

# Final Report

## Infrequent Flyers? Exploring the issue of air travel and dementia from the perspective of people with dementia, their carers, airline staff and airport services



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Translating dementia research into practice

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## **Disclaimer**

The views expressed in this work are the views of its author/s and not necessarily those of the Australian Government.

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*...my mum hasn't stopped talking about the trip... at the time she didn't remember where she was some days, or who she spent it with, and now she relays stories to the, like, to the every little detail, but doesn't remember that I was physically there with her, you know, "We went here and we went there and we saw so and so and we did this" and I'm like "Wow! " like, you know, you don't remember that you just made me four cups of tea!*

*(Companion 1)*

*But otherwise I could honestly say with my husband, except for a few things that we laughed about later that were quite stressful, in many ways he loved his travel... and when he got back he wouldn't remember everything about the trip but he remembered some things ...you have to be aware... and try and think ahead and plan, but it was really good experience in lots of ways*

*(Companion 2)*

# **Executive Summary**

## **Project Overview**

The research described in this report marks a beginning exploration into the issue of air travel and dementia from the perspective of people with dementia, their travel companions, airline staff and airport services. Air travel is accessible to many people including those who live with dementia. The need to cater for people with dementia travelling by airplane is likely to be of increasing urgency with the projected increase in the number of people living with dementia in Australia approaching 900,000 by 2050. Therefore the aim of this study was to investigate this topic from multiple perspectives and identify facilitators and barriers to safe, comfortable air travel; identify the training and preparedness of airport staff and flight crew and determine if there are any unmet needs of people with dementia when travelling by air.

## **Methods and Results**

We used several methods to explore this issue: online surveys, qualitative interviews, and consultations with an expert panel and representatives from airline and airport staff. We received surveys from 41 companions, 22 flight crew, 13 security staff and 7 people with dementia. We conducted qualitative interviews with 10 companions.

## **Main findings**

The survey results indicated that people with dementia were flying on average twice per year. The most common type of trip was international long haul travel, and the most common reason for travel was for leisure. Over half of the companions had experienced problems at the airport, such as finding restrooms and their boarding gate, hearing announcements, checking in, reading information on signboards and bag screening. Despite this, almost half of the companions surveyed planned to continue travelling by air with their companion with dementia. While we only received seven surveys from people with dementia, these surveys indicated that people with dementia enjoy travelling by air and plan to keep doing so. Many people assume that people with dementia would not travel alone, but three of the respondents indicated that they did travel alone occasionally.

The companions we interviewed described quite difficult experiences when flying. For most travellers the difficult part of the journey was at the airport. Nine out of ten interviewees reported difficulties with navigating through security check points. These problems were due to the person with dementia experiencing difficulties in following instructions and responding to questions. Most companions found flight crew to be very polite and accommodating to

their needs. Accessing onboard toilets was a common difficulty as they were too small to accommodate two people. Two companions reported that the person with dementia became agitated on the flight.

Three quarters of flight crew stated that they had never experienced a passenger who declared that they had dementia. Those who had encountered passengers with dementia described the frequency as twice per year. Half of the crew felt confident that they had the skills to be able to manage passengers with dementia. Just under half believed airlines should provide extra training on the issue.

One third of the security staff said that they experienced difficulties with passengers who appeared confused or had trouble following directions every day or week, and just over one third reported that they had encountered passengers who declared that they had dementia. Just under half said that they felt they would benefit from more training about passengers with dementia.

We have collated travel tips that the people we spoke to passed on to us

- Talk to the airline about the assistance they can offer people with disabilities. Some airlines will escort you through the security and immigration checkpoints and on to your boarding gate. In general, lower cost airlines offer less customer assistance.
- Find an airline you like and stick with them. Familiarity with the airline may help reduce anxiety.
- Book a flight that leaves at a quiet time of day. For example, some airports are very busy between 6am and 10am and 4pm to 7pm. It will be a lot easier for you to find your way and access assistance if you are traveling outside of the busy period.
- Plan to arrive at the airport an hour and a half early to allow unforeseen delays. Go through the security checkpoints straight away and then find somewhere to relax.
- You can often find information about the seating configuration of the airplane online. Find the best seats for you, for example, many people choose aisle seats close to the toilets. Being in a position to view the toilet door will allow the companion to monitor the person walking to the toilet and returning.
- Find out about the airport prior to the day of your trip. You can visit the airport beforehand to get your bearings and look for information on the airport website. For example, there may be special parking zones for people with a disability that you can use.
- Don't be afraid to ask for help and explain your medical condition.
- Keep hand luggage to a minimum.

- If you wear a lanyard with a pocket on it around your neck, you can safely tuck away your travel documents in a place that is easy to access when you already have your hands full.
- Long haul travel can be the most difficult, particularly during the stopover. Schedule flights which enable you to rest and give you plenty of time to meet your connecting flight. If possible, travel with others to allow everyone to get enough rest.
- Some people with dementia get agitated at particular times on the flight, such as when everyone is boarding, during the take-off or landing. The use of distraction techniques such as using noise cancelling headphones to listen to music, or eating a favourite snack can reduce anxiety.
- Research the ground transport services available at your destination so that you can get away quickly.

## **Limitations**

The results reported here are based on relatively small numbers and we relied on a sample of volunteers. We have no way of knowing how similar or different our sample is from the wider population of people with dementia and their companions. It was difficult for staff to know if a passenger had dementia unless it was explicitly stated; therefore the findings from the staff surveys need to be treated with caution. Nevertheless, this exploratory study has done much to open up the conversation on an area about which little has been known.

## **Summary and recommendations**

The results from this exploratory study show that people with dementia are travelling relatively frequently, and sometimes do so alone. People with dementia and their travel companions reported that flight staff were generally very accommodating to their needs. They reported that the most difficult part of air travel was navigating their way through the airport. Security staff and air crew suggested that providing appropriate service to travellers with dementia would be facilitated by disclosing the diagnosis and any related support needs. Therefore we make the following recommendations:

1. That airports investigate ways to improve the experiences of travellers with dementia who use their facilities, e.g. through dementia friendly design.
2. That airlines develop clear guidelines for travellers with dementia to minimise adverse events and misunderstandings.
3. That airlines implement systems to facilitate ways in which people with dementia and/or their companions can inform staff of their support needs.

4. That airlines and airport services consider ways for people to nominate they must travel together, for example by wearing a lanyard, name tag or badge in a recognisable colour.
5. That security contractors consider revising their processes to facilitate travel for people who are cognitively impaired, for example, by adding signage to the terminal landside that explains what to expect at security checkpoints.
6. That security personnel be made aware of the needs of travellers with dementia, for example, that they may not understand their questions, and may become agitated if something unexpected happens and that they will likely need the support of their carer throughout the process.

## **Introduction**

In 2013 Alzheimer's Australia released its report on "Dementia Friendly Societies", which advocated promoting social inclusion and engagement of people living with dementia, as well as eliminating stigma. To maintain optimal quality of life people living with dementia and their carers should have access to the full range of activities available to all members of society. The introduction of low cost airlines has made air travel increasingly accessible to many. A diagnosis of dementia does not automatically mean such travel ceases. With more than 300,000 people living with dementia in Australia, two-thirds of whom are living in the community, and a projected increase to 900,000 by 2050, the pool of potential travellers with dementia is large; making it an issue in urgent need of attention. People living with dementia and their companions/carers need access to sound information to assist with decision-making and preparing for travel, while those dealing with them on their journey, such as flight crew, need to be prepared and alert to their needs. A lack of knowledge and understanding may lead to the occurrence of critical incidents, such as in-flight agitation, confusion at check-points, and getting lost in and around airports. This report contains results from a small exploratory study, the aims of which were as follows:

### **Aims of the project**

The specific aims of this exploratory study were to:

1. Investigate issues and experiences concerning air travel for people with dementia in Australia from multiple perspectives.
2. Identify facilitators and barriers to safe, comfortable air travel for people with dementia.
3. Identify the training and preparedness of airport staff and flight crew regarding interactions with people with dementia.
4. Identify unmet needs concerning facilitation of safe, comfortable travel for people with dementia.

### **Background and Significance**

As air travel becomes more accessible and the population ages, increasing numbers of older people are choosing to fly (Castiglioni, 2013; Duchateau, Verner, Gauss, & Brady, 2012; Low & Chan, 2002; Reed, 2007; Sproule, 2011). Dementia is a condition of late life that is likely to affect a number of these older passengers. Currently more than 300,000 people are living with dementia in Australia, most of whom are living in the community, and this is

expected to grow to 900,000 by 2050 (Australian Institute of Health & Welfare, 2012). A diagnosis of dementia does not preclude the desire to travel for pleasure, and air travel may also be necessary for someone with dementia to move closer to family. However, given that a person with dementia can become confused and disoriented in unfamiliar environments, and that the effects of altitude have been shown to cause adverse medical outcomes, such as delirium (Castiglioni, 2013; Low & Chan, 2002; Rands, 2002; Reed, 2007), it is surprising to find little research on the topic (Low & Chan, 2002; Rands, 2002). While some authors recommended medical checks and cognitive screens (Kelly & Caplan, 2009; Low & Chan, 2002; Reed, 2007) they did not provide associated guidelines regarding flight fitness. In addition to the dearth of published research, there is also little to be found in the form of airline policies or passenger advice. Airline policies refer to the World Health Organisation recommendations for obtaining medical clearance to fly. These recommendations do not include specific information about people with dementia and/or cognitive impairments (World Health Organisation 2016). Policies on flying with special needs from the three major Australian airlines (QANTAS, Virgin and Jetstar) do not mention dementia or even "cognitive impairment"; neither do their medical clearance policies (QANTAS Airways Ltd 2013; Jetstar Airways Pty Ltd 2014; Virgin Australia 2014; Virgin Australia 2015). A search of major airlines in other English-speaking countries revealed no consistent policies, albeit more developed than in Australia. Air Canada, Delta and American Airlines all have some consideration for passengers with cognitive impairment (Air Canada 2016; American Airlines 2016; Delta 2016). British Airways has a policy for "developmental impairments" (British Airways 2016), and Air New Zealand offers assistance for "elderly passengers" (Air New Zealand 2016). EasyJet was the only airline reviewed which had an explicitly stated policy for travellers with cognitive impairments and/or dementia (EasyJet 2016). This was the first airline in the United Kingdom to join the "Dementia Friends" initiative. We have reproduced their policy relating to travellers with dementia below:

