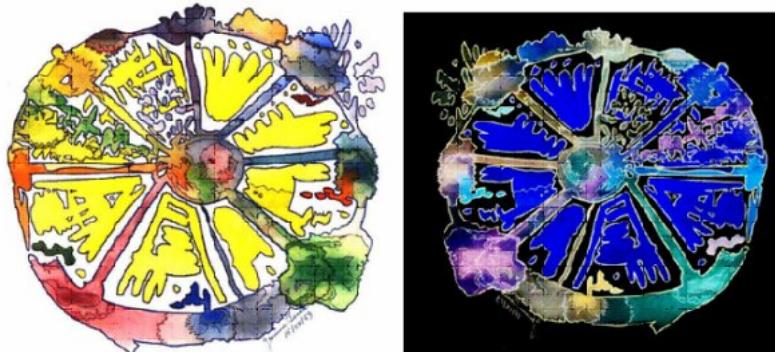


TAD (Thoughts About Dementia) Newsletter



#49: 13th July, 2012

Recognizing visuo-cognitive difficulties and fear behaviour in dementia care

Dear Reader

A 38-year-old repairman, I'll call him Chris, was at our home. He told me about his parents and growing up in a busy household. He knew that my work has something to do with dementia. He asked if I'd seen the recent programme on 'Extreme love, dementia', by Louis Theroux. I hadn't. Chris said he's never known anyone with dementia, but he wanted to see it because he likes how Theroux "gets to the tough, bottom-line questions". He made his 11-year-old turn off her computer to watch it with him.

When I asked what parts had made an impression on him, and on his daughter, he related the following:

- people mistaking their own reflections in mirrors ("*Imagine not being able to figure that out!*")
- the switch between a person *recognizing* and *not recognizing* their spouse (*What was that about? Was that a put-on?*)
- the gentleman with dementia in a care home, who was having a *new close friendship* with another female resident, even though his wife visited him frequently and was obviously still devoted to him! (*How could he?*)
- that the humour and personality of some of the care home residents, that shone out so clearly despite their forgetfulness(*He wouldn't mind visiting the one gentleman in the film, in particular.*)
- the young couple in their forties who had young children, and the wife had early onset Alzheimer's disease and the husband was a carer now (*This was so close to his own age!*)

Chris's daughter was totally fascinated by the programme, especially the thought that people could forget that they have children and grandchildren. She's close to her grandparents and couldn't imagine them forgetting her. It made her want to learn more about dementia. Overall, he said that dementia looked like a scary, crazy illness

to him; “imagine someone becoming two people – one you still know at times, and one you don’t know”.

He seemed to be thinking of people with dementia becoming ‘two people’, like old ideas about some types of mental illness. It sounded like he didn’t know that sensory perceptual difficulties that accompany some types of dementia. Nor was he making the connection that we all change our behaviour markedly when we’re frightened and/or angry, and that having dementia can increase the frequency of situations that can bring forth strong emotions.

When an opportunity arises, I try to provide some information about dementia to help clarify misunderstandings, and thereby try to reduce the associated stigma. I wondered if I could help change Chris’ impression of dementia in the next half hour, and started by asking him some hypothetical questions.

- What would you do if someone snuck up on you and said ‘Boo’, while you were carrying several bags of groceries into the house?

He said he’d ‘deck them’.

Would you ‘deck them’ if you’d seen them beforehand?

No, I wouldn’t be caught off guard then.

- What would you do if someone asked you to walk into an elevator, but it looked like the floor wasn’t there, just a deep, black pit to fall down into?

He’d tell them where to go – and that he would not stick his head in a gas oven either, just because someone told him to do something stupid.

Would you say that if you could see that there was a floor, though it was a dark colour?

No - a floor’s a floor.

- What would you do if someone told you to sit down and then started pushing you backwards - but you weren’t sure if there was a seat behind you?

He’d tell them what’s what and shove them back. He’d check for the chair himself, and then sit down, himself!

Would you do that if you knew there was a seat behind you, and the person was there to help you?

