

Notes from the Dementia_Carers presentation by Dr. K.J. Bute
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I have the privilege of knowing about dementia and looking after folk from several aspects, I used to be a GP, my father had dementia and I have Early Onset Dementia myself

This is some of what I have learned over many years and am still learning.

1. This picture of a mountain is an illustration of dementia It can be an awesome thing, difficult, frightening certainly challenging but also beautiful and glorious. However far down the path one is, feelings are not lost or the ability to appreciate beauty, pick up emotion, & the spiritual certainly remains. There is always a reason for everything, it a privilege to walk this path with folk and we learn from each other
2. There are different types of Dementia the commonest is Alzheimer's some people with Multiple Sclerosis or Parkinson's also get dementia (not all) diagram shows why. It depends which area of the brain is most affected The area of brain controlling movement is near the area affecting cognition or memory. In stroke it depends where the blockage is as to which part of the brain dies through lack of oxygen
3. In Alzheimer's the commonest form of dementia, the brain shrinks, amyloid plaques, like blobs of chewing gum gum up memory pathways if the neurons on the other side of the 'obstruction' are not used they die. things begin to 'unravel' resulting in agitation and confusion. (A friend reminded me one unravels things in order to reuse them again for something useful) We lose ability to do things, understand, remember find ones way around, communicate, eventually even to eat or drink.
4. THERE IS ALWAYS A REASON When someone with dementia appears to talk rubbish it is because the meaning of the words no longer tie up with their sound so they produce a word salad and may not realise but can join in the pattern of a conversation Folk with dementia communicate, always for a reason. to express how they feel, to show a need or sometimes just to get a response.
5. Even for folk not so far down the path you often need to hear the meaning behind the words. What time is it? might just mean, I don't know what I should be doing or I want to go home, might just mean, I don't feel at home here I don't feel comfortable. May not understand a clock anymore Many places or relatives just get a bigger clock Not best thing I have a digital watch and digital clocks or I get time badly muddled
6. Not sure how many of you have seen The Curious Case of Benjamin Button. Brad Pitt plays a person born old who becomes increasingly younger It works because he develops dementia and goes backwards in unlearning social skills fitting in with his diminishing size ending up as a baby there are a lot of similarities with dementia our problem is that we look older all the time it confuses people. I call it time travel going back in time but it might only be in part of ones life, If one thinks it is 30 years ago, one might not recognise folk because they look different so when someone asks you to tell her husband she is his wife, it won't work. You can reassure them it's because of Time Travel, perhaps her hair was a different colour then, tell the husband his wife will be there later. Some have 'comforters' like young children to soothe them a doll a handbag or a packet of tissues! Others Lose social inhibitions may flirt horrendously, others may shout inappropriately. I tell them when we have dementia we can lose our social inhibitions but it is not acceptable
7. Strange actions also have a reason. Is that vase real or not? We smell see and hear things that aren't real. We may Wander in response to hearing someone call or seeing something. Stanley has seen me conducting a conversation with my daughter in the doorway who also wasn't there You might see me suddenly look round to see who is blowing cigarette smoke over me. May pick up something and wonder what it is such as a fork but if one sees someone using it they might be able to match the pattern of the action. Sundowning is the term used for strange behaviour at the end of the afternoon when dementia tends to be worst, light may be decreasing and patterns emerge from the past memories of a busy time of day collecting children from school coming home from work. coping with the chaos of the rush hour They will be alright again in the morning If wander at night should not sleep in day it is a stage What do you see in this picture?
8. Lets say a bit more about visual muddle What about this picture? Some people are unable to see the other possibility so you can understand folk with dementia can misinterpret things They can look at a photo or see a reflection and not recognise themselves. Carpets can be a problem if patterned. My cousin also has dementia and my sister invited her for tea a little while ago and told me later it was very odd she put her food on the tablecloth I laughed and said Did you have a white table cloth Yes And was the plate White Edges are a problem, we need contrasting colours Often men with dementia are thought to be messy in the bathroom but if the floor and the toilet are white how are they to know where one starts and the other ends? This hall would be a nightmare
9. You often hear about Difficult behaviour but difficult to whom? Lets just call it Strange Behaviour. Aggression is usually due to frustration. not being able to communicate well, or frightened by a hallucination or a misinterpretation of events becoming agitated or being unable to cope with a task that is too difficult. There may be unwillingness to cooperate for

example someone refusing to have a shower cos showers weren't the social norm in their childhood and they are frightened by them. So understanding this helps