*If you have a learning or cognitive disability or a condition such as dementia, you should only travel alone if you are able to understand and react to safety instructions on board. It is also very important to think about all aspects of the journey, including finding your way through the airport and all the procedures such as security, which can be confusing and stressful.*

*People with conditions such as dementia (including Alzheimer's disease) are particularly at risk in the busy surroundings of a big airport and it is highly advisable that you travel with a companion. The environment in the airport and on board an aircraft can be very confusing and upsetting to people who may not understand*

*where they are. It is vital for the comfort and dignity of the passenger and for safety on board that these passengers travel with a person they know and who can give them confidence during the flight as well as in the airport.*

*If you have a learning or cognitive disability and you are travelling alone, assistance should be booked no later than 48 hours (2 days) in advance.*

*Assistance can be made available at both the airport of departure and the airport of arrival, including baggage retrieval. It is also vital that the cabin crew are aware of the needs of any passenger with dementia or memory loss so they can provide additional information or assistance but it is important to be aware that one-to-one personal care cannot be provided on board. If you are uncertain whether you, or a relative or friend, should travel alone please call our Special Assistance Team for advice.*

This advice gives a clear indication of the safety issues that can be problematic for people with dementia but does not discourage travel. Instead it offers information that can be used to assist decision making. Without clear guidelines, such as used by EasyJet, it is difficult for people with dementia and their carers to make informed decisions about air travel. People may not disclose their diagnosis out of fear that they will be precluded from flying, or their companion may over-sedate the person with dementia in an attempt to prevent issues arising mid-flight (Castiglioni, 2013). Airlines state that flight crew are trained to deal with a range of situations and medical emergencies, but their level of preparedness regarding passengers with dementia is unclear (Castiglioni, 2013). Dementia advocacy organisations within a number of countries, including Australia, provide information sheets about flying; however, the lack of research and medical guidelines suggests these are mostly based on anecdotal evidence rather than research. This study aimed to address these issues by exploring the experiences of multiple stakeholders: people with dementia, their companions, and airline staff. This information should then help inform future research directions and ultimately lead to more definitive guidelines for airline passengers and staff.

## **Method**

This was a mixed methods study which included online surveys, a search of media reports, qualitative interviews and consultations with an expert panel and staff representatives. Ethical clearance was granted by the Queensland University of Technology (QUT) Human Research Ethics Committee (approval numbers 1500000124 and 1500000135).

The research team wanted to conduct a study that had relevance for all stakeholders. To facilitate this we consulted with travellers with dementia, staff in different roles within the air travel industry and academic experts. At the beginning of the project we formed an expert panel which included consumer and carer representatives, an international commercial pilot with a special interest in disability, a former flight attendant, a representative from Alzheimer's Australia and academics with an interest in marketing and design. The panel provided invaluable advice on the formulation of the overall project, helped make links to key people in different organisations, and assisted with the design of questions for the surveys and interviews. We consulted different members of the expert panel throughout the year as the need arose.

## **Development of survey**

Survey questions were developed based on media reports published on Google News in 2015, a review of the scholarly literature on health problems for people older people when they travel by air, and literature on airport design (particularly looking at the needs of older people). Early versions of the survey were circulated to members of the expert panel for comment and their suggestions were incorporated. We had four surveys that targeted the different stakeholders: people with dementia; those who travel with a person with dementia; flight crew; and security staff. The questions for people with dementia and their companions were very similar. We asked about frequency and reason for travel; the type of destinations visited; the types of problems experienced when planning travel (obtaining medical advice, finding medical insurance); the experience of using airports, experiences during a flight; knowledge of help available; experience with staff and future travel plans. For the flight crew and security staff survey we began the survey with an description of the symptoms of dementia and included a link to a video produced by Alzheimer's Australia called "Is it Dementia?" (available from <http://isitdementia.com.au/>). This video was created for workers in the transport industry, specifically, bus and taxi drivers. We then asked if they had ever encountered passengers whose behaviour was consistent with the symptoms of dementia, the frequency of encountering these types of passengers and whether they felt they had enough training to handle passengers with dementia. (See Appendix A for the full list of the

survey questions.) The survey could be accessed online, completed over the phone, or a paper copy could be posted on request.

## **Recruitment**

The QUT media unit promoted the study and this resulted in wide publicity across radio, print and online publishing (see Appendix B for details). The media release text included links to access the online surveys. As a result of this publicity, we received completed surveys from 41 companions and seven people with dementia. Ten of the 41 companions who completed the survey volunteered to be interviewed. These interviews took place over the telephone and took on average 30 minutes. They were audio recorded and transcribed verbatim. The transcripts were imported into the NVivo qualitative data analysis software package and coded to identify key issues and barriers relating to air travel.

Beyond the expert panel, we also met with flight attendants at Aviation Australia to gain their perspective on the needs of people with dementia when they travel by air. They assisted us with drafting the survey for flight crew. This organisation was subsequently sent information about the survey for distribution. However, this avenue and the media release yielded a limited response from flight crew participants. We recruited more flight crew through the personal networks of our expert panel members. In total, we received completed surveys from 21 flight crew.

The results from the companion survey and interviews indicated that many travellers had trouble with security checkpoints. We made contact with a security contractor from Brisbane Airport to discuss this finding. They organised a meeting with the management and staff where we discussed our preliminary findings. We were able to distribute our survey for security staff through their employee communication channels. We received 13 completed surveys from security staff

We met with the manager and volunteers from the Airport Ambassadors program, which provide information and assistance to travellers at the domestic and international airports. They gave us a good understanding of the types of assistance available to passengers, the areas of the airport where people are likely to become confused and some helpful tips to pass on to other travellers.

## **Media Reports**

To get an idea of the kinds of issues that people with dementia might face when they are flying, we conducted a search of media reports from 2015 on *Google News*. We found five incidents that were widely reported. These are described below:

### **7 May, 2015**

A 78 year old man with dementia wandered for more than 30 hours at Kennedy Airport, New York. He became disoriented while waiting for a connecting flight after travelling from Senegal on his way to Chicago. At some point he became lucid enough to explain to an airline employee that he had missed his connecting flight and he was found on board a plane that was about to fly to Chicago.

(Stepansky and Tracy 2015)

### **26 August, 2015**

A 53 year old man with dementia went missing at La Guardia airport, New York. His daughter dropped him off at the airport at 4am and requested wheelchair assistance for him. She informed staff that her father had dementia and that he should not be left unattended. When he didn't arrive at his destination, his daughter raised the alarm. Security footage showed that he didn't pass through the security checkpoints and go towards the gate. He became disorientated and left the airport. He was found wandering 25 miles away, suffering from exposure due to the freezing temperatures. He spent two weeks in intensive care.

(Carrega-Woodby 2015)

### **30 October, 2015**

An 84 year old man with dementia died in shackles after being detained by immigration officials in Britain. He was found wandering in a confused state at Gatwick airport. He had travelled from Canada and was on his way to Slovenia to visit his daughter. When approached by airport officials he could not give a clear account of his onward travel plans. He was detained and placed in an immigration detention centre, which at the time contained 600 asylum seekers. He suffered a heart attack while handcuffed and chained to a custody officer. The chain was not removed until the custody officer noticed that he was no longer breathing.

(O'Carroll and Miller 2015)

## **November 10, 2015**

An 82 year old woman took a short plane trip from Dallas to Houston and on to Greenville Spartanburg, a 4 hour journey. She did not leave the plane when it landed, instead remaining in her seat. The plane then continued flying on to the other side of America to Baltimore. Her children had made contact with the airline prior to the flight to inform them that she had dementia and requested that she be escorted from the plane. This did not happen. The airline arranged flights for her to return to her intended destination.

(Schneider 2015)

## **9 December, 2015**

A young man from New Zealand organised a trip around the world for his mother after she was diagnosed with Alzheimer's disease. She had always wanted to travel and feared that now she had been diagnosed she would never have this opportunity. The woman with dementia travelled with her son and daughter-in- law. The trip was considered a success by all concerned due to the amount of effort they put into organising it, and ensuring the mother was accompanied by two others to care for her.

(stuff.co.nz 2015)

These stories highlight the following issues. In all four cases where people with dementia went missing, they were travelling unaccompanied. In two of these cases, the passengers became disoriented during the stop over period and did not board their connecting flights. In the other two cases, the special assistance that had been requested by family members had not been provided. For the man found wandering in New York, the airline policy for people with cognitive impairments stated that they would be escorted airside through security. In the other case, the family had requested that their family member be escorted from the plane. In the story about the successful trip, the travellers did plenty of research to prepare and the woman with dementia was accompanied by two companions.

