

Dr Joy Watson's talk given at the Health Care estates event at the Manchester Central Convention Complex on 5th October.

'The lived experience of dementia in daily life'

Having lived with a diagnosis of dementia for three years, I've had good and bad experiences when negotiating different environments. The level of dementia friendliness is often determined by the degree of awareness about dementia, and the effects the disease can have on people living with the condition and those supporting them.

Sometimes, people's perception of dementia can influence design and planning, and it is quite often left to us to bring issues to the attention of the people responsible for bringing about change. For example, in my role as ambassador for The Alzheimer's Society and associate for the Institute for Dementia at Salford University, I get to travel a fair bit, but my experience of finding a seat at many of the main line railway stations can be a nightmare. I contacted the rail companies suggesting they might look into introducing designated seating in their waiting areas. People would feel more confident in requesting a seat if there was a sign their entitlement to needing that seat.

We all know that rail stations, bus stations, airports and the like are all hectic places, but for someone living with dementia it can be the difference of venturing out or staying at home.

These environments can be daunting places. The sheer volume of people moving in different directions, the tannoy announcements being high pitched and loud, the signage not always clear and locating a member of staff, well, these all add to the anxiety of what is already a challenging expedition.

Where possible, I take advantage of the disability lounges. I ensure that I find out from the staff on hand what platform my train is coming into, thus enabling me to avoid the rush when the information is presented on the screen. If you are organized enough, you can request entry to the train earlier than other passengers, but that involves having a good memory, something I don't possess any more.

Friends have struggled at airports. Travelling with someone with dementia is hard enough with some of the previous problems I've mentioned being relevant to airports as well. Imagine trying to collect your luggage from the carousel, or waiting for your case to be extracted from the inside of a coach, and the person you are supporting doesn't see any reason to be waiting around, so they take off into the crowds or worse still, into the road. Panic takes over and what should be a pleasant experience, turns into a nightmare.

I recently had a difficult experience with trying to locate my car. I knew exactly where I had parked it, because I've learnt to take a note of the car parks name and what street it is in, the level and which bay. But on returning to the car park, every staircase I climbed led me to the roof. On my third attempt I got quite upset. My situation was made worse when the

security man, on hearing my dilemma said “ Yes, you need to go right, left along that way”. I explained that I had dementia and was finding it difficult following his instructions, and anyway, I couldn’t face climbing the stairs again as they were badly lit, smelly and due to my special awareness I was falling into the walls, which was adding to my frustration.

The lift wasn’t an option as it was out of order, so I was hoping this gentleman might offer me some assistance. But no, he just turned and walked away with the comment “ Well I have to use the stairs”.

So sometimes it is not just the environments that give cause for concern, it can be the people who are allocated to supervise those environments. You will have gathered that public car parks are not my favourite places.

I’ve encountered many obnoxious people in these environments. Sensible thinking goes out of the window where there’s a space to be got to, and on occasions, telling people you have dementia isn’t always the best thing to do. I don’t want people to feel sorry for me, but neither do I want to be abused. One encounter I had involved the lady calling the police, her comment to the police officer being “ This lady says she has Alzheimer’s but she doesn’t look like she’s got Alzheimer’s to me” My trying to convince her that I did indeed have Alzheimer’s only served to irritate her even more. Her comments being “ If you have Alzheimer’s you shouldn’t be driving should you?” The parking space only got resolved when she decided she didn’t want to stay in the town after all. Her parting comment being “ Yeh, thinking about it, you do look as if you have dementia”

But things aren’t always so negative. There’s a lot of good stuff going on, and I am witness to some of that good stuff. As part of the Institute for Dementia and on a personal level I get invited to evaluate some environments and establishments with a view to them becoming more dementia friendly. We have a dining group in Salford, set up for people with dementia, but before we make a meal booking, we do a reccy of the premises and establish how suitable the environment is. We ask questions that are relevant to the people attending, like would you be willing to turn the music down, have your staff any experience of dementia? Can we put up temporary signs to show the way out of the toilets? It’s one thing knowing how to find your way into an area, but its often confusing for some living with dementia to know which way is out. A small temporary sign can mean the difference between a person having a good eating out social experience, or one of despair and fear.

There are things in the environment that we can have influence over, and my experience tells me that most people want to do what they can to establish dementia friendly spaces. After all, dementia friendly benefits everyone in society, whether it be improved signage or non shiny floor surfaces.

For me it’s about being respected and treated as an equal. OK so you don’t get many people living with dementia riding the white knuckle rides at Alton Towers, but those of us

who do, need to know that the environment can cater for our needs. Being able to join the fast track queue was immensely helpful for several reasons, namely, feeling unable to escape were I part of a crowd, would freak me out.

I guess my biggest bone of contention is disability parking. I have a radar key, which entitles me to use disabled toilets, I have a disabled rail card, I get disability concessions in some places. All these allow me to keep my independence and not having to rely on my carer all the time. Everyday tasks would be so much easier if designated bays were made available for people living with dementia. I feel it is grossly unfair that the criteria is focused on physical disability. If after negotiating a busy supermarket with all that entails, I come out and it takes me 20 to 30 minutes to locate my car, my stress levels are through the roof. My back is aching with the weight of shopping. I can end up in floods of tears simply because the environment has changed. The half empty car park I drove into is now full and I'm disorientated. Were I allowed to use one of the small number of disabled bays, I could find my car, no problem. It would be tempting to put a baby on board sticker in my window and park in the family space, but I'm too honest and if anyone was going to get caught, it would be me.

It's encouraging that many public places are recognizing the need to offer dementia friendly facilities. Looking back to a time when wheelchair access was limited and people struggled, to now, when accessibility is written into law. The importance of the architects, designers, planners and builders coming on board from the very onset of a new build is, in my opinion, vital.

Well, I can't finish my time with you without introducing you to Demi. Demi is my life line and my best companion. She's given me the confidence to go places I would never have the courage to go. Sadly, not every environment welcomes us. In some towns I can almost die of thirst before I've found an accepting café. The Welsh seem to have sussed that by allowing well behaved dogs, they are gaining more custom. There is nothing worse than being in the middle of a park and desperate for the loo, only to find the toilets are inside the building and you are told you cannot bring the dog in. When you point out that there are no rings to tie the lead to, you are then told to ask one of the other customers to take care of her. **WHAT!!**

Demi comes with me on the majority of my trips. It's not so bad getting lost with her by my side as opposed to getting lost alone.

Yes, having dementia has its challenges when it comes to the environment, but I guess the only way we are going to improve things is by pointing out things that would make our lives easier and hope someone is going to listen. I for one, don't intend staying at home isolated and lonely. My towns, cities and countryside are there to enjoy and explore. We all need to work together to improve our environments, not just for those affected by dementia, but for everyone.