10. In order to avoid or prevent aggression/agitation one needs to be aware of what can cause the problem I have produced a leaflet for family and friends to help prevent me going into Meltdown (I get agitated & cry) Christmas can be difficult with too many flashing lights of different colours When a person is ill the dementia gets worse I had flu & thought my clothes were Stanley's workshop rags felt insulted, refused to get dressed
11. This picture upsets some people as it appears to be whirling round which it isn't In the same way people with dementia can get upset because the part of the brain that processes vision is also affected, colours can get muddled, not only tablecloths but furniture on carpets Steps can be difficult cos of the edges, this 'missing' stuff is v hard, misidentification, misperception misnaming recently put 68p stamp on uk postcard completely different colour! (misidentification) I tried to glue the stamp onto one to Ukraine & couldn't understand why there was no glue I had not taken off the lid, I couldn't get the lift to work but was pressing the key button (misperception) asked for cauliflower cheese pointing at the Stroganoff (mismaking)
12. So what do you do when someone is agitated? Don't ask what the problem is or overwhelm them with words or instructions. Show them, if necessary remove offending items or even them from the scene of the incident They will pick up your mood as to whether you are calm or agitated yourself. Feelings remain and are 'catching' don't ask Can you find your way home we are not going to admit the answer might be no Different colour doors are brilliant but there are more than one of each colour and if the door is open it can't be seen from a distance I went into the wrong flat myself and got very upset over it
13. I am sure you always remind people who you are and what is going to happen next Whether you call someone by their first name or surname depends on the individual and is not the same for all. In one care home the staff prided themselves on being creative with the residents hair but folk got distressed as it was unfamiliar Don't ask What would you like to wear today, rather would you like to wear your blue jumper we can't cope with too many choices which can be another problem at meal time We get muddled with buttons so encourage folk to have buttonless garments and always leave with a smile or we might wonder what we have done to upset you and show agitation later I've seen it here always a misunderstanding
14. So remember it is the feelings that remain Just as I now have no idea who gave me that bunch of roses or when and I can't count them any more, I remember the occasion warmly cos the feelings one if left with, remain and you are brilliant at that by your warmth and smiles so thank you The book Contented Dementia explains all these very well and how important it is the way one says goodbye and how to manage folk looking for absent people whether dead or alive No need to tell lies
15. Memories still exist but are gummed up by "blobs of chewing gum" but just as on the London underground there is more than one way to reach a destination there are different ways to access memories, If we don't and neurons are not used they will die and the brain will shrink a little more. We are whole people trapped inside an illness But just as when a house is on fire and the front door is blocked neighbours don't wait for the professionals to get out the ladders before trying to rescue those trapped inside Folk like you are constantly providing rungs to ladders to enable memories and communications to emerge and continue.
16. We must not forget Carers including yourselves, it can be very stressful & upsetting folk may talk to you about their families some children 'run away' because they are grieving for the parent that was, or frightened about themselves Spouses need a break to enable them to carry on for longer.
17. There are lots of books of which I recommend two, Contented Dementia details strategies planning ahead for when things get worse one needs to plan ahead, Frank & Linda's story is the best if you only want to read one It is a Christian book but I have recommended it to many folk who have found it very helpful even if ignoring the Christian bits For me my faith is very important as I know exactly where I am going medically and spiritually and have no fear of what lies ahead my leaflets can be downloaded from my website.
18. If you only remember 2 things from this talk
There is always a reason
Feelings remain when Facts are forgotten