## **People with dementia – survey results**

### **Sample characteristics**

A total of seven people with dementia answered questions on our survey: four women and three men. The average age was 63. Six of the seven had received a diagnosis of dementia between two and five years ago. Most (6) travelled by air one or two times per year, the other respondent travelled eight times per year.

Three occasionally travelled alone, the other four always travelled with a companion. Six had travelled less than 6 months prior to completing the survey, the remaining one had travelled within 12 months. When asked about destinations, four usually travelled on long haul flights (to Europe or the Americas), and three usually travelled within Australia. Five travelled for leisure, three to spend time with friends and family, three to attend conferences and two for special events such as weddings.

### **Travel Experiences**

A number of difficulties were reported at the airport, including finding their boarding gate (3), checking in (2), bag screening (2), finding restrooms (2), hearing announcements (2) and reading signboards (2). Two respondents reported having no problems at the airport. When asked if they had any other problems in airports, one person stated "*understanding questions*" and the other "*I have a tendency to wander, especially when I get anxious about boarding on time.*" Whilst on board, most respondents were positive about their in-flight experience. They found the staff members were helpful and accommodating to their needs. One respondent said they had requested particular seats, but these were changed after check in to accommodate a family travelling together. They found this change troubling. Four of the respondents knew that they could request assistance from flight crew to open packages for their meals. Three respondents reported they felt anxious during the flight. The types of things they felt anxious about were: turbulence, answering questions, when other people boarded, finding the bathroom and wondering if they would arrive on time. One person said they took medication to alleviate their anxiety. Four respondents said they would continue to travel by air (two of these were those who travelled alone occasionally), as it was "*still a reasonably positive experience*" and another wished to continue to visit family. Three said they had no plans to cease travel at any point. Others felt they may cease travel when the stress becomes unmanageable, or if it took them too long to recover from long haul travel.

Three respondents suggested that airline and airport staff could be more friendly and understanding of their need to take more time to do things. One respondent commented:

*Be more patient and considerate towards us as we are often slower than others to absorb information. For some of us the crowds and excessive noise is somewhat problematic as the extra stimulation can cause confusion and anxiety.*

Overall, the respondents to our survey who had been diagnosed with dementia enjoyed air travel and suggested to others – “*Don’t be afraid to ask for help.*” and “*Do it and enjoy it!*”

## Travel companions of people with dementia – survey results

### Sample characteristics

A total of 41 companions completed the survey. They ranged in age from 55 to 65, with an average age of 60 years ( $SD = 10.2$ ) and the majority of companions (90%) were female. Almost all of the people with dementia with whom companions were travelling had received a diagnosis of dementia (98%); and the average duration since diagnosis was 4.7 years ( $SD = 2.8$ ). On average, companions reported taking two trips by plane per year ( $M = 2.15$ ,  $SD = 2.4$ ) with the person with dementia with whom they were travelling. Most companions (70%) stated that their most recent trip was in the last year. When asked what type of resources companions accessed when planning a trip, most answered ‘the internet’, and some also used books and travel agents.

### Travel destinations

The most common destinations reported were international long haul travel ( $n=22$ , 54%); and domestic short travel ( $n=20$ , 49%); followed by international short travel ( $n=14$ , 34%); and domestic long trips ( $n=7$ , 17%). This could indicate the most popular destinations were Europe and the Americas and shorter trips within Australia, probably between capital cities. See *Figure 1* for details.

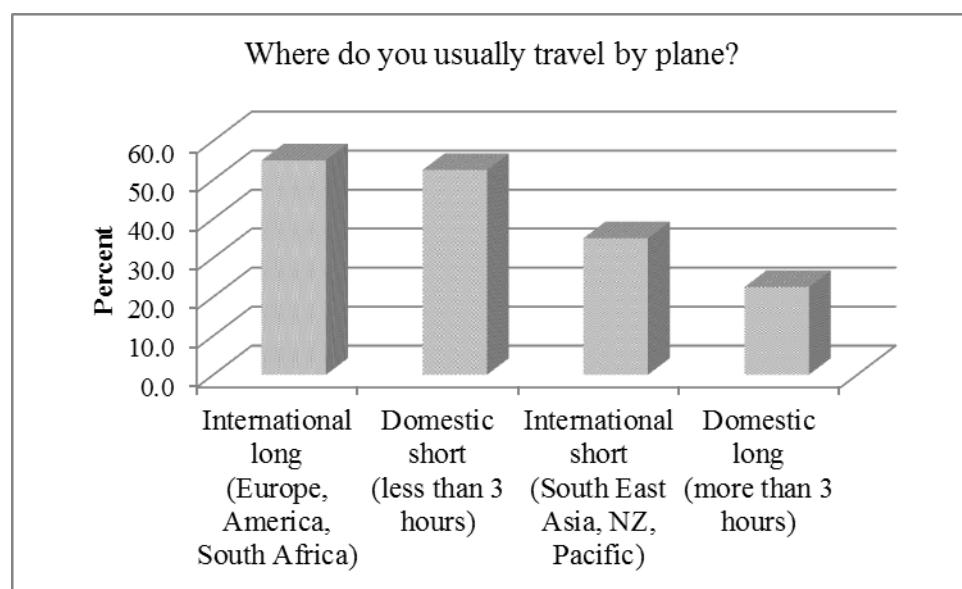
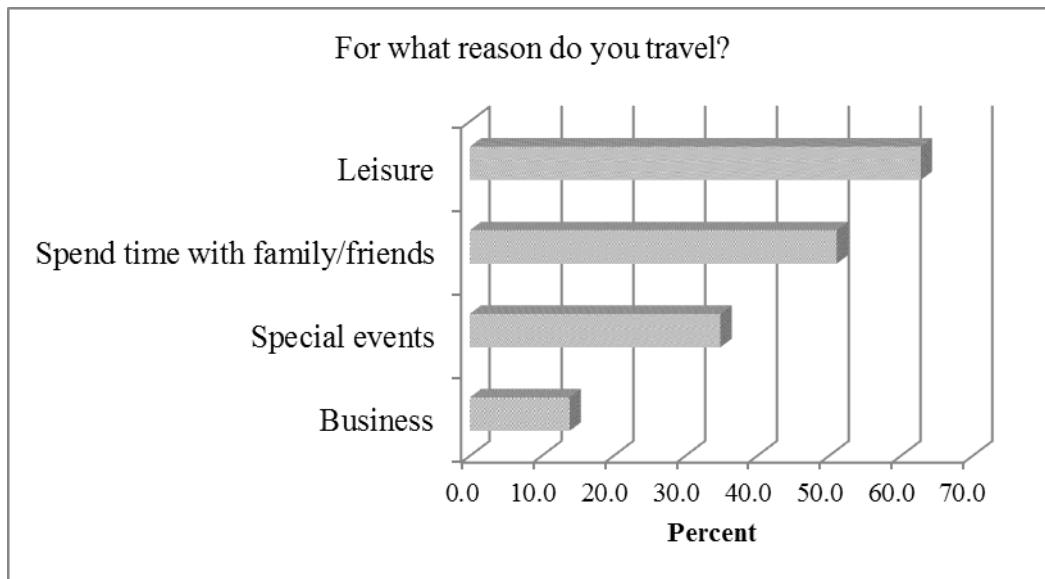


Figure 1. Usual destinations when travelling with a person with dementia. n=42

The most common reason was travel for leisure (n=26, 63%); followed by travel to spend time with friends or family (n=22, 54%); travel for special events (e.g. wedding n=14, 34%), and travel for business (n=6, 15%) (see *Figure 2*).



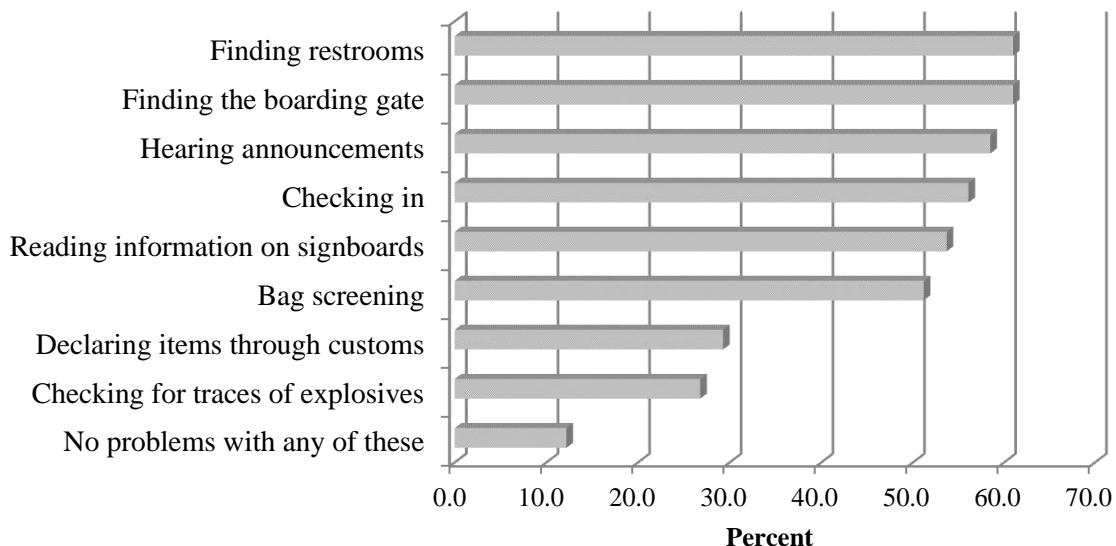
**Figure 2. Reasons that people with dementia travel, as stated by companions. n=43**

### **Problems experienced whilst planning travel and during travelling**

Thirty-nine percent of companions (16) had experienced problems obtaining travel insurance; 15% (6) obtaining larger amounts of prescribed medication; and 7% (3) obtaining medical clearance from the doctor. Just over half of companions (n=21, 51%) had not experienced problems with any of these.

