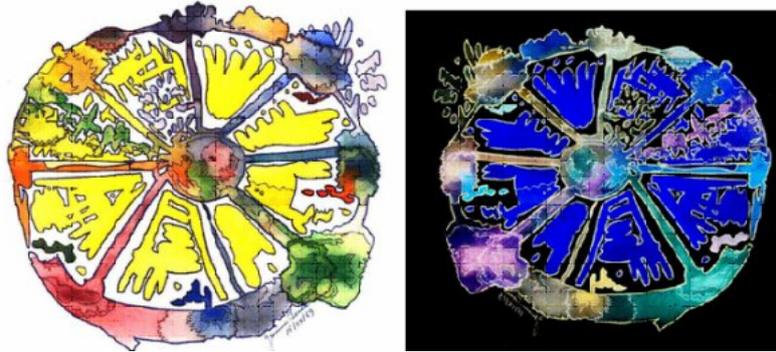


## TAD (Thoughts About Dementia) Newsletter



**#46: 10th April, 2012**

### **Accepting a diagnosis of dementia; letting denial be replaced with something better**

Dear Reader

Denial and blaming are universal *coping mechanisms* - part of our psychological armour for the purpose of trying to avoid mental pain and/or punishment. Everyone uses denial at times, even when they're not aware of it; people with dementia, family carers and professional caregivers also.

It's said that "a bit of denial is acceptable and may be helpful, but a lot of denial isn't." A little denial can assist our functioning, problem-solving ability and growth, by providing us with some buffer-space in which to gain a new perspective and adapt. Maintaining a lot of (even complete) denial, in the face of evidence to the contrary, is energy-consuming and puts us and others in uncomfortable positions of pretending and avoiding dealing with reality. Yet, some people remain in a state of denial for years; even indefinitely. Such denial can be detrimental in that it can distort relationships.

Several years ago, a gentleman at an Alzheimer Café asked if we could arrange for a presentation about 'denial', and how to break through denial, to help everyone understand it better. His wife had denied having dementia and having any difficulties, vehemently, for over five years - right up until she went into a care home. Any attempted discussion with her was so acrimonious and emotional, that he considered her denial to be as difficult to live with as her forgetfulness and mistakes.

As you will see in example four, although it is not the purpose of an Alzheimer Café to make people *break through denial* - attending a café and seeing people speak about dementia openly and sensitively, and feeling supported can help people to stop denying - when they're ready<sup>1</sup>.

Gero-psychologist, Dr Bere Miesen, the founder of the Alzheimer Café, has repeatedly said<sup>2</sup>,

*“Don’t be too quick to assume that people with dementia don’t want to talk about [the illness]. It may be easier than you think.”*

How can this be? - given that so many of us, like the gentleman above, have seen people with dementia vehemently denying their limitations, difficulties and mistakes (and sometimes even denying their diagnosis - despite the evidence of their poor performance on cognitive assessment results.) Such denial, has even been given as one of the reasons that some doctors and professionals are wary of giving someone a diagnosis of dementia.

I’ve seen numerous occasions where Dr. Miesen’s statement was right – that people with dementia are often relieved and even pleased to speak about dementia openly. This usually occurs after they’ve gone through the experience of first ‘hitting a brick wall’ – the painful shock, confrontation with, and some grieving about the diagnosis and its implications. This is based on their own experience and understanding of dementia, which is also dependent on the type and amount of support they have, think they have, or allow themselves to make use of.

### **What’s known about denial in people with dementia?**

Studying ‘denial’ in people who have dementia isn’t as straightforward as it might seem. Not everyone with dementia denies their difficulties, though it appears that most do, if only briefly (weeks to months). The issue with much research is that it doesn’t distinguish between different levels and types of denial and awareness, or in different types and stages of dementia.

The 1991 study by Feher et al<sup>2</sup> distinguished between people with a *lack of awareness of their cognitive symptoms/difficulties* (anosognosia), and those with awareness of - but who deny their difficulties.

### **People who are *unaware* of their difficulties don’t try to camouflage them**

A lack of awareness may be:

- 1) as a result of a large, sudden deterioration resulting from localized brain injury (for example from an infection, stroke, tumour), temporary illness or injury, adverse amounts or combinations of medications
- 2) from progressing to a later stage of dementia, and having additional difficulties in logical thinking, time perception, problem solving, understanding the context of events, and visual-perceptual ability - such that awareness of one’s difficulties and mistakes is reduced. People remember themselves as they used to be, or as their ‘preferred image of themselves’.

### **Example 1**

A gentleman in his sixties, with no previous signs of forgetfulness or dementia, awoke from routine surgery, unable to:

. recall where he was, or what month or year it was

- . recollect his age
- . recognize his wife
- . groom himself.

