

Dementia Awareness on the Norwich-Sheringham "Bittern Line" railway

Presentation to Railfuture East Anglia in Norwich on 29 September 2018 by Liz Withington

Sheringham Dementia Friendly Community SDFC







To help Sheringham become understanding of, accepting of and inclusive for those living with Dementia



- By being dementia-accessible people living with dementia are able to continue to take part in the activities they have always enjoyed and continue to be active in their community
- For this to happen public transport has a very major role to play and needs to ensure that it is socially responsible

Passengers make profits!

- This is also a commercial decision which can benefit the turnover of the transport company and also its sustainability
- Showing a commitment to dementia awareness, which is high profile, has also to be a plus for any future rail franchise application
- In 2016 there were 850,000 people diagnosed with dementia in the UK – this will grow:
 - By 2025 about 1 million
 - By 2050 over 2 million
- 30% are undiagnosed
 - Realistic figure for 2016 is 1.1 million of the adult population

Passengers make profits!

- In North Norfolk there are 3,800 people diagnosed with dementia
- 30% of all those living with dementia do not have a diagnosis
- A more realistic figure is 5,000
- The demographic of over 50% over 65 in Sheringham also shows you this is much needed
- As you can see it also a commercial decision at individual railway line levels which can benefit the turnover of the line and also its sustainability

1 in 14 over 65s will develop dementia 1 in 6 people over the age of 80

- WI group of 50 will have 3 members living with dementia in addition to those who may be caring for a partner or family member with dementia
- A bus of 52 passengers will have similar numbers
- This is therefore a significant customer base which if not enabled to use public transport will be lost to Greater Anglia and the Bittern Line
- This is also a significant group of people who are in danger of becoming isolated. Alleviating loneliness also a major area of concern for the Government

What makes a service dementia accessible?

- An understanding that dementia is not just about losing your memory
- An understanding that public transport has a vital role to play in enabling people to continue to be part of their communities and to live well with dementia
- A will to break down the fear and stigma associated with dementia
- A determination to take action and build dementia accessibility into design, process and customer service

Fairy Lights – function failure



With dementia the lights gradually go out

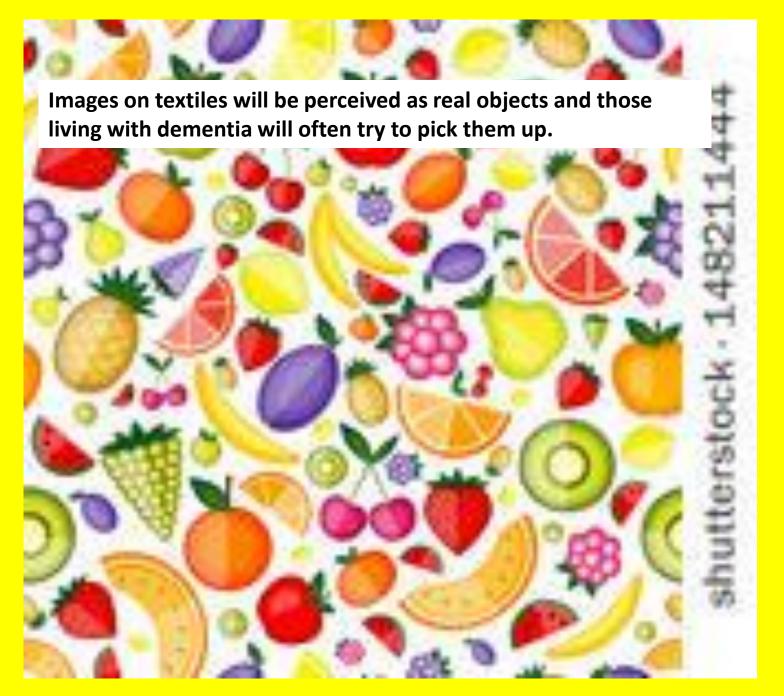
Dementia is not just about memory loss

- Communication
- Gross and fine motor skills
- Balance
- Sequencing
- Perception
- Anxiety
- Every person with dementia will be different

Dementia can also affect people's perception

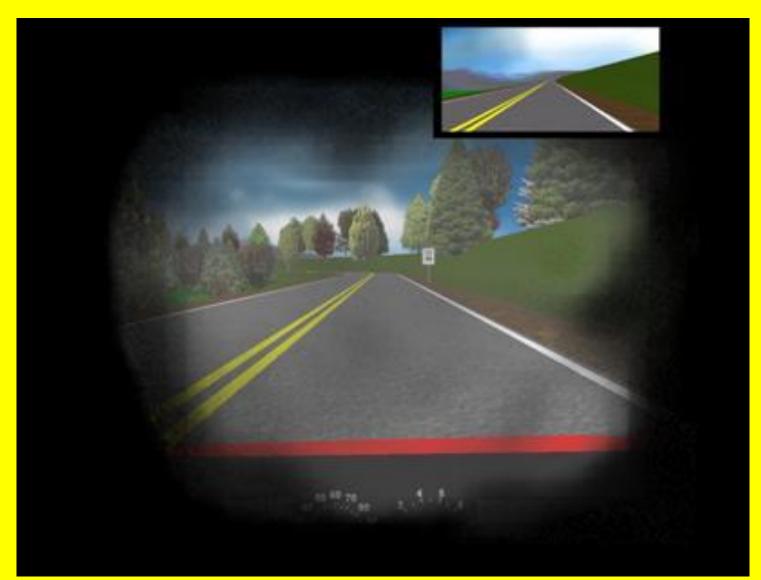






A black door mat can be perceived as a hole and can lead to confrontation and anxiety. This is also true of our modern cars with our lovely black leather interiors, which can be seen as black boxes.....why would you let someone put you in a box!