*Figure 3* shows problems experienced by the person with dementia at the airport, as reported by their companions. People could choose more than one difficulty. The most common difficulties were finding restrooms (n=25, 61%), finding boarding gate (n=25, 61%) and hearing announcements (n=24, 59%). Checking in (n=23, 56%), reading information on signboards (n=22, 54%) and bag screening (n=21, 51%) were other common issues. Almost one third (n=12, 29%) also had had problems declaring items at customs and during explosive checks (n=11, 27%). Twelve percent had not had problems with any of these.

Has the person you travel with ever experienced problems with any of these?



**Figure 3. Difficulties experienced at the airport, as reported by companions. n= 41**

Just over one third (n=14, 35%) of the respondents reported that their companion experienced anxiety when flying. Almost half (n=20, 49%) said they plan to continue travelling by air with their companion with dementia. The remainder had decided not to do any more travel due to the declining health or death of their companion.

### Using available assistance

Assistance is available for travellers both in the airport and once on board their flight. Almost half (n=18, 44%) said they had requested assistance with boarding or disembarking at some point. Most companions (n=30, 73%) stated they usually request particular seats (for example, window or aisle, extra leg room, near to restrooms) when they travel. Most companions (n=32, 78%) were *not* aware that one can request cabin crew to assist with meals, such as explaining what each item is and helping to open packaging. Only 17% (7) reported making use of a 'quiet space' within an airport (such as a prayer room or airline lounge), as a strategy to reduce the anxiety of their companion. Most companions were not aware of this type of space in the airport.

## **Travel companions of people with dementia – Interviews**

### **Sample description**

Interviews were conducted by telephone with 10 companions; 8 female and 2 male. They were all located in Australia. We did not ask them any further personal information.

### **Reason for travel**

Similar to the general community, people with dementia choose to travel for leisure or to attend special family events. Many Australians are migrants or descendants of migrants and people often wish to travel to visit their homelands. Out of the 10 companions interviewed, four described trips involving travel to the place of the person with dementia's birth. Two companions had plans to do more long haul travel in the future.,.

### **Planning the trip**

Two of the interviewees said that when their companion was diagnosed, doctors recommended doing any trips they had been planning sooner rather than later, due to the progressive degeneration that was characteristic of the disease. For example:

*...when she received [the] diagnosis 5 years ago her neurologist said you know "if there are places in the world that you'd like to travel to or Australia or whatever, get your bags packed and start doing it" because he couldn't guarantee how long she would be able to sort of see things. (Companion #3)*

Three of the companions said that when they spoke to a doctor about their upcoming trip, the doctor did not recommend flying. These people had more advanced cases of dementia. The remaining companions did not comment about doctors' advice.

Travel insurance was difficult to obtain for people with dementia. Companions described having to call several companies to find one with a policy that would cover them. Some found insurance that would cover everything except conditions directly related to dementia. Others simply did not declare anything about the dementia.

### **At the airport**

## **Security check points**

Nine out of the ten companions reported difficulties navigating through security checkpoints, such as bag screening, customs, and immigration areas of the airport. Often the person with dementia would proceed well through the checkpoints if things happened in a routine and expected way. If, however, something unexpected occurred they would not know how to respond. For example, if they were selected for extra security checks, they might not understand the instructions of the security staff nor be able to answer questions in a satisfactory manner. This difficulty was compounded by the need to go through these areas and answer questions alone.

A few companions said the person they travelled with did not understand queueing protocols or could not understand which way to walk (or look) to pass through the scanning equipment. The pressure of having to complete tasks such as removal of shoes and jewellery while in a queue of other hurrying and stressed travellers added to the difficulty of negotiating these checkpoints. One companion made the suggestion that it would be beneficial if there was more signage prior to meeting the bag screening area that would explain the processes that people were about to go through.

Some older people have metal body parts that trigger off the security scanners. This can lead to more intrusive security procedures and the travellers becoming separated. This situation can lead to a lot of distress for both travellers, as this man described:

*And so at the international terminal and as soon as the scanner goes they treat, the person who has rung the buzzer as a, you know, a suspected terrorist I suppose, in their jargon and so we are separated and without pre-warning [my wife] gets really quite difficult. On one occasion... they are saying "take off your shoes, take off your belt"... that alarms [my wife], she comes over and tries and grabs me and they say "no you are being touched, you've got to go through again" – we did this...three times on that first incident. (Companion #6)*

This man and his wife were regular air travellers and he had tried different tactics to make passing through the security checkpoints go more smoothly. In the quote below, he describes how speaking with the security staff at the screening checkpoint appeared to arouse more suspicion:

*...I went to what looked like the senior guy and said ...“look, I need to have a word, there is a particular issue here.” I explained to him the situation and ... he*

*said “that’s fine, that’s fine, I’ll go and talk to my colleagues”. When we came round and there was two security zones both with the scanners, one to the right and one to the left, he was on the right one. As we came up to him...he then indicated us not to go through his scanner but go through the one to the left. We went to the one on the left and of course they didn’t know anything about it. So the circus began again...so I don’t know by talking to that particular chappy, he then identified us as suspect...it back fired on me.* (Companion #6)

## Wayfinding

Companions described navigating their way through airports as stressful, particularly on long haul trips that necessitate stopovers. Often there was a requirement to change to a different terminal, or walk a long distance to catch a connecting flight. The companion would often be sleep deprived, and have to decipher where they needed to go for their next flight, in a busy, noisy airport. They would need to be thinking for two, and for those who had companions who had a tendency to wander, they would also need to keep in physical contact with them.

*... international travel can be stressful for everyone... the confusion and you know the busy-ness of an airport and you know the noise at the best of times and... with someone at your side that you’ve got to say well come here, we’ve got to walk here, you’ve got to turn here and then at the same time you’re looking for signage and getting in to the right queues and avenues and fronting up and wheeling your trolley with your luggage - I mean all of that puts stress on the carer.*

## Toilets

Using toilets at the airport can be another challenge. They often have multiple doors, multiple exit points, mirrors, and/or unusual tap and sink designs. Travelling companions reported that their companion with dementia may become lost within the toilet, or once they leave the toilet, they cannot remember how to find their way back to them. For this reason some companions used the disabled toilets, which were large enough to accommodate two people. This could present problems if others perceived that they were using the toilets without good reason:

*...If I have to come out of a disabled toilet and someone says “what the hell are you doing in there, you don’t look disabled!” then ok we’re going to have to address that issue because usually the disabled toilet has the wheelchair symbol*

*on doesn't it...I guess what we have to say is there's other forms of disability that -where a carer is needed.*

Sometimes disabled toilets were located within the male or female toilets. This creates problems for people travelling with a spouse of the opposite gender. Unisex disabled toilets are the preferred option, as this person described:

*...disabled bathrooms, you know, a lot of the times you've got to go into the male toilet to take a male to the disabled toilet, and, you know, that's just so inappropriate on many levels, for me to walk through a male toilet, through the urinals to get back to the toilet to go to the far end of the bathroom where the disabled toilet is [laugh] You've got to be kidding me!*

### **Special assistance**

Those who had requested special assistance at the airport reported that this had made navigating through the airport much easier. However, not all people with dementia have mobility impairments, which meant that they could be resistant to the idea of using a wheelchair, as these people described:

*[My husband] didn't look unwell, he looked quite normal and he was 57 when he was diagnosed... So he didn't look like he had dementia and people would not suspect it even if he had odd behaviour, so we had, you know, I arranged for special like assistance at the - at Sydney airport, all the way through to London. And he was quite frustrated to have that assistance because he didn't feel like there was anything wrong with him, that's part of the dementia (Companion #5)*

*He was ok when we left Sydney, by the time we got to Singapore, we were asked to wait behind for the wheelchair. "No!" He wasn't going to wait for anybody, he has to be first out, so there he is...he's sort of hobbling along, meanwhile I've sort of waited and explained and apologized and all the rest of it ... but meanwhile we'd lost the wheelchair, and ...he kept wandering all over the place and I was absolutely terrified of losing him (Companion #8)*

One person related an upsetting experience she had when requesting special assistance from the airline. The airline assigned an escort to them with a group of others who required assistance. When the person with dementia encountered a problem with security, the escort

left them behind and carried on with the others to the boarding gate, as she describes::

*...we were bailed up the both of us [at the screening checkpoint] and ... you know it was the question “is this your bag, sir?” “Aah” you know and he couldn’t communicate very well so he didn’t know what to say so he was very nervous and it was the whole dice and the lady, the escorting lady said “well you just catch us up” and she just left us there.... for the lady to just leave us there was not appropriate. And so we had to, you know, eventually make the way to our gate on our own ... and then I, you know we had to bundle on to the plane with everybody else because by that time...everybody was already on the plane. It was very upsetting. (Companion #5).*

There were a variety of experiences relating to ground staff as people were recounting stories from their travels to many different countries. Travelling to countries where they did not speak the language was most difficult. However, people had fairly positive experiences on the whole.