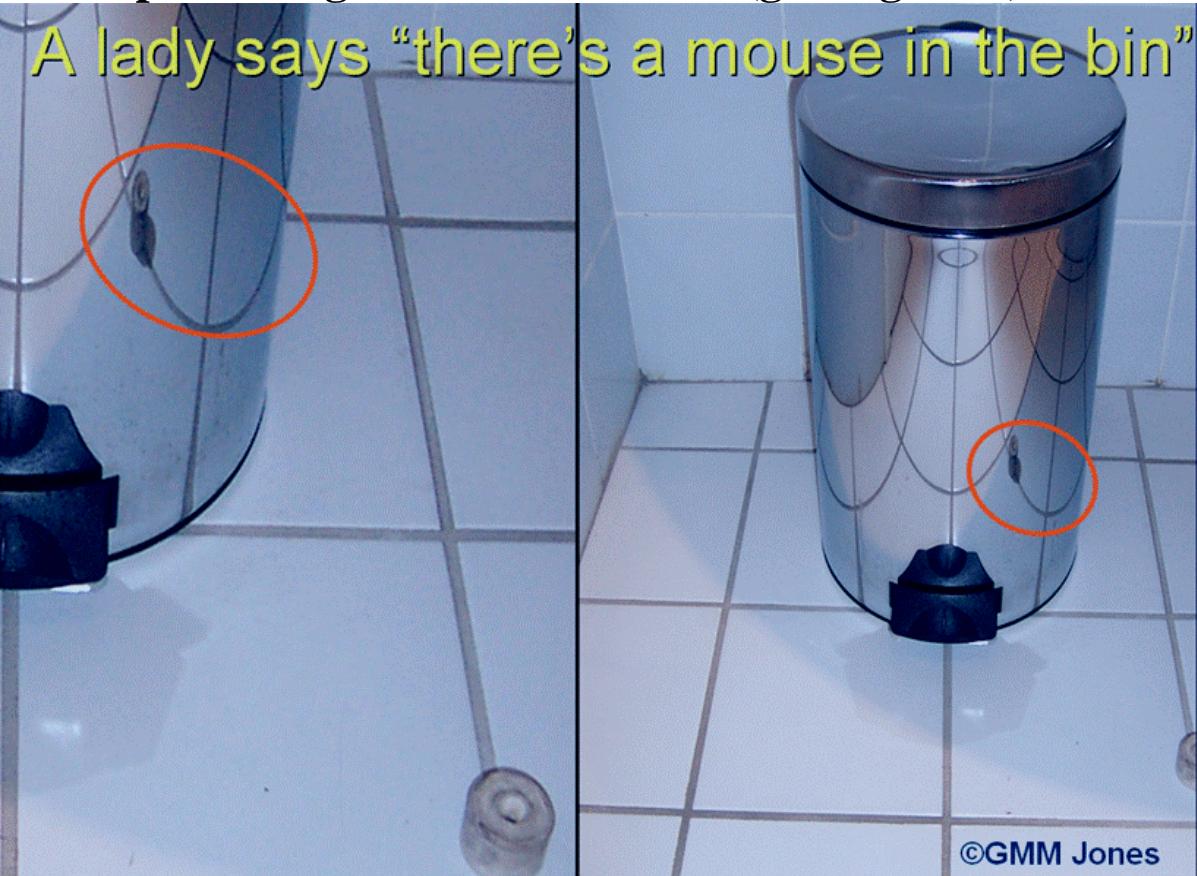
No.

I explained that people with Alzheimer’s disease could encounter comparable situations - daily. They could miss bits of information that we take for granted from having a combination of difficulties with memory, attention and vision - among other things. At some point, such missing bits can make it impossible to stay oriented and aware all of the time. If people were older, they could also have additional age-related visual changes and eye conditions. If taken at face value, some of their behaviour could be misinterpreted as being ‘challenging behaviour’ – uncooperative and aggressive. At worse, people might mistakenly be thought to be having hallucinations and delusions, and given anti-psychotic medication - with a range of

potential, negative side effects. Was this really so? Chris was interested.

I showed the picture of the ‘mouse in the bin’ and told him the story (below).

Misperceiving a mouse in the bin (garbage can)



©GMM Jones

An 85-year-old lady who had been diagnosed with Alzheimer’s dementia, was living in a care home. She was irritating staff and other residents because she said over and over again, *“There’s a mouse in the bin. There’s a mouse in the bin!”* Staff told her to ‘be quiet’, and to ‘stop saying that’. (Some of the other residents were not as polite.) Yet, she continued.

Visitors would be arriving, and having mice around wasn’t very good advertising for the home. A caregiver tried again to get the lady to stop saying this; she went to the bin, lifted the lid, looked in and told the lady, *“I’ve checked and there is no mouse in the bin, so you can stop saying that.”* However, the lady continued.

Exasperated, the caregiver finally asked herself an important question and sat beside the lady. **“I wonder what that lady is seeing/experiencing, to make her keep saying that?”** [This question is a fundamental for good dementia care.]

