M and Hron M, Improving Bus Accessibility Systems for Persons with Sensory and Cognitive Impairments, Publication DOT-T-94-04 (1993), Federal Transit Administration, Washington, DC

36 The Right to a Grand Day Out (2018) https://dementiaenquirers.org.uk/wp-content/uploads/2020/12/9527a_deep-and-de-the-right-to-a-grand-day-out_v6.pdf

4. Adjustments and solutions

Reasonable adjustments (and Dementia Friendly Communities)

While most transport providers make at least some reasonable adjustments for those with physical or sight impairments, adjustments for people with cognitive impairments are less mainstream. Poor signage, too much echo and noise, busy platforms, complicated timetables, poorly educated staff, bewildering floor surfaces and much more can result in people with dementia feeling frightened, de-skilled, and exhausted by their travelling experiences.

However, many areas have made real efforts to improve the external environment, including public transport. This has often been as part of a dementia friendly community initiatives which have blossomed since around 2010. The evaluation of the York Dementia Friendly Communities Programme³⁷ (Dean 2015) described how transport featured in many conversations with stakeholders and people with dementia and their carers. For some, participation is simply not possible without the provision of timely, safe and appropriate transport, sometimes expressed as simply as the need for clear timetabling and signage, that enables people to access the places, activities and services they want to maintain their interests and normal lives. Even organisations who have adopted a high profile approach to training staff still find it difficult to guarantee a good service until there is a better underlying awareness of what people with dementia (and all of us who value good customer service) actually need. The key message about transport which emerged from the York evaluation and which have wider resonance is that inequality of access including transport is a barrier to dementia friendly communities.

Mackett came up with a number of suggestions based on his review:

- Enhancing the skills of the traveller or modifying the travelling environment to reduce the needs for such skills.
- Interventions to help preparation for travel include travel training and clear pre-travel v information, including inclusive travel guides.
- Making the local environment easier to understand, providing car parking near the destination and providing special transport services.

³⁷ Evaluation of the York Dementia Friendly Communities Programme, Dean, J et al, (2015) JRF

- Better support from people on the journey can be provided in various ways including staff training, travel assistance cards and Safe Place schemes.
- Appropriate information can be provided on the journey using audiovisual systems and mobile phone apps.
- Interventions can be packaged together through schemes such as personalised travel planning and dementia-friendly communities.:

Co-produced research

The co-researchers in 'The Right to a Grand Day Out'³⁸ (2018) project produced the following suggestions:

Planning a journey



Positive ideas:

- Writing down the start and end point helps.
- Using familiar routes e.g. driving to park and ride.



Challenges:

- Buses changing number on the way.
- Worries about how the journey will turn out.
- Worries about toilets.
- No visual display of the route on buses or at bus stops.

38 The Right to a Grand Day Out The DEEP Network (2018) https://dementiaenquirers.org.uk/wp-content/uploads/2020/12/9527a_deep-and-de-the-right-to-a-grand-day-out_v6.pdf



The journey itself



Positive ideas:

- Sitting at the front so we can see where we're going.
- Familiar places for getting off.
- Counting the stops.
- Parking spaces available for people with dementia.



Challenges:

- Bus setting off too soon.
- Not sure whether we want to be identified as having dementia.
- Ticket barriers.
- Last minute platform changes.
- Bad customer service.
- Length of walk at train station.

The people we meet



Positives:

- One person got lost on the way back from shops, but a lady stopped and helped.
- It would be good to feel we could ask someone who would put us right if we get lost. It would raise our confidence in getting out and about.



Another group of people with dementia, [Thred in Liverpool](#), have explored the accessibility of urban and rural transport systems for people with dementia³⁹ (2022). This study was based on the premise that “Transport is more than just travel. It connects people; it provides access to jobs, communities and goods; it delivers vital social services.” The group 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. The project concluded that we need to:

- instil confidence in people with dementia in order to encourage them to use public transport, taxis, the ferries and the airports.
- work with transport providers to ensure that their training reflects the problems that people with dementia and other hidden disabilities experience when using public transport, airports etc.