*I found the staff of all the airlines were really good, if I just went up and spoke to them, and asked if I could be boarded early while we were at the departure gate, there was never a problem (Companion #2)*

*Sydney is utterly fantastic: the people who go to meet you they’re impeccably dressed, they’re incredibly well-spoken, they’re kind, they’re polite, really – they’re a credit to Sydney Airport, they are fantastic. (Companion #8)*

## **Managing luggage**

Collecting luggage and bags was difficult for companions. They often had to manage luggage for the person with dementia as well as their own, all the while trying to ensure their companion did not wander away, as one interviewee described:

*The biggest challenge I had was picking up bags. Getting bags off the carousel, cause again, I’d have to hold on to him or put his hands on the trolley and say “don’t move” but I couldn’t trust him not to move so I’m trying to look for bags and keep one eye on him or keep one hand on him the whole time so he didn’t go anywhere (Companion #2)*

## **During the flight**

### **Experience with flight staff**

None of the companions described a bad experience with flight staff. They found them extremely polite and accommodating of their needs.

*... they're very astute generally, flight attendants and she was seeing how I was having difficulty managing [my husband], so yes she was very helpful, very compassionate and I have no idea what would have happened had he become overtly aggressive I guess, but I certainly felt very confident – it meant that I went from being alone to knowing that there was someone there in authority who was aware of what was going on and that made me feel you know, in a sense supported.*

*(Companion #2)*

### **Toilets**

Using the toilet on board was a difficulty for five of the companions. The toilets are usually too small to accommodate two people and inside there are a lot of different slots and spaces for things, which can be confusing for anyone, but especially a person with dementia, as this person described:

*Going to toilets is the other issue... there's not many plane toilets that allow room for two people... I've taken her to the toilet door and I've said "here's the door, here's the latch on the door, once you get in, slide that knob across so that it puts up the engaged light so that no one else is going to barge in on you" and sometimes she's done it but once in there and she's locked it then she can't get out because she can't find the knob again ... I can imagine that finding the controls to flush the toilet, the taps and everything else are always a bit confusing and where are the slots for which particular, you know, towel, paper napkin... all those sorts of things are not easily labelled either , or not conveniently labelled for people with dementia...Or even for older people – I mean a lot of the issues for people with dementia also apply to people, you know, elderly people who might travel as well.*

*(Companion #3)*

## **Agitation or confusion during the flight**

Only two of the interviewees reported that their companion with dementia became agitated during the flight. In most cases, any mild agitation could be managed by the companion talking calmly to the person with dementia, or distracting them with snacks. This companion had a particularly bad experience:

*The return trip to Australia was the biggest nightmare of all. This was 3 weeks after our initial flight. I gave [my husband] a sleeping pill early in the flight, as I needed to get some sleep. He became more agitated as the flight went on, and I talked to one of the flight attendants about his condition and that I might need some help. At one stage [he] said he was going to the bathroom (we were sitting front row) and he walked up to the cockpit door! I was convinced all the alarms would go off. Thankfully, I was able to quickly turn him around to the bathroom door. After 9 hours of constant agitation, [he] finally succumbed to sleep one hour out of Sydney - too late for me to get any sleep. The flight was quite terrifying for me as I had no way of knowing what he would do next. I was totally exhausted when we got home. (Companion #1)*

One companion reported that her husband became delirious after landing, and would take some time to return to normal.

*And last year when we finally got to [our destination], he was as mad as a meat axe, and I suddenly put it all together; I began to realize that his really aggressive and shouting behaviour when we got to [the] airport was probably the result of the cabin pressure (Companion #8)*

## **Strategies used by companions/advice for others**

### **1. On long flights, travel with others**

Some of the companions who had done long haul travel had a difficult time, particularly during stop overs. The companions were sleep deprived and needed to work out where to go to catch their connecting flights, while dealing with agitation, confusion or the risk of wandering. If two people accompany the person with dementia, one person can rest or deal with travel requirements while the other attends to the person with dementia.

### **2. Request assistance**

Companions suggested that travellers ask for available assistance. Special assistance from the airline is available for all people with disabilities. However, as indicated above, most airlines have focused their disability access plan on people with mobility impairments. The special assistance available usually involves the provision of a wheelchair and an escort through security checkpoints. Companions reported positive experiences with airline staff when they received assistance, for example:

*But I do have to say that all the help that we asked for...was exceptional and caring and compassionate and very friendly and you know they didn't just treat [my husband] as someone who was a blob in a wheelchair, they talked to him and that sort of stuff, so I was very impressed with the way they respected him and treated him. (Companion #1)*

Some companions chose to use a wheelchair even if the person with dementia did not have mobility problems to ease the passage through the airport. Although not an option that is available to every air passenger, three travel companions suggested that booking premium seats (business or first class) made their journey more bearable as it gave them access to the most assistance and allowed them to board and disembark first.

### **3. Minimise luggage**

Some carers needed to keep in physical contact to make sure that the person with dementia did not wander off. This was more difficult if they were also trying to juggle large suitcases and multiple items of hand luggage.

### **4. Use distraction techniques to reduce agitation**

Some people with dementia felt anxious when the other passengers were boarding, or during take-off and landing. Companions reported using distraction techniques, such as offering a snack or starting a conversation at these times. Using noise cancelling headphones for listening to music or watching movies was recommended by one regular traveller.

### **5. Request aisle seats**

Companions suggested requesting aisle seats near toilets was helpful if frequent toilet trips were needed during the flight.

### **6. Research destination airport**

One companion recommended people researched the ground transport options at the destination airport, and book transport ahead of time. This made it easier to get away from the airport as quickly as possible.

### **Suggestions to airlines/airports for improvement**

The people we spoke to described quite different experiences that related to the type of the dementia and the symptoms displayed by their companion. Some people with dementia were aggressive and rude towards their companion, ground staff and airline staff and would wander off in airports. Others were fairly placid and happy to sit in one place. If the person with dementia did exhibit difficult behaviours, instead of being offered help, they might in fact trigger a more aggressive response from airport or flight staff. When a person uses a wheelchair it is more obvious that two people are travelling together. However, for travellers with dementia, the invisibility of the condition can make it more difficult for staff to recognise that they need to stay together. This is how one companion described the problem:

*I suppose visual impairment and physical disablement I guess are the two that where it would be more noticeable and special attention would be given by the airlines to people with such a condition travelling...could people with dementia...also be treated similarly in everything from word go? (Companion #3)*

Many companions' suggestions were around ways to tackle this invisibility. One suggestion was that people with dementia could wear some kind of identifier, such as a badge, or a coloured tag on a lanyard that would identify them as needing assistance, for example, when going through security checkpoints. Or a card that says "*I am travelling with a carer*", as these two companions suggested:

*If you could just perhaps be given something that identifies that you should be staying together, that you need to stay together, or something like that, you know, just a card (Companion #4)*

*[Something that indicates] "we're together", so that in itself is a flag saying these two are together for a reason, not just because they want to be together because they love each other, because they're looking after each other or whatever, there's a special need here (Companion #5)*

Companions wondered if there could be some way of indicating the person had dementia when booking the ticket. They said that you could request particular meals if you had special dietary requirements, perhaps there could be some way to indicate that you had dementia and may need extra assistance. This information could be encoded on the boarding pass, for example:

*Well that's why I thought on the boarding pass because..., you've got your frequent flyer number, they have all sorts of information...there would be a code on there that, you know, every time you go through something at least they look at it go "Ah ok", that's why she doesn't understand she needs to go down those stairs or up those stairs. (Companion #9)*

## **Flight crew and security staff – survey results**

### **Sample Description**

A total of 22 flight crew completed the survey. The majority (n=19,) were pilots, 2 were flight attendants and one person a retired pilot. The majority of crew (18) worked mainly on international routes, and most crew (21) had been in their current role for more than 5 years (the remaining one for 1-2 years).

A total of 13 security workers completed the survey. Five worked in management roles and the remainder worked in customer service roles. Just over half worked at both domestic and international airports, the remainder worked at the international airport only. Most had been employed in their current role for 1-2 years (46%); followed by more than 5 years (39%) and 2-5 years 15.4%.

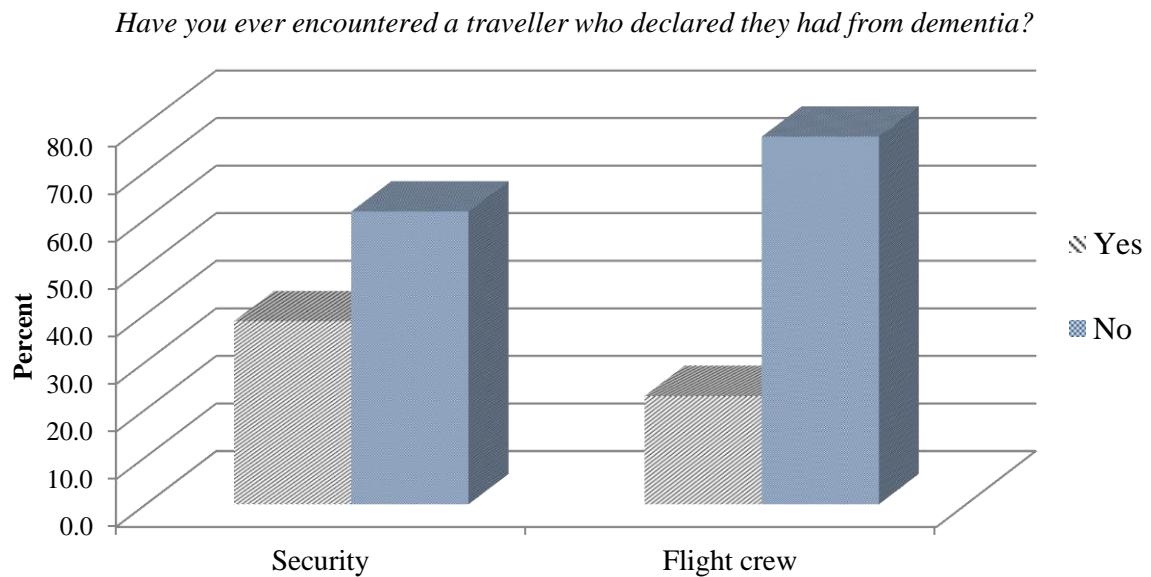
### **Flight crew**

#### **Experience with travellers with dementia**

It was difficult for crew to know for sure if they were dealing with a passenger who had dementia. The majority of flight crew (n=16, 77%) reported they had not encountered a passenger who declared that they had dementia (either as part of the booking process , or by informing a staff member). They reported that they often encountered passengers who were confused and that part of their role is to provide assistance to people who needed it. One person related an anecdote about an incident where a passenger tried to open the door of the aircraft because they thought they were on a bus. The passenger's family had booked them onto the flight alone and not informed anyone of the dementia. Flight crew were of the opinion that all persons with dementia would be travelling with a carer. Most crew stated that they did not need extra training about the needs of passengers with dementia, but an awareness of ways to recognise that a person had dementia would be helpful.