The caregiver did three things to try to discover what the lady might be seeing:
-she sat next to the lady and imitated her posture, to discover what was in the lady’s visual field (and remembered that peripheral vision is reduced and that colour perception is changed with age)

- she squinted (to try to imagine what the lady might be seeing with slightly blurred vision since glasses aren't always clean, or prescriptions current)
- she imagined wearing sunglasses (to try to figure what the lady would be seeing with reduced light reaching her retina because of normal age-related visual changes)

Lo and behold, the caregiver saw the mouse too! There it was, and in sharp focus! The doorstop and tiles, reflected in the bin, *looked like* a mouse ‘in the bin’. The lady could not work out (test reality accurately), that it was only a distorted illusion of the doorstop and tiled floor in a highly polished, cylindrical surface. Since the lady continued to see the mouse, and seemed amused by it, she was repeating aloud what she saw. (If she had been frightened of mice she would have shown fear behaviour.)

The lady was misperceiving/ misinterpreting what was there, but she was not hallucinating since there really was ‘something there’. Given language difficulties in dementia, even if the lady had realized what she was misperceiving, she would have found it difficult to say, “I’m experiencing an illusion of a distorted, reflected image.”

The caregiver realized there were several solutions possible: engage the lady with an activity; move her; move the bin from view; or put a different covering on the bin.

Chris said, “I’d have done the same thing - told the lady there was no mouse in the bin, and to shut up! I wouldn’t have known she couldn’t figure that out. Surely staff get taught that if they work with people with dementia?”

I gave him another example - of a resident with dementia, who had been a farmer’s daughter. As part of an intended reminiscence activity about hats, she had been given a **white, feathered hat** to admire and try on. However, she left it on her lap, turned it around several times, squeezed it, stroked it, and then, lightning fast, she plucked it bald. She then took the handbag of another lady, collected the feathers from the floor and put them into it. She had mistaken the hat for a chicken, despite that the weight, temperature, smell and other cues were not accurate for a chicken. (She had difficulties with visuo-perceptual ability, and also with integrating sensory information.)

Her behaviour could have been taken literally, negatively – as destroying an item intended for the memorabilia collection and taking another lady’s handbag without permission. It could also have been seen more positively - as an indication of how limited her vision and thinking ability was (visuo-cognitive ability), and yet - that she remembered helping with chores.

Then, we went back to the earlier questions - what if what(ever) you see is

frightening to you

. like, not noticing that someone is approaching from behind or beside you; then they suddenly there! Could this make you startle, shout out suddenly and think they ‘snuck up on you’?

. like, seeing a dark hole that you didn’t want to fall into -instead of a dark floor surface? (a colour illusion)

. like, having difficulty constructing and remembering ‘visuo-spatial maps’ of what objects and people are around you. If you can’t remember there is a chair or a toilet in the room, and a caregiver is trying to help you to sit down, but you’re afraid of falling on the floor, wouldn’t you resist and try to check?

What people see or misperceive in the world around them, or experience with their other senses, can directly affect their behaviour - and emotions.

Last, recalling that Chris had said his own father was a bricklayer/ plasterer, I told him about a former construction worker, who was nearly kicked out of the care home within weeks of arriving - for being thought to be aggressive.

The gentleman used a lounge area on the first floor of the care home. There was a black-framed, large TV in the darkest corner of the lounge. The wallpaper behind the TV was a dark burgundy colour, which became even darker-looking with the shadows of the TV on it. The TV was not on much, because few of the residents could follow a TV programme. Next to the TV, was a small lift which was used throughout the day. Sometimes when the lift opened, small gusts of wind could be felt across the room. Unbeknown to the staff, the gentleman mistook the dark TV, for a hole in the wall that was blowing cold air onto, what he saw as, the ‘fragile old ladies’ seated around the room. (He was not aware of his own old age.)

Within days of his arrival, the gentleman had started being angry and saying things to staff, like:

- ‘Couldn’t you just get that fixed? It’s not right for them to be in a draft.’

[Staff, completely unaware of what he was referring to, made non-specific replies that, they would report it to be sorted. They assumed he’d forget because of his short-term memory difficulties – but he didn’t.]

- ‘I can’t believe it’s that difficult to close that up. It wouldn’t take any time at all. What’s taking so long to repair it? Don’t you care that these ladies could catch their death of pneumonia?’

- ‘This is intolerable. If you don’t do something soon I’m going to report this.’

- ‘If you get me some mortar I’ll fix it for you myself, for nothing.’

[Staff had started documenting his comments, interpreting them as him shouting at them and the residents, as ‘obsessive, aggressive behaviour’. They had requested a specialist consultation for medication to *calm him down.*]

Things got worse. The gentleman had been observed telling the ladies they had to move, and moving the chairs around the room. He had been seen pushing some ladies

around the room while they were still in their chairs! *It turned out, that, in his perception, he was moving them out of the draft, until the repairs could be done.* [This was interpreted by some staff as dangerous behaviour, and it was documented that he was ‘being physically violent’ to some of the old ladies and pushing them about. After several weeks the manager decided they could not keep him, and notified his daughter that she would have to seek another placement.]