[Go Upstream](#) is a Scotland-based project that brings disabled people, including people with dementia, together with transport operators and other service providers to design more inclusive journeys. For example they have worked with people with dementia and local authorities to provide better bus services. Working with organisations such as Calmac and Northlink ferries, and Scotrail, they have also looked at [changing from one mode of transport to another](#)⁴⁰, (2019) navigating the spaces between services, where one ‘stops’ and another ‘starts’. The project contributed ideas to 52 action points from Accessible Travel Framework (2016)⁴¹. The report also sets out (page 85) how to co-produce a Making Connections process.

Blackman et al (2008)⁴² found that using virtual reality (VR) can be a useful tool for the evaluation of outdoor environments and for identifying improvements for people with dementia.

39 How can urban and rural transport systems help people diagnosed with dementia live independently for longer? (2021) https://dementiaenquirers.org.uk/wp-content/uploads/2021/05/thred-in-liverpool_report.pdf Accessed 8 August 2022

40 Making Connections (2019)

41 Accessible Travel Framework, Transport Scotland 2016 <https://www.transport.gov.scot/publication/going-further-scotland-s-accessible-travel-framework>

42 Involving Persons with Dementia in the Evaluation of Outdoor Environments. Van Shaik, P et al Published Online:23 Aug 2008 <https://doi.org/10.1089/cpb.2007.0105>

The Dementia Policy Think Tank, a group of people with dementia who are interested in human rights, also recommended in their report⁴³ (Innovations in Dementia 2017) that transport and parking providers and local authorities should review staff attitudes and arrangements, so that all people with dementia can exercise their right to get out and about.

Groups in DEEP, the UK Network of Dementia Voices, have co-produced a [template for personalised travel plans](#) which can and is used to help people get themselves to events, meetings etc.

5. Conclusions

Transport is usually a means to an end to reaching an activity, a friend, an appointment etc. It can be a barrier or facilitator to achieving these ends. But it can also be a barrier or facilitator to wellbeing (i.e. good mental health) in its own right.

The evidence shows that, although many of the solutions are about infrastructure, it's also about the skills and confidence of the person themselves. We need to recognise the complex cognitive skills needed to use transport.

The Risser review⁴⁴ (2015) found that there is a knowledge gap on public transportation and people with cognitive impairments, and closing these gaps is an important task for future research. A specific problem of research on problems with daily activities among cognitively impaired people impairment is that issues with local public transport use are identified but not further specified. Here a more in-depth assessment of causing factors and actual barriers experienced in all sections of the travel chain would yield insights helping to improve both accessibility and usability for these specific user groups. Studies based on real-world experiences are essential, and more user-centred approaches should be adopted. Moreover, there is a need for the development and evaluation of evidence-based rehabilitation. Finally, more research is needed to foster societal awareness of the problems and needs in the public transport travel chain of people with cognitive impairments.

43 Our Lived Experience Current Evidence on Dementia Rights in the UK: An Alternative Report to the UNCRPD Committee (2017) Innovations in Dementia <http://www.innovationsindementia.org.uk/wp-content/uploads/2018/01/Our-Lived-Experience-270717.pdf>

44 Use of local public transport among people with cognitive impairments – A literature review . R. Risser et al (2015) Elsevier Transportation Research <https://www.science-direct.com/science/article/abs/pii/S136984781500008X>

However, from the evidence we do have it is possible to summarise 8 key factors in the relationship between dementia, transport and mental health:

1. Accessibility of information

2. Accessibility of design and environment

3. Signage and navigation

4. Skills and confidence of the traveler

5. Personalised journey plans

6. Costs (including eligibility for, and awareness of, concessions)

7. Training, presence and approachability of staff

8. Quality and reliability of assistance arrangements, especially when journeys change or go wrong

Innovations in Dementia

Is a not-for-profit Community Interest Company (CIC). People with dementia are at the heart and start of all our work. We promote a positive but realistic view of dementia, demonstrating that, although it is life changing, it does not have to be life ending. We support people with dementia to live with hope and keep control of their lives.

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