For a few of the items we made comparisons between the answers of flight crew and security staff; *Figure 4* shows the percentage of crew and security who had ever encountered a person who declared they had dementia. A greater proportion of security staff reported this compared to flight crew, with approximately 35% (5 out of 13) of security staff encountering someone who declared they had dementia, compared to just under 20% (5 out

of 21) of airline staff. This may be because many of the flight crew that answered the survey were pilots rather than flight attendants

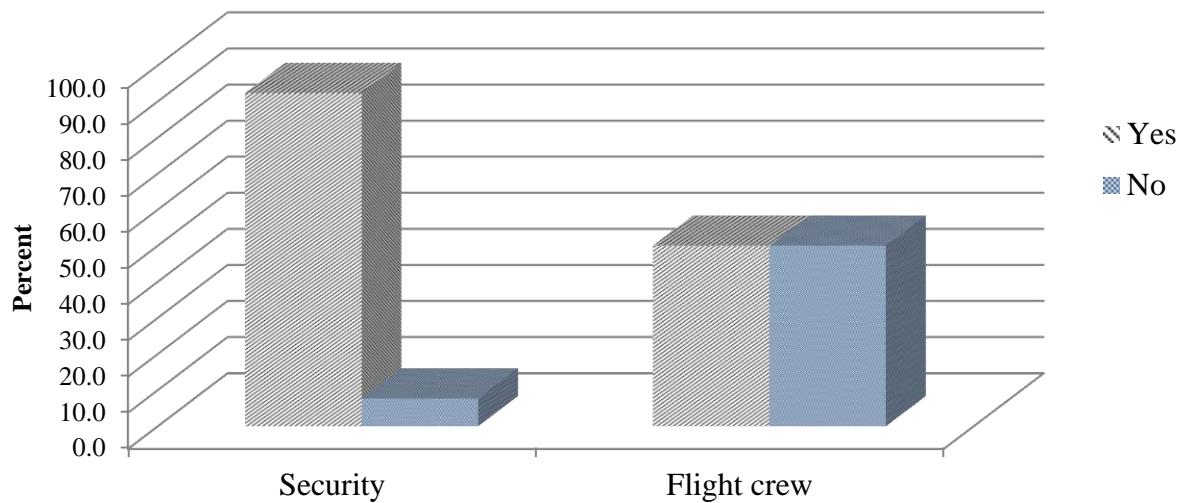


**Figure 4: Comparison of how many security staff versus flight crew had encountered a traveller who declared they had dementia. Security n=13, Flight Crew n=22.**

Flight crew who had encountered a person with dementia said that the passenger had told them directly or that it was recorded as part of their booking. The security personnel reported that the passenger told them directly and/or the passenger had obtained special assistance from airline staff.

Figure 5 shows the percentage of flight crew and security staff and their confidence in managing travellers with dementia. A greater proportion of security staff felt confident in their ability: over 80% (n=12) said "yes" compared with 50% (n=6) of flight crew.

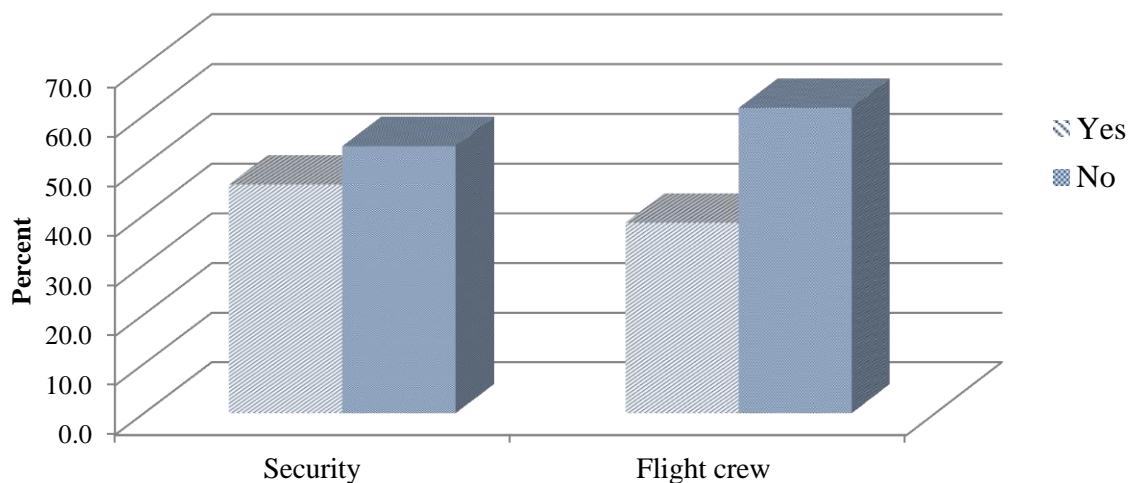
*Do you feel confident about your ability to manage travellers who show some of these symptoms?*



**Figure 5: Comparison of how many security staff versus flight crew feel confident in their ability to tend to travellers with dementia. Security staff n=13, Flight crew n=22.**

Crew and security staff were also asked whether they believed they required more training to understand how to work with people with dementia. As seen in *Figure 6*, slightly fewer flight crew believed they needed more training compared to security staff.

*Do you think that you need more training to deal with people with dementia?*



**Figure 6: Comparison of security staff versus flight crew who believe they need more training in dealing with people with dementia. Security n= 13, Flight Crew n=22.**

## **In-flight issues**

Flight crew reported that problems with passengers that would be consistent with a diagnosis of dementia were infrequent, only once or twice per year. Half of crew (n=11, 50%) said they had never had to request assistance from other medically trained passengers to assist with a person who may have dementia, nor had they ever been on a flight where emergency action (such as physical restraint, flight diversion) had to be taken because of a person showing symptoms that may have been due to dementia (10 flight crew skipped this question).

## **Training and skills**

Stakeholder consultation indicated that flight crew receive comprehensive training about a range of medical issues. However, in the survey half of the flight crew (10) reported they had not received information about dementia in their First Aid training. Of those who answered the question about training, the same number felt confident about their abilities (6), as those who did not (6). Ten people skipped this question. Just under one half (8) did not believe that airlines needed to provide them with more training to deal with people with dementia. In the open ended question responses staff indicated that generally providing good customer service would be enough to meet the needs of passengers with dementia.

Almost half of the flight crew said they did not think that airlines need to change their procedures to accommodate people with dementia. Crew said if they are aware of the problem, they already do what they can to assist. However, two crew members thought more could be done; that more help is needed for the elderly in general, and that there could be a special pathway and early seating on the aircraft for people with dementia.

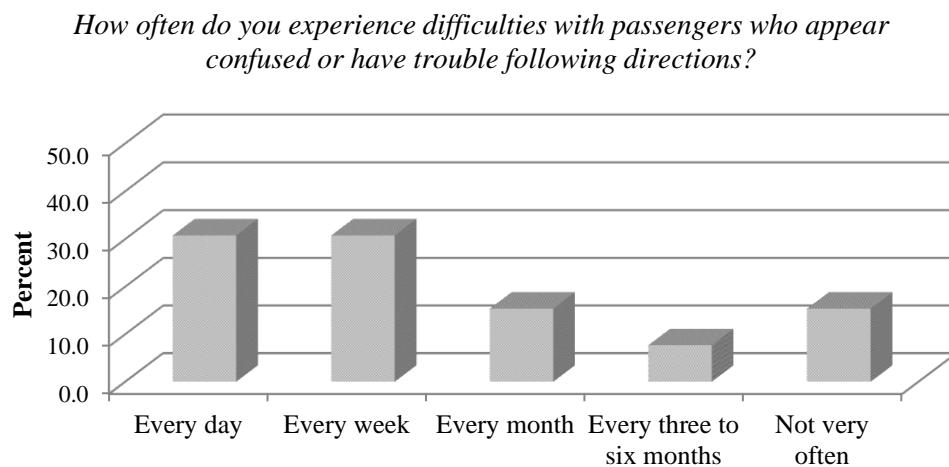
## **Advice for travellers**

Their advice for travellers was to investigate the assistance that was offered by airlines, as this can vary widely. When booking, inform the airline of the diagnosis and the traveller's needs and also let flight crew know during the trip. Some dementia symptoms could be interpreted as rude or due to intoxication so it would be beneficial to let staff know. Provide specific information about the person with dementia, especially when travelling alone (e.g. travel destination, reason for travel, functional effects, specific issues that might arise, contact details, and medication information). Some suggested having this information available in writing, attached to the person; another suggested they obtain medical clearance

and carry other documentation that might be required when travelling. Another suggested easily identifiable clothing in case the person with dementia gets lost. They suggested that companions ensure that the person with dementia is well hydrated, avoids alcohol, takes their medication and allow plenty of time at the airport.

