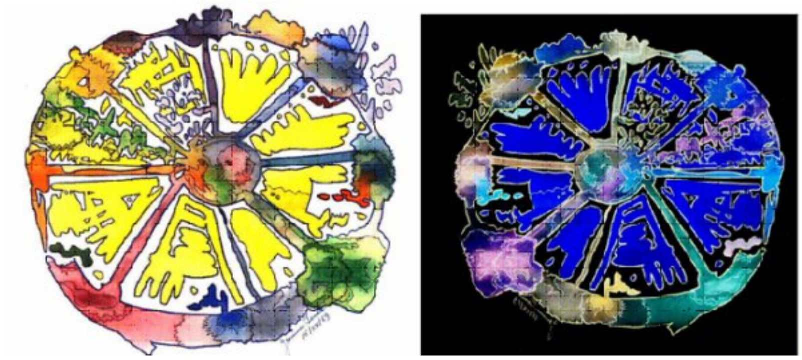
TAD (Thoughts About Dementia) Newsletter



#38: 10th August, 2011

Fluctuating abilities, facades and fear

Dear Reader

The message of this this newsletter is multi-fold:
. it can take time and knowledge (including of people’s fears), to assess a person with signs/symptoms of dementia thoroughly – especially if they have concurrent illness
. those closest to the person may have valuable observations that can contribute to the assessment, and for planning support and care. They, like the person being assessed, need to be given the opportunity to speak with professionals ‘in private’.
. people’s abilities, awareness, and competence can fluctuate markedly, for a number of reasons. It is helpful to note difficulties to help with assessment. Repeat assessment may be needed to get the full picture*.
. people who live alone need to be assessed extra thoroughly. Fear and loneliness may not be admitted to readily; but alleviating them are focal points of good care. Fear, not dementia precludes happiness and quality of life.

[Although this newsletter uses examples of doctors to illustrate these points, they are relevant to all those who the person with dementia holds in high regard, is wary of, needs, or fears – such as: lawyers, notary publics, clergy, representatives from social services, care assessors, or family members who live far away and visit infrequently.]

Three examples are given of
1. a lady on an assessment unit
2. a gentleman in a care home, afraid of going to a nursing home
3. a lady still living at home, alone, who has been having some slowly progressive forgetfulness in recent years, but who is experiencing rapid cognitive changes in recent weeks. She has no children, but does have geographically dispersed nieces and nephews who are trying to assist her

‘Why’ and for ‘how long’, can people with dementia maintain a façade?
People can have large, intermittent fluctuations in their cognitive ability for many reasons including old and new illness, fatigue, medication, time of day, mood, … and progression of the dementing illness. Fluctuations can be complicated by the determined (almost super-human) efforts to hide their difficulties to ‘save face’. This is done by: denying, camouflaging, blaming others for their difficulties, emphasizing and exaggerating their real abilities; and inventing information (confabulating and lying) to try to highlight their competence. But ‘facades’ take effort to maintain, and cannot be sustained indefinitely.

Fear is a powerful motivating factor. **It is easy to forget that fear raises adrenalin levels, and can give people extra-ordinary abilities….but only for a while**. Spending sufficient time with the person, to see what they are like when they feel safe, ‘without fear’, (so that fear behaviour is not mistaken for ‘dementia behaviour’, or a person’s personality), is part of careful assessment.

What sort of things are people frightened of?
. losing of control
. being wrong, making silly mistakes, of (important) others noticing
. being ‘crazy’ (and only spoken about in whispers)
. being corrected, ridiculed or talked about disparagingly
. being isolated, separated, removed from one’s own home and contacts
and worst of all – of being abandoned
. being useless, a burden
. the loss of awareness of oneself (as one understands that)….with whatever inaccurate assumptions go with that - about loss of mind, personality, and self
. of being like other people one has known who’ve had dementia – and fears associated with that; that whatever happened to them, may now happen to oneself, (i.e. experience of poor care, family members not knowing how to visit, being upset by visiting, and limiting their visits)
. of an undignified decline, …and of death

1) Multi-disciplinary team meeting on an assessment unit
There was a team meeting about a lady on an assessment unit. The doctor thought that Mrs. W, was in a better state than the other professionals did. The doctor said that during each conversation with Mrs. W - she was polite, appropriate, engaging – and certainly seemed competent enough to return home to live alone, as independently as possible. That is what she spoke of wanting in every conversation he had with her, and that is what he was recommending the team do...

However, the nurses, occupational therapist and social worker disagreed strongly. They told stories that sounded exactly opposite. They spoke about Mrs. W being muddled about the date, month and year; of her confessions to them about being lonely at home - afraid of going out because she was easily overwhelmed, having difficulties dressing and grooming, and asking of staff repeatedly throughout the day, “What am I supposed to do now?” She sometimes cried and said she didn’t want to be alone because she knew she was ‘going doolally’.