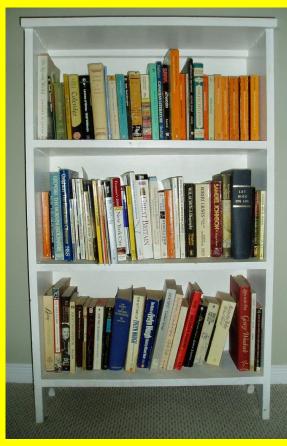
Perception changes



A person with dementia loses the ability for the brain to read the messages from the eye as to what is being seen. It is not their vision which has deteriorated.

Try walking around with binocular hands in front of your eyes. How does it make you feel? How would it affect you using trains?

How dementia affects someone "The bookcase analogy"



Factual memory (left)
Oldest memories at
bottom remain; newest
memories at top are lost as
books fall off when the
shelf wobbles

Emotional memory (right)
Sturdy bookcase does not
wobble so emotional
memories (sense of
happiness or stress) from
most recent activity is not
lost



https://www.youtube.com/watch?v=kkvyGrOEIfA

Emotional Memory

Understanding emotional memory is the key to being dementia accessible

 A positive experience on a train from arrival at the station to, obtaining tickets, the journey and leaving the station

Means a return passenger

 An anxious or stressful experience will be remembered as an emotional memory, a feeling associated with the train

Passenger doesn't return!

End-to-end journey experience

Arrival at the station - clear directions and signage are needed





Perception issues here will make it difficult to see the gate and where to go.

Supporting signage but also design of access-simple and leading people.

E.g. a large sign to the trains on level of fence or paint the area around the gate a different colour



Use of colour to direct people

E.g. sign at entrance to the trains with a red line leading of along the railings.

New design floor surfaces can play a big part Naturally direct people. Applies to many issues

- Visual impairment
- Learning disability
- Visitors new to the area



Coloured surfaces

Road/pavement surface-difficult to perceive changes in slope/ridges
Street furniture – can't see this: not only colour but height /position.

Shelters blurring into environment – see the need as banded the lamp post.

Being DDA compliant is insufficient.



Coloured surfaces

Top photo:

- Can't see the seats
- Difficult to sit on with balance issues

Bottom photo:

- Colour contrast between seats and wall
- Proper seating with hand rails to support sitting and standing up

Locate sign for help point close to it (not on a different pillar)

Bad





Good



At which station am I?

View from train seat looking out of window





Lowering station name sign height can help

Commitment to dementia

- Experience starts outside the railway station
- Need to locate signs go where they are needed - not simply where there is a convenient wall
- Colour needs to be used appropriately can direct people away from spaces as well
- Colour needs to be maintained and checked as part of the maintenance schedule (ensure it is not faded)

Reducing carer's stress

- Arrival and where to go needs to be simple, as carer may have wheelchairs to manoeuvre
- Carer may have a person who is anxious as they don't know what's happening or where they are going
- Signs with directions on the diagonal are very confusing - e.g. Norwich station toilets on entrance and the customer service signs are poor
- Clear labelling of buildings are needed e.g.
 Customer Service at Norwich station has no label

Disorientation

- Vulnerable adults
- Does the train company have a policy on how to deal with a disorientated adult? Are staff aware of it? Neither conductors when I audited the Bittern line were aware of this. One was particularly concerned that younger staff wouldn't have a clue and would be less willing to intervene.
- This is about customer service don't be too frightened to approach people and ask if help is required.
- A person living with dementia may be able to cope when everything goes to plan but a change/delay/mishap may cause issues
- Got on the wrong train/not recognise where they are/dark so can't see/ poor signage/dirty windows in winter - When should staff intervene? How can staff help best? What do they do?
- What do you do? Would you let that person get off the train?
- Design: Clues as to where people are, access to help points not only signage but also position - Most importantly availability of staff and knowledgeable staff- training

Take Action

- Develop understanding of all levels of staff on need and requirements of Dementia accessibility
- Include Dementia Accessibility in all strategy decisions
- Station accessibility: in particular signage and identifying steps/hazards as a result of perception issues. Prevention of hazards in design process. Use of colour and design to create zones and lead people to direction you want them to go
- Station Arrival and Way out signage
- Ticket systems
- Staff understanding and behaviour
- Vulnerable adult training for all staff

Dementia awareness key messages

- Dementia is not a natural part of ageing
- Dementia is not just about losing your memory
- It is possible to live well with dementia
- Others can help to generate change
- Talk about dementia awareness to every railway person you meet
- Look with dementia-friendly eyes and encourage others to become dementia aware and find opportunities to encourage training