For months, this sudden dramatic deterioration was blamed on *post-surgical trauma* as a result of the anaesthetic. Eventually, vascular dementia was diagnosed – he'd had a major stroke during surgery, which had damaged some of his cognitive abilities. Puzzlingly, he seemed oblivious of his new limitations and memory difficulties. If someone asked him something he didn't know, he cheerily replied, "Ask my wife, she'll know – she knows everything." At home, he was eager to help his wife with any task, unaware of his mistakes, (and also unaware of how frequently she was asking him to re-do things - like re-paint the hallway.)

### **Example 2**

A lady with dementia came to reside in a care home after becoming severely disoriented in time and unsafe at home. She thought of herself as the hard working, competent adult that she had previously been. She kept herself busy each day in the care home by polishing tables and handrails, and wiping the large tables - endlessly - even when there were no crumbs or marks on them. She told everyone that she was the cleaner, (and she had not been paid in many months)! Some staff members, realizing that this lady did not have a current, accurate notion of the cost of salaries and other goods, solved her distress by putting some money in an envelope, with a card of thanks for her hard work. This seemed to work just fine the first time. The question now was, who was going to take responsibility for and maintain doing so, and for how long?

### **In some people, denial only becomes evident in crisis situations**

The real struggles of some people with dementia who deny their difficulties expertly, do not come to light until there is a **crisis** (e.g. such as being sent home from hospital alone although they cannot care for themselves at all.) They may tell others and professionals, so convincingly that they are still competent doing everything, that they are believed outright, without further assessment.

### **People who are aware and upset by their mistakes, may deny them**

The Feher et al study found a relationship between the degree of denial and scores on a 'depression rating scale'. This suggested that the greater a person's awareness of their cognitive deficits, the more distressed they were by them. It supports the many anecdotes of people with dementia (diagnosed and undiagnosed), who are so *painfully aware* of their mistakes that they cover them up by for as long as possible to 'save face' - even when others are able to see through their excuses and blaming.

Without some awareness of their difficulties and mistakes, people would not try to camouflage them. (Anecdotally, denial seems to be most extreme in people who have had very demanding jobs where mistakes were not permissible, and where one's competent functioning was essential.) The denial of difficulties is usually finally detected when excuses and blaming are *obviously fabricated* or *totally*

*implausible*. A person with dementia may still try to maintain their façade or excuse, despite being questioned, when they lose insight into how transparently false (poor) their excuse is. The next example is a familiar one.

### **Example 3**

A daughter visits her widowed mother, and finds a dozen boxes of partly-nibbled cakes and pastries in the kitchen and living room. Knowing that mother was never fond of sweet things and desserts, the daughter asks about them, expecting to hear that visitors had been over. Mother denies knowing anything about the boxes, or eating from them, and suggests that someone has entered her house and put them there without her knowledge. [The daughter does not believe this and is worried. Her mother has been showing slowly progressive signs of cognitive difficulties - but has stalwartly declined to go and be checked by the doctor. Signs of difficulty include: forgetting appointments, getting lost driving on familiar routes of 40 years, increasing repetitiveness in conversations, struggling with shopping and preparing food, letting her post pile up, and avoiding paying bills and attending to her finances.]

The daughter suggests that maybe her mother forgot who had brought the desserts. She asks her mother, again, to see the doctor to have her forgetfulness checked out. Mother replies that she's already seen the doctor this week. The doctor said she's 'fit as a fiddle', bar her cough, for which he gave her a prescription. The daughter is dismayed and puzzled. She phones the doctor's office, explains she is concerned about her mother and asks to make a joint-appointment - despite that her mother has already had an appointment this week. She is told that her mother had not been in, and had not had an appointment for many years.

So, her mother lied to her! Well, at least about the appointment, and maybe also about the desserts since there wasn't any other food in the fridge.

Aside from the practical concerns, the daughter doesn't know how best to converse with her mother. Should she:

- . confront her mother directly about the lies
- . confront her mother again, indirectly the other difficulties, and lies
- . watch and wait - observe and document her mother's difficulties for some weeks until she has more evidence
- . wait till after the joint-appointment to see the doctor to discuss her increasing concerns about her mother's various difficulties with her, and ignore the lies totally?

### **Several other possibilities also exist**

These other possibilities are not mentioned very often, but they're important for carers and caregiver to know about.

. **selective denial** - where a person with dementia maintains denial of any difficulties to everyone, with the exception of (usually only) one trusted person, to whom they admit their difficulties and their real emotions. Selective denial

actually means that the person is not in total denial, but that they are fearful and wary of others.

. **intermittent denial** - where someone with dementia intermittently camouflages and admits their difficulties to trusted family and/ or others, but forgets that they have previously admitted their difficulties to them and resumes the facade. This type of intermittent denial suggests that a person is progressing in their dementing illness, corresponding to their fluctuating awareness. In keeping with this, their denial will gradually also becoming more limited.

