



# Improving the accessibility of UK air travel for passengers with non-visible disabilities

## Lessons from the Dementia Friendly Flying Research



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Pseudonyms have been used throughout this document to protect the identity of research participants.

The importance of improving accessibility to air travel



As an Ambassador for The Alzheimer’s Society and Co-Chair of the Prime Minister’s Dementia Challenge Groups, I have taken a keen interest in the research done by the University of Plymouth over the past 7 years, into the accessibility of air travel for people living with dementia.

I’ve heard about so many poor experiences that passengers within this group have endured. And each and every one saddens me greatly. I’ve heard stories of people being publicly embarrassed; being confused and disrespected; having their holiday and travel experience ruined because their condition – dementia – has not been understood. I also know, from personal experience, that when someone with dementia loses their confidence to do something meaningful, something that they enjoy, like air travel, it can take an awful lot of time to get that confidence back, if indeed they ever do. I have even reported on some of the challenges that people living with dementia have faced when travelling by air, to raise awareness of these issues. It was all part of a concerted effort to make air travel more accessible and less stressful. And I am delighted to say *it was working*.

With the help of this research, and the wider work of the Prime Minister’s Dementia Challenge Group for Air Transport, air travel was becoming more accessible for so many passengers who have non-visible disabilities like dementia.

Then came the Covid-19 pandemic; the closed borders, the grounded aircraft, the job losses, and the devastating impact this had on the aviation industry. Thankfully, we are beginning to return to some semblance of normality now, but there is much work to be done to get back to where we were. However, we do now have the opportunity to build on all the good practice that has gone before. And to give all passengers with dementia, and other non-visible disabilities, the confidence to return to air travel after the isolation of the last few years.

I am sure that, like me, you cannot wait to go travelling again – to explore the world and to see those people and places that mean so much to us all. Sadly, as demonstrated in this document, the expectations of many people living with dementia remain poor. Travellers with dementia continue to face stigma and restrictions every day. And frankly they shouldn’t. Which is why the research done by the team at Plymouth University is so important. It asks the question “Why should people living with dementia be denied the right to travel by air if they wish to? Without having to face unnecessary stress and lack of understanding?” After the restrictions of the “lock downs”, don’t we all now know, from personal experience, what it feels like to be isolated and to be told we cannot go where we want to go and see the people we want to see?

This document is short but contains a wealth of information on both the key barriers and the simple steps that can be taken to make air travel more accessible for passengers living with dementia and other non-visible disabilities. I do hope that you will take the time to read this document and take any steps that you can to make air travel more accessible and enjoyable. People living with dementia want to live well with their dementia and keep on living a life filled with challenges and experiences. Please, never underestimate the role you can play in making that possible.

Angela Rippon, CBE

# Introduction to The Dementia Friendly Flying Research and the 5 Key Points

**Prior to the pandemic, anecdotal evidence began to appear on the challenges faced by people living with dementia when travelling by air, including several devastating and distressing incidents and reports of passenger mortality.**

Despite the seriousness of the situation, the authors of this report only identified one research project on this topic which had been conducted in Australia [1]. Consequently, a doctoral research project funded by the University of Plymouth was undertaken to identify the barriers and facilitators to air travel for people living with dementia and those who travel with them in the United Kingdom (UK) [2]. Due to the implementation of key Civil Aviation Authority (CAA) guidance in 2016 [3], research participants needed to have travelled after this date to identify whether this advice was assisting airport accessibility for this group.

## 1. Societal expectations of people living with dementia remain poor

Both participant groups reported experiencing ongoing challenges with how people living with dementia are seen and treated by society, with stigmatisation, paternalism, risk aversion and ignorance still considered to be widespread within the general population.

This point is important as how individuals perceive someone with dementia affects how a person with dementia may be treated in a range of settings, including within aviation.