Different observations lead to an Impasse

The doctor thought his colleagues were molly-coddling Mrs. W, and not respecting her wishes. How did such ‘differences in perception’ between professionals come about? The doctor spent less time with Mrs. W than the others, and in a different context. They saw Mrs. W at her brightest and when she was tired and unable to maintain a ‘social façade’. They had a more informal rapport with Mrs. W; she often mistook them for caregiving staff and didn’t try to impress them. Mrs. W held ‘doctors’ in high regard; more so than the other professionals. Also, the doctor wore a distinctive white uniform which could be recognized from a distance, and gave her a signal before engaging in conversation.

The doctor asked about medical/physical matters primarily, and Mrs. W seemed healthy enough; hence he was eager to help her return home. When he enquired about her ability to do ‘activities of daily living’, he assumed her replies were accurate, though did not observe her doing things. She said she could do everything.

A suggestion (actually - it was a dare), was made to the doctor at the end of this team meeting. It was taken up, and helped resolve the impasse.
The dare was this: observe Mrs. W twice on the same day – once as a doctor, and then also ‘incognito’. See if there are any differences in what in what she tells you, and what you notice.

- have the first contact in the afternoon, your normal doctor’s visit, wearing your usual doctor’s uniform. Make it formal – e.g. have a nurse announce to the lady that the doctor would like to see how she is doing.
- have the second contact in the evening, after dinner, when many residents are sitting in the lounge area, hoping a family visitor will come. Sit in the lounge area, wearing normal clothes like a visitor. Observe and listen to what Mrs. W speaks about to others. After 15 minutes engage her in conversation, e.g. ask her if she’s waiting for someone to visit, and how her day has been. See if you can spend half an hour with her.

The first visit was like his usual ones with her. He expected Mrs. W to recognize him during the second visit, but she did not. He told the team this experience had been an eye-opener; without having done this – would not have believed it possible that Mrs. W could present so differently on the same day. Mrs. W had actively ‘hidden’ much information from ‘the doctor’, especially about her emotions and vulnerability. Yet, she had freely revealed this to an ‘unknown visitor’ with whom she did not need to keep up any pretence. The doctor had spent over an hour with her as a visitor.

2) Frustrated caregiving staff in a care home

Mr. S has been ‘a bit off-colour’ for a few days now. (He is thought to be in early stages of dementia - but has never been diagnosed.) On this particular morning, the caregiver could barely get him dressed and sitting up in the chair. Normally, he manages to wash and dress with some prompting and cues, and brushes his own dentures - but not at all today. The caregiver did everything for him. He then sat in his chair - weak, and noticeably slumped over. He only made short mumblings instead of his characteristic chatty manner of responding. He did not have his usual appetite and didn’t want to go to have breakfast. The caregiver was worried about him; she didn’t know what was wrong, but knew that something was. She reported her concern to her (non-nurse) care home manager, who went to see Mr. S. and agreed that something was very wrong, and called for Mr. S’s doctor (GP) to come.

Mr. S was still sitting alone in his bedroom when the doctor arrived some hours later. The manager knocked on the door and announced, “The doctor is here to see you Mr. S.” Almost instantaneously, Mr. S managed to sit bolt upright; he looked the doctor in the eyes, smiled, and started a conversation. It went something like this:

“Good morning doctor. Nice to see you; it’ been a while. What brings you here today?”

GP - The staff here were concerned about you and I’m here to see how you’re doing.

“The staff? - don’t take any notice of what they say - they don’t know what they’re on about. As you can see, there’s nothing the matter with me – I eat like a horse, sleep like a baby, and could out-work most any of the youngsters here still… By the way, how are you keeping doctor?”

GP - I’m fine, thanks. But I’d like to know more about what’s up with you. Has anything changed the past while? Has anything unusual happened?

“Not a thing. As I said, I’m fit as a fiddle, and reckon I could still beat you at golf if it weren’t for my wooden leg. [a joke - since he hasn’t got a wooden leg]

GP - let’s do a little check though, while I’m here. I’d like to take your pulse and blood pressure, if that’s OK?

“There’s no need - but suit yourself.”

[Mr. S’s pulse and blood pressure seem reasonable to the GP].

Some more moments of conversational banter are exchanged before the GP leaves.

He tells the nurse that 'there appears to be nothing wrong with Mr. S', and that his visit certainly wasn't 'urgently needed' - with the implication that his time has been wasted.