## Security staff

When asked how often security staff experience difficulties with passengers who appear confused or have trouble following directions, almost one third (n=4, 31%) said 'every day' and 'every week'; 15% (n=2) said 'every month'; 8% (n=1) 'every 3-6 months' and another 15% (n=2) said 'not very often.'



**Figure 7: Security staff reported frequency of experience with confused passengers. n=13**

The majority of security personnel (n=12, 92%) said they felt confident about their ability to manage travellers who showed symptoms of confusion. Almost even numbers believed that they did and did not need further training about how to assist people with dementia.

## **Experience with travellers with dementia**

We asked security staff to tell us about the types of things that appeared to be challenging for older passengers. They reported that older people often had difficulty following instructions, such as understanding what they needed to take out of bags, following direction to a particular screening lane, how to walk through metal detectors, how to pass through the body scanners; and where to go after screening. They sometimes needed practical assistance such as help lifting carry-on bags onto the screening scanner, assistance with luggage, and removing items such as shoes and belts. Some would forget where they had put things or what was in their bag. Some older passengers found it difficult to stand and wait in long queues; and finally, they reported that some older passengers did not understand why security is important, why they cannot have sharp items, or were incredulous that security staff could consider them to be a security risk.

When encountering passengers who were confused or disoriented, most security staff said they did not follow any special procedures. It was part of their general customer service to be polite and helpful. If they had difficulties they would refer to their supervisor and/or request some assistance from the airline. A challenge with airports is that passengers have to pass through different zones that are controlled by staff from different organisations. This staff member said:

*"I help them with their bags and speak gently and kindly with compassion as they get very upset easily. I make sure they get through the screening point but after that they are on their own, but again I tell them to ask someone for help. Often I have agitated family members at the departure door who want me to assist them which I am unable to do, I suggest they go and get someone from the airline to assist them."*

Security staff suggested that airports could provide more informative signs that explain security processes, or that there could be a special lane for people requiring assistance with security, or more staff available who could escort passengers who required assistance. Someone suggested that travellers with special needs could be provided free, short movies of what they can expect when going through security check points and airports.

Their advice for travellers was to inform the airline of any special needs, such as those related to the effects of dementia, or the presence of any metal body parts; airline staff can then assist them through the express security lane. They also suggested travellers could do some research prior to the day of their trip to ensure that they were not carrying items that would trigger the security system.

## **Discussion**

The aim of this project was to explore the issue of air travel for people with dementia from different perspectives. We consulted widely with different stakeholders, surveyed people with dementia, surveyed and interviewed their travelling companions, surveyed airport and airline staff.

People with dementia and their travelling companions reported that they enjoyed travelling by air. Companions told us that even if the person with dementia was not always aware of their surroundings or where they were going, they still happily told stories of their journey when they returned. Around half of the companions planned to keep travelling by air for as long as they could.

The collated media reports from 2015 about people with dementia travelling reinforced our findings that people with dementia sometimes travel alone, that they can become disoriented in airports, especially during stop overs, but also that people with dementia *can* travel successfully, particularly if they travel with well-prepared companions.

The main reason for travel reported by people with dementia and their companions was for leisure. The most common type of air travel was international long haul trips, followed by domestic short trips. This pattern of travel reflects the nature and location of the Australian continent. Many Australians are European migrants or descended from migrants, and many wish to visit countries in which they have family connections. Many people within Australia travel by air to visit other capital cities.

A perception held by airline and airport staff was that people with dementia would not be travelling alone. However, our results indicate that people with dementia do indeed travel alone at times.

The broad and open approach taken in this project allowed us to discover which part of air travel was the most difficult for people with dementia. The initial review of the literature indicated that people with dementia may experience delirium induced by the experience of air travel (Aquilina and Matthews 2006). The reduced availability of oxygen can cause headaches, dizziness, impaired coordination, fatigue and confusion (Rands 2002). Two of the companions reported very difficult experiences consistent with this. The remainder described the use of distraction techniques such as bringing snacks, listening to music, or engaging in conversation was enough to reduce any agitation. What was consistently

reported by people with dementia and their companions was the difficult time they had in airports.

### **Barriers to safe and comfortable air travel**

In our background research and consultations we became aware that little information was provided on airline or airport websites regarding the available assistance for people with dementia. While airlines have special assistance guidelines for travellers with physical or sensory disabilities, very few guidelines were available for travellers with dementia or other cognitive impairments. At Brisbane Airport there are volunteer Airport Ambassadors who provide assistance with giving directions and information, but the airport's website provided very little information about this service. The lack of specific guidelines for people travelling with dementia means that people are not aware of the assistance that is available to them. Some people may be afraid to ask for assistance for fear of being denied the ability to travel by air. However, many of our respondents emphasised the importance of disclosing the diagnosis and requesting assistance.

More specific barriers that we found were in the physical layout of airports, the availability of unisex disabled toilets, and the processes involved in passing through security checkpoints. Some consideration may need to be made to alter the signage to ensure that it is clear that the toilets were for anyone who required assistance, whether they were in a wheelchair or not.

Regarding the training and preparedness of staff, we found that most staff felt they had adequate training in handling passengers with dementia. This was reinforced by the survey findings, where most people were very appreciative of the kindness and courtesy shown by staff. Some interview participants expressed the wish that security staff could be more sensitive to their needs, and security staff showed more interest in further training than flight crew. As the security checkpoints were highlighted as the most difficult part of air travel, further training and revision of security processes for these types of travellers seems warranted.

Unmet needs identified through carrying out this exploratory study are that airlines and airports need to improve their accessibility policies to cater for people with cognitive impairments such as dementia. Airports and airlines could give consideration for ways to streamline the movement of people with cognitive impairments through from the check-in counters to boarding gate. There needs to be a clear way for passengers to indicate that

they wish to travel together through the airport. People reported to us that when they had tried to inform staff of their needs, this would not always result in receiving assistance. For example, informing the airline would not necessarily translate into assistance with security. One passenger who had tried to inform security they needed assistance was treated with increased suspicion. A clear way of identifying people who were travelling together would resolve this problem, for example, if airports used a recognisable lanyard that indicated this to staff.

A guide to the airport could be developed so when people are planning their travel, they can get some idea ahead of time of the number of checkpoints, the layout of the airport and the location of toilets and quiet spaces. This guide could outline the types of assistance available, for example, by making it clear that an airline staff member can assist a passenger to move through the security checkpoints.

In conclusion, this research project found that people with dementia do travel relatively frequently, with their most common destination being international long haul travel (for example Europe, America or South Africa). Some people with dementia travel alone at times. The airport was consistently identified as the most challenging component of the journey. Thus, improving airport processes and procedures for identifying passengers in need of assistance would improve the experience of air travel for people with dementia.

## **Limitations**

The results reported here are based on relatively small numbers and we relied on a sample of volunteers. We have no way of knowing how similar or different our sample is from the wider population of people with dementia and their companions. A larger, randomly generated sample would increase our confidence in the generalisability of our results. The results from the staff surveys have reduced validity because it was difficult for staff to know if a passenger had dementia unless it was explicitly stated. Nevertheless, this exploratory study has done much to open up the conversation on an area about which little is known.

## **Suggestions for future research**

Given the specific challenges experienced in the airport, we have commenced further research assessing the dementia friendliness of airport environments. It is also recommended that further research be undertaken targeting airport design and processes.

We received very few responses from people with dementia. It would be of benefit to expand on the knowledge gained in this exploratory study to examine things such as the extent to which people with dementia travel alone. The use of a prospective research design, in which participants were followed through their journeys and interviewed after they returned, would provide more accurate and detailed information about the challenges and rewards of travelling with dementia.

Our review of the medical literature showed that there was a lack of evidence available to doctors to make recommendations to their patients who wish to fly (Rands 2002; Aquilina and Matthews 2006). For example, a recent guidebook on travel medicine included a chapter on “High risk travellers” which discussed the needs of the elderly, but did not discuss dementia (Suh, McCarthy et al. 2013). Our research has established there is a clear need for further research in this area to allow doctors to give informed advice to their patients who are considering travel.

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## **Appendix A. Survey Questions**

### **Survey for Person with dementia**

*(The survey for travellers accompanying a person with dementia was very similar to this, so is not included here)*

About You:

1. Please select your gender:
  - a. M
  - b. F
2. What was your age last birthday?
3. Have you ever been diagnosed with dementia? (Y/N)
  - a. If Yes, how long ago?