*“People don’t know how to treat people with dementia. They have this image of... somebody sitting gaga in the corner of a room dribbling and they look at you gone out... They say ‘you can’t have dementia you speak too well’ and I could thump them”*  
(Amanda – living with dementia)

Both people living with dementia (n=10) and travel companions of people living with dementia (n=10) participated in the in-depth interviews that formed part of this research. This enabled the researchers to take a holistic view of the barriers faced by both people living with dementia and their travel companions as many (but not all) people living with dementia prefer to be accompanied when travelling by air. As a result of the research, **five key learning points** were identified as detailed in this document. These points are further supported by anonymised quotes from the research participants and specially commissioned cartoon images from award winning cartoonist, Tony Husband, which are also based on key findings from this research. We gratefully acknowledge a grant from the Plymouth Institute of Health and Care Research which made the creation of these cartoons possible [4].

All participants spoke about the importance of remaining engaged in air travel as it connected them to people and places of significant meaning, as well as being a link to a reinvigorating and restorative escape from everyday challenges and expectations.

It is therefore vital that aviation staff understand that people living with dementia still want to continue travelling by air, *with the appropriate support*, for as long as possible post symptom onset/diagnosis.

### Recommendation:

Greater awareness of the needs of passengers living with dementia is required to enable them to continue travelling by air. This can be incorporated into a future context specific training package (see recommendations for key point 4).

## 2. Many passengers living with dementia are unaware of their right to request special assistance when travelling by air

Despite the CAA guidance on how airports and airlines should support passengers with a range of non-visible disabilities [3, 5], most research participants indicated that they were unaware of their right to access special assistance when travelling by air. Surprisingly, this included those participants who might consider themselves to be dementia activists, in that they are aware of their rights and are not afraid to request that these rights be upheld in other situations. This suggests that much more needs to be done to raise awareness of the rights of passengers with non-visible disabilities when travelling by air from/to the UK in the future.

The continued use of wheelchair symbolism to advertise special assistance services is also thought to be a further contributory factor in the erosion of the rights of passengers with non-visible disabilities, as it reinforces the preconceptions and stereotypes of what someone with a disability looks like and how they should be supported by aviation staff. While it is recognised that the term ‘passengers with reduced mobility’ or ‘PRM’ is enshrined within aviation legislation [6, 7], it is estimated that only 5-7% of the UK disability population uses a wheelchair [8].

This concept of disability is so ingrained that, for those participants who were aware of special assistance, the majority had been automatically offered the use of a wheelchair when requesting support.

While it may be an isolated incident, one participant also reported that a member of special assistance staff had *specifically asked them* to use a wheelchair as it would prevent other passengers from questioning why they were receiving special treatment when there did not appear to be anything physically wrong with them.

To counter this inequality, some airports are choosing to use more inclusive symbolism such as the United Nations’ symbol of accessibility or signage with the wording ‘not all disabilities are visible’. While other airports have adopted the use of a hidden disability identifier such as the sunflower lanyard to enable their staff to identify passengers who may require additional support [9].

While many participants felt these actions were a step in the right direction towards greater understanding and acceptance of the diverse needs of people living with non-visible disabilities including dementia, they felt more needed to be done to make other passengers and aviation staff aware of their rights in this setting.

Given that the most popular hidden disability identifier, the sunflower lanyard, was used extensively during the Covid-19 pandemic to identify someone who was exempt from wearing a face mask, further consideration also needs to be given to how such lanyards will be used, recognised, and responded to within special assistance services in the future.

### Recommendations:

- Rights based media campaign to highlight that special assistance services are for people with any disability and not just for wheelchair users, to encourage passengers with non-visible disabilities to return to air travel.
- Inclusion of more information on passenger rights within aviation with other disability travel literature e.g., a leaflet on accessible transport (in its widest form) could be sent out with each new blue badge issued.
- Greater use of more inclusive disability signage/ symbolism at special assistance counters and on accessible and priority facilities throughout the airport environment.
- Increased range of terms/aviation codes beyond ‘PRM’ to better reflect diversity of passenger needs.
- Increased training on how aviation staff can support passengers with non-visible disabilities.
- Consideration of how the sunflower lanyard can be used to identify passengers with non-visible disabilities post Covid-19.