The daughter was incredulous, saying her father had never been aggressive or violent to anyone in his life. She couldn’t believe what was being said about her father, and decided to spend the day with him in the care home, to see what behaviour staff were referring to. It didn’t take long before the father told her about his many requests to fix the hole in the wall, his offer to fix it, and his continued concern for the old ladies sitting in the draft. He pointed to it’s source. It took the daughter a while to figure out that her Dad wasn’t seeing the TV, and was misperceiving it and the drafts from the elevator - for a ‘hole in the wall’. And then it all made sense. His anger, worry, and moving the ladies around, was a result of being concerned for them – so typical of her Dad. She explained it to staff. The TV was moved, the lighting in the room improved, and the chairs re-arranged. This gentleman was fortunate - he might have been medicated, moved, and the notes about his “obsessive, aggressive, violent” behaviour would have followed him.

Chris could relate the story to his Dad, who he said was also a caring, observant person. He could imagine his Dad behaving similarly. I asked Chris if he could he see how ‘close others’ might then have seen his Dad as ‘two people’ - a familiar and an unfamiliar person – rather than seeing him as one person, both with and without the strong emotions of fear and anger?

We talked about Alzheimer’s disease increasingly being understood as a ‘visuo-cognitive illness’. Also, about how dementia education for family carers and professional caregivers puts a focus on better understanding the experiences and perspective of people with dementia. Such improved understanding is generating a range of new ideas for helping people more effectively. This includes listening and communicating better - because people are no longer assumed to be ‘crazy’. Also, making environmental adaptations can help - increasing ambient light levels, eliminating shadows, avoiding shiny surfaces and patterns which are readily misinterpreted, and clearly emphasizing important objects with bright colours (like plates, cups, people, specific rooms and objects like toilet doors and handrails).

Chris left, wanting to tell his family and friends about dementia. He wanted to show the ‘mouse in the bin’ pictures to his daughter for a school project. Imagine if someone in their family ever got dementia - how they might be able to help them, if they all knew about such things. Who would have thought that people could misperceive things so drastically because of brain damage, which can affect both cognitive and sensory abilities? So-called ‘crazy behaviour’ was not so crazy. Instead of thinking that: “people with dementia behave abnormally in a normal world”, carers and caregivers are learning how helpful it is to understand that “people with dementia

behave [relatively] normally in an abnormally perceived world.”

Chris may not realise it just yet, but he has become a ‘dementia educator’.

Related ideas for observations and research:

- Do you see yourself as a ‘dementia educator’, and tell others about dementia if the opportunity arises?
- Have you noticed similar types of visuo-perceptual errors?
- Were they documented accurately, and explained to staff and family members?

Best Regards,
Gemma

References-

- (2010) Alzheimer Society Factsheet on Hallucinations www.alzheimers.org.uk/factsheet/520
(2010) Alzheimer Society Factsheet on visuoperceptual difficulties www.alzheimers.org.uk/factsheet/527
M, van der Eerden WJ (2008) Designing Care environments for persons with Alzheimer’s dementia: visuoperceptual considerations. Reviews in Clinical Gerontology. 18; 13-37
M, van der Eerden-Rebel W, Harding J (2006) Visuoperceptual-cognitive deficits in Alzheimer’s disease: adapting a dementia unit. In: vol 4 Care-giving in Dementia (BML Miesen & GMM Jones (Eds). Routledge, London. Pp 3-58
M, Harding J, van der Eerden-Rebel W (2006) Visual phenomena in Alzheimer’s disease: distinguishing between hallucinations, illusions, misperceptions and misidentifications. In: vol 4 Care-giving in Dementia (BML Miesen & GMM Jones /Eds). Routledge, London. Pp 59-104.

To quote or reference this material please use the newsletter name, article title, date, and ‘The Wide Spectrum’ website. Thank you for respecting this.

To view previous newsletters, go to www.thewidespectrum.com, log-in and click the 'Newsletters' tab.

Idea: Forward this letter to a friend. They will NOT automatically be subscribed to The Wide Spectrum newsletter. They have to do it voluntarily and can find out about it by going to The Wide Spectrum website.

Feedback: We are not yet set-up for feedback, but hope to be in the future.

© Gemma M.M. Jones 2012

You have been sent this email because you are either a previous The Wide Spectrum customer, or you have expressed an interest in receiving our newsletter. If you wish to unsubscribe, [click here](#)

[Get your own email newsletter tool from www.immediaside.com.](#)