The manager and caregiver return to Mr. S; he is in his 'pre-doctor-visit state' – slumped in the chair, weak, and not wanting to talk, or leave the room. They conclude that he has pulled off a 'masterful performance', for a few minutes, for the doctor. Mr. S wants to be seen as competent, in control, witty, - at least to those who have the power to influence whether he stays in this residential care home, or is moved to a nursing home. He's heard about those places and they terrify him – he's just gotten used to this place and he wants to stay there. He cannot risk being unwell.

The manager is upset because:
a) the GP did not see the evidence that they did (and also, that they had not fully documented what they saw) – (she wants to introduce the UFAR index to caregivers in the future, so their observations will be documented and used**)
b) the next time she asks the doctor to come 'urgently', it may take longer
c) there seems to be a loss of respect occurring between them.

3) Doctor makes brief home visit - finds no cause for concern

Mrs. P is 85 year - the last survivor of seven siblings. Mrs. P was widowed several years after marrying, had no children and never remarried. She has lived had alone since the sister she shared a house with, died some years ago. Mrs. P worked full time in a management position until her retirement.

She never cooked; since her sister's death has managed on frozen dinners and meals with friends – mostly from the Ramblers, and local Bridge Club which she's attended for forty years. Mrs. P recovered well from four fractures and injuries the past decade. Two of her sisters have died of dementia in the past five years. She is terrified of becoming like them and has made frequent references to 'topping herself' if she should get it.

She is the aunt of a score nieces and nephews. They are spread around the country; she visits them and sees them at family events. They've noticed her 'forgetfulness' has been increasing slowly for several years. She repeated reminiscences several times a visit – but she seemed to be managing well - still driving. Her grooming and attire has been 'spot on'… until recently.

Three months ago -
Family noticed some marked changes since Mrs. P's previous visit:
. grooming changes - not noticing stains, wearing soiled clothes

. repetitiousness – (well known) stories repeated, sometimes ten times an hour; but now….with different endings!
. reading – avid reader, but now only reading/re-reading the first chapter
. time disorientation: couldn't remember: what day she was going home; how many days were left of the visit; whether she was supposed to visit elsewhere before going home; that she was being driven home – and she kept talking about taking the train back a (which she had never done, and wasn’t planned)
. writing – she signed her name on a card with difficulty; didn’t write anything
. walking – enjoyed short walks in the garden, but now only sat on terrace; grimaced at getting up (new weakness and pain?)
. driving – said that following traffic from both directions is difficult; she has found new routes to the shop and Bridge Club that only require 'left turns'
. ‘off times’ – some hours she seemed ‘distant’ ; (maybe tired during the day; she only ever slept about five hours a night, and never took ‘cat-naps’)
. medication - forget to take her ‘stomach medication’(?), resulting in pain and sleepless nights; won’t show her medication to family members

Two weeks ago – more signs that need investigating
Family members phone each other - worried about events the past weeks
. Mrs. P’s closest friend from the Bridge Club had phoned a niece several times to ask what is the matter with her? She says that it was getting awkward having Mrs. P there because she isn’t playing well anymore.
Also, last week, Mrs. P had phoned her in the morning, not knowing if it was 9am or 9pm, and asked ‘where’ they played Bridge. [Her friend told her – ‘in the church hall, as always’]. Mrs. P arrived, but did not play - only observed. Instead of driving her friend home afterwards as usual, she dropped her off at a supermarket, and left without further comment.
. Mrs. P ‘let slip’ that she’d had some car accidents recently; one involved hitting a bus, which she said she didn’t see. There are ‘dings’ on both sides of the car that she couldn’t recall how she got. She didn’t involve the insurance, worried that she might have to take her driving test again
. there were a dozen, half-eaten cakes in her kitchen; when asked about them, she denied buying or eating any of them - little other food in the house
. a month earlier, Mrs. P went holiday with family, and had become incontinent of urine several times. When it was suggested that she ‘change and tidy up’, she refused – “Not to worry, it’ll dry on its own.”

Family visit to speak with Mrs. P.
Thereafter, several nieces visit their aunt, to express concerns about her memory, driving, how she’s managing, and to suggest she see her doctor. She tells them sharply that her driving and memory is as good as theirs –there is nothing to see the doctor about. She said she’s had antibiotics recently for her cough and they’ve helped.

She admits to one niece that she is having some trouble with her memory, ‘getting muddled’ and being frightened – and that she’s even been wondering if she can continue living alone. However, thereafter, she again says she's fine, really.

Family member contact the doctor

One of the nieces agrees to phone Mrs. P's doctor to explain recent concerns, and mention Mrs. P's unwillingness to make another appointment after having seen him recently about her chest. The doctor checks, and says that she hasn't been seen by anyone in the practice for several years, and agrees to make home visit.

He visits for 15 minutes and finds "no apparent memory difficulties". The niece is incredulous, doesn't accept this conclusion, and makes an appointment to accompany Mrs. P to a follow-up visit to the doctor.