### 3. Passengers living with dementia and their travel companions experience physical barriers across the travel chain – from the point of booking to their return home

*“When you go to register that you need special assistance they’re set up around physical disability... so they want to know if you want a wheelchair... do you need this... do you need... and some of them you end up having to phone... because he just fell through the ‘no, no, no...’. You drop out the bottom, [because] you clearly don’t need [their idea of] special assistance”*

**(Millie, travel companion)**

Participants reported that the barriers to air travel began at the point of booking, as the emphasis on physical disability is as prevalent on airline websites as it is in airports.

Clearly, the inability of passengers with non-visible disabilities to book special assistance online, while those with physical disabilities can, is not in keeping with UK equality legislation [10].

#### Recommendations:

- Provision of guidance and the option to book special assistance for passengers with non-visible disabilities, including dementia, on airline websites.
- Increased training for travel agents and tour operators on the needs of passengers with non-visible disabilities and the support that should be available to them to enable equity of access to airport/airline facilities.

Once at the airport, orientation and wayfinding were reported as being a major challenge for people living with dementia, with the lack of toilet exit signage proving particularly challenging for some participants who had needed help to exit these facilities.

Other challenges with wayfinding were poor quality signs, signs that were too high up or the use of directional arrows, which some participants had found to be ambiguous. For example, an upward facing arrow could mean either to go upstairs or to go straight on depending on interpretation. Indeed, guidance produced for American Airports stipulates that directional arrows should be replaced with plain language wherever there is a risk of potential confusion to avoid such ambiguity [11].

Other challenges included a lack of landmarks at key decision points to help with wayfinding. Landmarks can provide useful visual clues for a range of passengers and not just those with dementia as they allow passengers to navigate from landmark to landmark, reducing route complexity. Installation of something as simple as a piece of artwork or indoor planting at such key decision points/areas of route divergence, can significantly aid route finding if these landmarks are also included in written and verbal directions/guidance.



Perhaps the greatest challenge experienced by participants living with dementia, however, was the continued pressure of the airport journey and the over stimulation this provided in terms of negotiating crowds, noise, brightness, and scents, particularly in the retail areas.

Some participants found this continued pressure overwhelming and anxiety provoking which, in turn, exacerbated their symptoms of dementia leading to increased word finding difficulties, fatigue, impatience, and repetitive behaviours. While the design of the airport, including the ‘boutique’ sparkle effect flooring extensively used in retail areas and other use of high sheen flooring caused participants to worry that the floors were covered in ice crystals or were wet/slippery.

Although the CAA has already recognised the need for quiet routes and rooms to support people living with dementia [3], most of the participants were not aware that such facilities existed within airports and that they could request access to them. Nor were they aware of other initiatives such as the airport familiarisation visits that some special assistance teams have put in place. This again suggests that greater awareness of the facilities available to support passengers with dementia and their travel companions is needed to increase travel confidence for this group.

#### Recommendations:

Small changes in airport design can assist all passengers and not just passengers living with dementia, making such changes highly cost effective. Simple changes include:

- Installing exit signage for toilet facilities and ensuring any ambiguous signs (e.g., upward facing arrows) are accompanied by text to increase clarity of meaning.
- Providing access to quiet routes, rooms, and other facilities such as security slow lanes with seating to allow for resting and taking off shoes/belts, etc.
- Avoiding ‘sparkly’ or high sheen floors in future airport design.
- Greater use of physical landmarks the descriptions for which should be replicated within verbal and written communication to aid wayfinding.
- An up-to-date CAA document on the special assistance facilities offered by all UK airports to aid passenger information, confidence, and choice.

4. Aviation Staff are unaware of how to support passengers living with dementia and those who travel with them

Most of the participants reported experiencing poor communication from airport staff, although some participants felt that cabin crew were much more skilled in identifying when a passenger needed additional support.

The main challenges around communication were twofold: Firstly, people living with dementia reported that they frequently were spoken to quickly, loudly, and sharply, the pressure of which exacerbated their symptoms of dementia as previously noted. Secondly, the areas of the airport where those living with dementia needed the most support were the same areas where they were most likely to be separated from their companions. This was the case even when they were wearing a lanyard, as the nature of the airport environment, such as male and female lines in security, meant they would be automatically separated whether they needed to stay together or not.