Attitude toward air travel:

4. How often in a year would you travel by plane?
5. Do you travel on airplanes alone?
  - a. No, I always travel with a companion
  - b. Yes, occasionally
  - c. I always travel alone
6. When was your last trip?
7. Where do you usually travel by plane (check all that apply)?
  - a. Within Australia: short trips (less than 3 hours)
  - b. Within Australia: longer trips (3 hours or more)
  - c. International: short trips (South East Asia, New Zealand, Pacific)
  - d. International: longer trips (Europe, North America, South America, South Africa)
8. For what reason do you travel?
  - a. Business
  - b. Leisure
  - c. Special events (e.g a wedding)
  - d. Spending time with friends or family
  - e. Other
9. What type of resources do you access when planning a trip? (e.g websites, travel forums or books)
10. Have any of the following been problems for you when preparing to travel?
  - a. Obtaining medical clearance from the doctor

- b. Obtaining larger amounts of prescribed medication
- c. Obtaining travel insurance
- d. Other

11. Please describe any problems you have encountered when preparing for travel here:

#### Experiences with airports

12. Have you ever experienced problems with the following? (check all that apply)

- a. Checking in
- b. Bag screening
- c. Checking for traces of explosives
- d. Declaring items through customs
- e. Finding your boarding gate
- f. Finding restrooms
- g. Hearing announcements
- h. Reading information on signboards

13. Have you had other problems at the airport?

14. Have you ever made use of a quiet space within an airport (such as a prayer room or airline lounge)? (Y/N) Comments:

15. Please describe anything that has helped you have a positive experience at the airport.

#### Experiences during a flight

16. Have you ever requested assistance with boarding or disembarkation? (Y/N)

- a. If yes, did you find the staff to be helpful?

17. Do you request particular seats (for example, window or aisle, extra leg room, near to restrooms)? (Y/N)

- a. If yes, has there been a time when there was a problem with your request?  
Please describe what happened.

18. Are you aware that you can request cabin crew to assist with meals, such as explaining what each item is and helping to open packaging? (Y/N) Comments:

- a. If yes, did you find staff to be helpful?

19. Do you experience anxiety during a flight? (Y/N).

- a. If yes, what in particular worries you?
- b. Do you use any strategies to reduce your anxiety?

20. Thinking about your recent trip.s, did you have any problems during the flight? If so, describe them below.

21. Thinking about your recent trip/s, was there anything in particular that assisted you to have a positive experience during the flight?

Experiences with staff

22. Thinking about your recent trips, were flight staff able to accommodate your needs?

Future plans

23. Do you plan to continue travelling by air? (Y/N). Please describe why you have made that decision.

24. Are there other modes of travelling that you like to use as an alternative to air travel? (for example, train, car, caravan or cruise ship?) If yes, please comment below:

25. Is there a point when you plan to cease air travel? What would determine that decision? Describe below.

Summary

26. Overall, what is the most challenging aspect of air travel for you?

27. What suggestions do you have for airport and airline staff to improve the way they handle passengers with dementia?

28. Do you have any suggestions for other people with dementia who are planning to travel by air?

29. Is there anything else you would like to mention about travelling by air?

30. How did you find out about the survey?

## **Survey for flight crew**

About You:

1. What is your current work role?

- a. Flight attendant
- b. Pilot
- c. Ground crew
- d. Other (please specify)

2. Which routes do you mainly work on?

- a. Domestic
- b. International

3. How long have you worked in this role?

- a. Less than one year

- b. 1-2 years
  - c. 2-5 years
  - d. More than 5 years
4. Have you ever had a passenger who had declared they suffered from dementia, either as part of booking their ticket, or by informing a staff member? (Y/N)
- a. If yes, how did they declare this?
    - i. As part of their booking
    - ii. By telling a staff member
    - iii. Showing a card explaining their condition
    - iv. Other
5. In your role, have you come across a passenger displaying symptoms of dementia that couldn't be explained by other reasons (such as intoxication, fear of flying)?
- a. Yes
  - b. No
  - c. Unsure
6. Can you describe any incidents involving this type of passenger?
7. Have you ever had to request assistance from other medically trained passengers to assist you with a person who may have been suffering from dementia?
- a. Yes
  - b. No
  - c. Comments
8. Have you ever been on a flight where emergency action had to be taken because of a person showing symptoms that may have been due to dementia? (For example, physical restraint, flight diversion?)
- a. Yes
  - b. No
  - c. Comments
9. How frequently would you encounter passengers whose behaviour may be due to dementia?
- a. Daily
  - b. Weekly
  - c. Monthly
  - d. Twice per year
  - e. Once per year
  - f. I don't know

- g. Has this changed in recent times? If so, comment here:
- 10. Did your First Aid training include information about dementia? (Y/N)
- 11. Do you feel confident about your ability to manage passengers who show some of these symptoms? (Y/N) Please explain your answer
- 12. Do you think that airlines need to provide you with more training to deal with people with dementia? (Y/N) If yes, please comment.
- 13. What kinds of suggestions would you make for people with dementia and their travelling companions who are planning air travel?
- 14. Do you think that airlines need to do anything else to make air travel more comfortable for people with dementia?
- 15. Do you have any other comments about this issue or the survey?
- 16. How did you find out about the survey?

## **Survey for security staff**

- 1. What is your current work role?
  - a. Security staff
  - b. Security management
  - c. Other
- 2. Which type of airport do you work in?
  - a. Domestic
  - b. International
  - c. Both
- 3. How long have you worked in this role?
  - a. Less than one year
  - b. 1-2 years
  - c. 2-5 years
  - d. More than 5 years
- 4. Which type of things appear to be challenging for older passengers when passing through security check points?
- 5. How often do you experience difficulties with passengers who appear confused or have trouble following directions?
  - a. Every day
  - b. Every week
  - c. Every month
  - d. Every three to six months
  - e. Not very often
  - f. Can you tell us more about these experiences?

6. Have you ever encountered a traveller who had declared they suffered from dementia? (Y/N)
  - a. If yes, how did they declare they had been diagnosed with dementia?
    - i. By telling you directly
    - ii. By obtaining special assistance from airline staff
    - iii. Showing a card explaining their condition
    - iv. Other
7. Do you have any special procedures you use for people who appear to be confused and disoriented?
8. Do you feel confident about your ability to manage travellers who show some of these symptoms? (Y/N) Please explain your answer.
9. Do you think you need more training to deal with people with dementia? (Y/N)  
Please comment.
10. Do you have any suggestions to make it easier for people with dementia and their travelling companions to pass through security checkpoints?
11. Do you have any other comments about the issue or the survey?
12. How did you find out about our survey?

## Appendix B - Media Coverage of the project

### Traditional news outlets

1. *Air travel and dementia – understanding the challenges for travellers, carers and airlines*  
**QUT News**, 18 Jun 2015  
[https://www.qut.edu.au/news/news?news\\_id=91260](https://www.qut.edu.au/news/news?news_id=91260)
2. *Air travel and dementia – understanding the challenges for travellers, carers and airlines.*  
**Health Canal**. 18/06/15
3. QUT researchers are looking into the impact of dementia and how to manage it during air travel  
**4BC, Brisbane, 11:00 News**, Newsreader 18 Jun 2015 11:03 AM
4. *CheckUp* medical column for June 19 ("Air Travel and Dementia")  
**AAP Newswire, Australia**, National, AAP 19 Jun 2015. This appeared on Channel 9 News news.com.au, capital city and regional newspapers.
5. Cathy Van Extel reports on travelling with dementia.  
**Radio National, Canberra, Breakfast (Early)**, James Carleton 23 Jun 2015 6:43 AM

*Also broadcast from the following 8 stations:* Radio National (Sydney), Radio National Melbourne), Radio National (Brisbane), Radio National (Perth), Radio National (Hobart), Radio National (Adelaide), Radio National (Darwin), Radio National (Newcastle)

This was also published online on 25<sup>th</sup> June on **abc.net.au**

6. Airlines unprepared for increasing number of travellers with dementia. **ABC Radio National** 24/06/15
7. Bartholomew says the travel industry is expecting an increase, but with more elderly ...  
**ABC NewsRadio, Melbourne, Mornings**, Glen Bartholomew 23 Jun 2015 11:54 AM

*Also broadcast from the following 7 stations* ABC NewsRadio (Sydney), ABC NewsRadio (Brisbane), ABC NewsRadio (Adelaide), ABC NewsRadio (Perth), ABC NewsRadio (Canberra), ABC NewsRadio (Newcastle), ABC NewsRadio (Gold Coast)

8. Interview with Dr Maria O'Reilly, Qld University of Technology.  
**774 ABC Melbourne**, Melbourne, Drive, Rafael Epstein 23 Jun 2015 3:27 PM

*Also broadcast from the following station:* ABC Ballarat (Ballarat)

9. Sanders says the travelling industry is anticipating boom  
**ABC Southern Queensland, Toowoomba**, Mornings, Belinda Sanders 25 Jun 2015 9:19 AM
10. Understanding the challenges of air travel and dementia, **Medical Xpress**, June 18, 2015.  
<http://medicalxpress.com/news/2015-06-air-dementia.html>
11. Avoiding confusion in the air

**Senior Traveller Extra #72.** 30<sup>th</sup> of June.

12. Travelling with dementia. The Senior 15<sup>th</sup> December 2015.  
<https://www.thesenior.com.au/news/travelling-with-dementia/>

## Blogs/ support groups etc.

1. An article was posted on the Younger Onset Dementia Facebook support group page on travel tips for people with dementia
2. A longer article was published on the dementia.org website:  
<https://www.dementia.org/how-to-fly-with-dementia>
3. "Improving air travel for people with dementia" by By Keryn Curtis *Frank and Earnest* on June 24, 2015. <http://frankandearnest.net.au/improving-air-travel-for-people-with-dementia/>
4. Carer's Queensland. We were listed on the "Latest News" section of their website under the category of "Improving the quality of life of carers"

5. An article was published on the Ozcare Dementia Support website.  
<http://www.dementiasupport.com.au/Learning-Centre/News-and-New-Research/July-2015.aspx>
6. The media release was reposted on the Senior Citz website on 30<sup>th</sup> June 2015.  
<http://seniorcitz.com/?p=93>.