The niece arrives an hour before the appointment, to 'soften Mrs. P up'. Mrs. P says she can go to the doctor on her own; why does she need to go at all? The niece reminds her of the family visit the previous week - about their concerns for her difficulties. Mrs. P does not recall the visit, and denies that it happened. The niece again explains that she's worried about her aunt's driving and would like to get her checked so that she doesn't come to any harm. If doing this means falling-out with her – then so be it. It's worth it - this is a serious concern - family have her best interests at heart. Mrs. P walks to the doctor with her, just around the corner, and is breathless on arrival.

The doctor asks Mrs. P if she knows why the appointment had been made. She says she doesn't know why she's there – she's fine.   He replies that, since she's here it makes sense to examine her. He finds she still has a chest infection. He also mentions to Mrs. P that her niece is concerned about her.

He asks Mrs. P her age; she answers incorrectly.   In the next minutes, he asks again – still incorrect (84, 81, and 83). She doesn't seem to notice that she has been asked this already. She is shown 3 objects, none of which she can recall a few minutes later. He writes a sentence - then asks her to write one. She writes, "I'm not bloody stupid." He agrees, and says that's why he wants to get to the bottom of her current difficulties.

The niece has prepared a page of notes summarizing recent changes noticed by family members. She gives it to the doctor when Mrs. P steps out of the room - he reads it before she returns. More questions - also about her driving. He tells Mrs. P that something isn't right - he wants to make another appointment, and refer her to the memory clinic. She consents. He advises that, being the conscientious person she evidently is, she wouldn't want to cause an accidents, so should stop driving – today. The niece offers to look after the car keys, and in the interim, help her learn to take the bus and taxi. Some protests, but Aunt P hands over the keys (she has a set hidden at home). The doctor was sensitive and respectful of Mrs. P. As they leave, he quietly admits to the niece that he had been fooled on the home visit.

The niece stays with Mrs. P for some hours afterwards. She had 'risen to the occasion' - stayed as focused as possible, and was very matter-of-fact in responding to the doctor, but her difficulties had showed and she was upset. They went out for lunch; Mrs. P ate little, remained stoic and silent except for the occasional quiver in her lower jaw. As her niece was leaving, Mrs. P told her she didn't want to take a bus - she'd never taken buses. "What am I going to do now if I can't drive… be frightened and lonely at home, until I'm dead?"

The niece replied that she didn't want her to be lonely at home, and would help her find a solution to getting around; she could accept that her aunt was angry with her. Mrs. P paused, and then said she wasn't "very angry" … she understood, and finally.... after holding in her emotions all day.... she shed a tear. Then, she said that had better start looking for her bus pass.

Help and support had been set in motion that day; it could not have happened if the doctor had not noticed that Mrs. P was having significant difficulties. Otherwise, it might have taken a hospitalization or crisis – and the extra challenges and emotional upheaval they involve.

Related ideas for observations and research:
. Have you been involved with examples like those above?
. How did you learn about the variety of reasons for 'fluctuating abilities' in people with dementia?
. Are changes in behaviour/ cognitive difficulties well documented at your work?
. How do professionals at your work deal with the concerns/observations of family?

Best Regards,
Gemma

*'Dementia: ethical issues' Report (2009) by the Nuffield Council on Bioethics, refers to concerns about fluctuating abilities that affect the assessment of 'having', or 'not having' mental capacity.
"[Capacity] may fluctuate; a person may lack the capacity to make a particular decision in the evening when they are tired, for example, but be quite capable of making the same decision in the morning." P77/ Item 5.10
"It is well established that the capacity of an individual with dementia may vary considerably in relation to the same decision: people often have 'good' and 'bad' times of the day, and cognitive abilities may also be affected by a range of factors unconnected with their dementia, such as the presence of other illnesses or their current levels of emotional well-being….the way a person is approached and spoken to may in itself affect their capacity or apparent capacity to make a decision." P79 / item 5.18
. "*One possible approach that has been suggested for avoiding, or at least reducing, the problems inherent in borderline capacity is greater emphasis around joint decision making with trusted family members. It is suggested that such joint decision making might help bridge the gap between the time when a person with dementia is fully able to make his or her own decisions, and the time*

when some kind of formal proxy decision making becomes necessary on a regular basis." P 80/ item 5.21

A free downloadable copy of the report can be obtained using this link: http://www.nuffieldbioethics.org/fileLibrary/pdf/Dementia_report_for_web.pdf
Further information is available from: **www.nuffieldbioethics.org/dementia**

References-

** 12 Oct., 2010,The CARPE DEM model – towards an ideal dementia care pathway? The poster, tool kit, and documentation are about CARPE DEM are available free-of-charge from thewidespectrum.co.uk

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