All participants felt that aviation staff did not understand the importance of the travel companion's role, both in terms of being a calm and comforting presence to the person living with dementia at times of pressure, nor in terms of their expert knowledge of how to communicate complex instructions to the person with dementia in a way that would be helpful to them.

Where this skill was recognised and the companion was allowed to help, it proved to be a positive support to the airport staff in areas such as security.

Given that large numbers of aviation staff were furloughed during the Covid-19 pandemic, and many hundreds if not thousands of staff did not return to their original roles [12], it is likely that much of the special assistance training and knowledge that was in place pre-pandemic no longer exists and needs to be urgently repeated or refreshed.

*“The first time I went [into a body scanner] I was totally thrown and Judith was trying to come forward [shouts] ‘WHOA, DON’T COME ANY CLOSER’. She said, ‘he’s got dementia, I just want to explain to him how you stand’”*

(Alan, living with dementia)



Recommendations:

A context specific aviation training package designed and delivered for UK airports/airlines is urgently needed to drive equity of access for passengers with dementia and other non-visible disabilities. Such training should include:

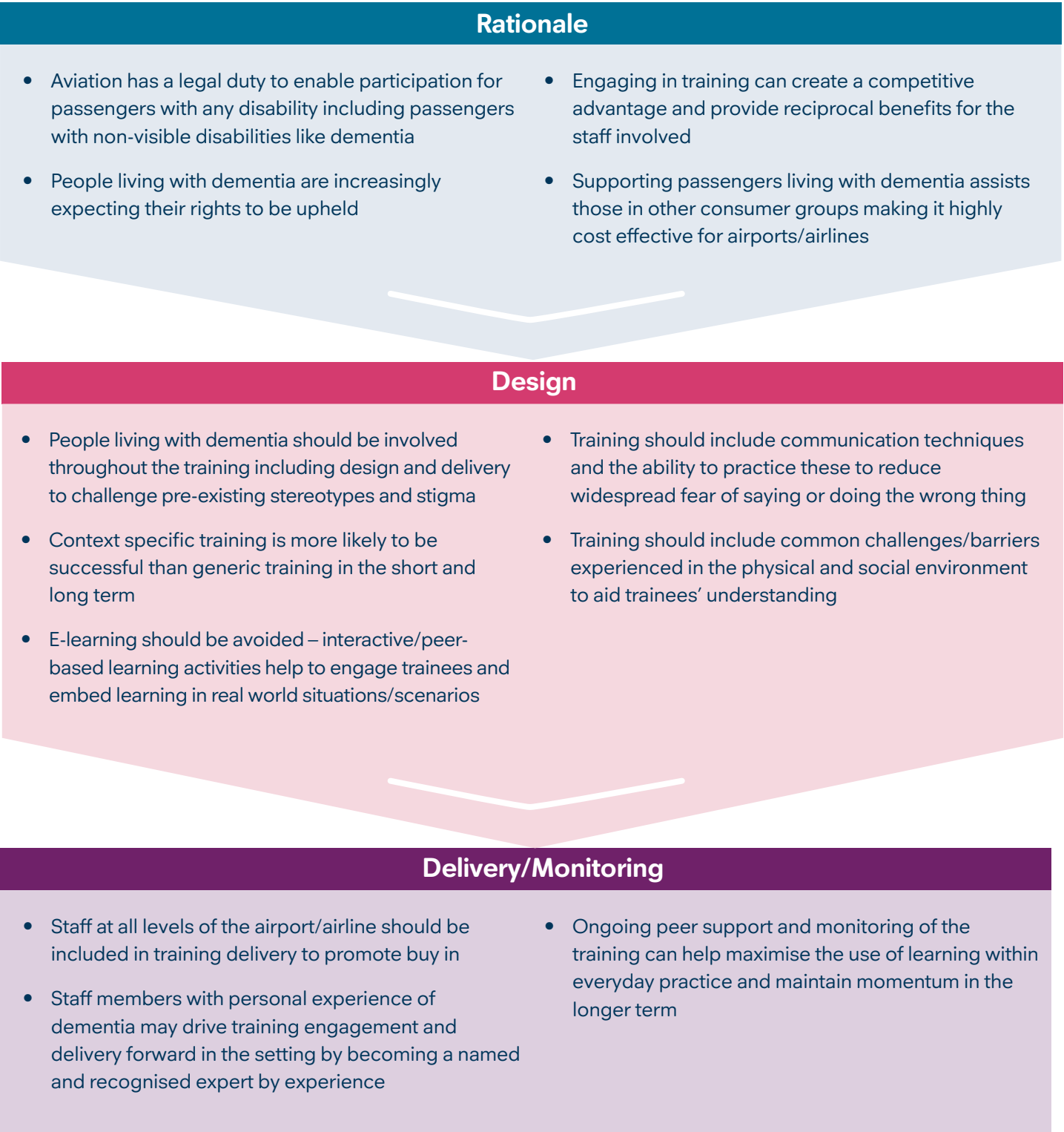
- The importance of not separating the person living with dementia from their companion at points of stress and complexity; and
- Recognising that travel companions can be expert communicators who can assist aviation staff in relaying complex instructions in a way that the person living with dementia will understand.

As part of the research, a realist synthesis was undertaken. A realist synthesis is a systematic review of the wider existing literature which seeks to identify not just if something works, but also why it works and in what circumstances [13]. As a result of the synthesis, a quality training framework was developed for use in

aviation that includes a series of steps or mechanisms from pre-training implementation through to post-training delivery.

A diagram representing these mechanisms is shown. Further information on how these steps have been derived is available in the first author’s doctoral thesis [2].

Context specific training in Aviation: A realist approach





## 5. Passengers living with dementia and their travel companions should be actively included in accessibility audits, committees, and design

It has been recognised that people living with dementia are frequently excluded from taking part in activities and discussions that directly affect their everyday life. Indeed, evidence of consultation with disability forums forms part of the CAA's quality standards for airports [14], with the CAA explicitly stating that they 'strongly recommend' that such consultation should take place with those living with disabilities and committees should not just consist of representatives of disability organisations. However, as the CAA do not currently report on such matters in their annual report on airport accessibility, it is unclear whether the voices of

people with non-visible disabilities are being heard on such forums or whether there remains an overuse of professional proxies within these groups.

Interestingly, some participants to the research had been invited to undertake a 'walk through' of their local airport as part of a dementia support group that they attended. However, they reported that they had not received any feedback on the change or difference their suggestions and involvement had made and were equally unaware of the existence of a disability forum at their local airport and had not been invited to join this.

### Recommendations:

- Airports utilising accessibility audit support in the future should provide feedback to the groups and individuals concerned and invite any interested members to take part in their wider consultative committees, particularly if those with direct lived experience of disability are underrepresented in these groups.
- That the CAA specifically include a question on the makeup of disability committees as part of their airport accessibility audits to identify whether those with lived experience are being included on such groups as intended.

## Conclusion

The UK Government's focus on building back better post-pandemic [15] is as applicable in aviation as it is in any other sector. Prior to the pandemic the number of air passengers requiring assistance was rising exponentially. Good practice guidelines had been put in place for how airports and airlines could support passengers with non-visible disabilities like dementia and some improvements had been made to the barriers experienced by this passenger group. However, there still was and is more work to be done to improve the air travel experience for such passengers following the Covid-19 pandemic.

While supporting air passengers with a range of disabilities, both physical and non-visible, is a legal duty for both airports and airlines, the number of passengers with a non-visible disability should not be

overlooked in terms of revenue generation at this time of post pandemic recovery. Therefore, encouraging and supporting passengers with non-visible disabilities to return to air travel is of significant benefit to both the aviation industry as well as to this passenger group and the recommendations contained in this report are provided in support of this endeavour.

As the realist synthesis we have undertaken indicates that generic dementia training is highly unlikely to be effective in this setting, the next stage of the research is to create a context specific training package for aviation based on the key mechanisms identified within this document. Enquiries from any parties interested in working with the University of Plymouth on this training design and delivery would be most welcome.

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