### **How can denial of dementia be dropped or replaced?**

In people who are aware of their difficulties, it seems that *denial* is replaced by (reluctant) *acceptance* when:

- . there is enough, undeniable, evidence
  - . when they feel safe and supported enough, to not need to continue denying.
- This next example shows how quickly this can happen when someone has accurate information and feels safe (enough), in a supported environment.

### **A happy turn-around at an Alzheimer Café**

Although *denial* is not one of the standard themes discussed at an Alzheimer Café, it is addressed in detail on the course<sup>4</sup> for Alzheimer Café coordinators and interviewers'. Since the Alzheimer Café is a post-diagnostic intervention, it is assumed that (most) people attending a café already know their diagnosis of dementia, and are ready to learn more about it - and hopefully even talk about it. That is why it is not one of the aims of an Alzheimer Café to 'break through denial'. (However, though people with dementia as well as family carers can accept a diagnosis, they can be in denial about some aspect of the diagnosis or the progression of the illness.)

### **Example 4**

A gentleman and his family experienced a remarkable turn-around during the course of the evening. (This is an anonymized synopsis of what happened.)

This gentleman was already 'more open to the idea of having dementia' than it might seem, since he did not object to attending the Alzheimer Café with his family and had attended previously. It is as if he had been waiting for the right opportunity to discuss his concerns. (If a person is in complete, or early stages of denial, they would not likely attend.) The theme for the evening was discussed in the form of an interactive talk. See Box 1.

#### **Box 1** Theme for this Alzheimer Café: **What is dementia and how is it diagnosed?**

During the presentation various things were discussed – including:

- . old, new and metaphorical definitions of dementia,
- . the many different types of dementia

. **Examples of *difficulties with activities and work*, that need to be investigated by a doctor** (they may be related to treatable illnesses, not necessarily dementia)

Including:

- remembering appointments
- work (slower, more mistakes)
- driving (e.g. small accidents, difficulty reversing, preferring left turns to crossing a lane)
- getting disoriented or lost – (in familiar roads, neighbourhood, large stores, car parks)
- misplacing things more frequently
- word-finding (nouns), and comprehension
- activities of daily living
  - shopping (forgetting items needed)
  - cooking and preparing meals
  - grooming
  - household chores
  - managing finances

- . what type of assessment and testing is entailed in getting a diagnosis
- . the various reasons why people delay and post-pone getting a diagnosis
- . why some doctors don't like giving a diagnosis

**. advantages of getting an early, timely diagnosis**

some cognitive difficulties are reversible

to get timely support for the person with dementia and the whole family

anti-dementia medications can help some dementias for some while

Carer's Allowance requires a diagnosis

the chance to be open about it (versus secretive)

the chance to tell others, and help them understand so they can be supportive

to prevent the *emotional distancing* that can occur when behaviour and abilities change intermittently, and may seem deliberately unkind and unhelpful.

Damaged, and sometimes broken relationships, have knock-on effects for the ability and desire of family/friend carers to keep a person in their own home and to sustain good care.

- . different types of experiences that people have had in getting a diagnosis
- . reasons why it can sometimes be difficult to get an accurate, timely diagnosis.

Some slides were shown with examples of *difficulties with daily activities and work*, that need to be investigated by a doctor – they may not be related to dementia, but to other conditions or illnesses

After the presentation, a **gentleman (G)** came to speak to the **presenter (P)**. Moments later, his wife and son also came up, introduced themselves and then stood a little behind the gentleman, to listen unobtrusively to what he was saying to the presenter.

G - "That was an interesting presentation. May I speak with you about it?"

P - "Of course."

G - "I have all those things that were on the slides, and my doctor said I have dementia, but I don't. I'm fine." [*The slides the gentleman was referring to are shown in Box 1.*]

P - "You've noticed that you have difficulties with *all* the things that were shown?"

G - "Yes, every one of them, but I don't have dementia."

[*His wife, unseen by him, rolls her eyes – the son puts his arm around his mother.*]

P - So, you don't think you have dementia, but the doctor thinks you may. That

sounds like a serious difference of opinion.

*[His wife and son nod their heads behind him, without him seeing.]*

G – Yes, but doctors can be wrong.

P – Yes they can be sometimes, and sometimes not. And you're angry about the thought of this possibility - and scared?

G – I don't want to have dementia.

P - No, I understand that. No one wants to have dementia, but some people do get it, un-asked for. What do your family think?

G - They think the doctor is right, and that something's the matter.

P - May I ask - is there upset at home sometimes because you disagree with them?

G – [nods]

P – Do you ever have unpleasant silences and words about it?

G – Yes, at times.

*[The wife and son, still standing behind G, make affirmative non-verbal signs to P]*

P – Do you understand that they're worried too? [Gentleman nods.]

If you won't talk about dementia being a possibility, and they see you struggling with things – it makes it more difficult for them to give you their help? It means that you're all upset and worrying, but there's little talking and not much support.

G – [remains silent, then nods again]

P – Have you thought about what *if* your doctor could be right? What would happen if you could think about that you *might* have dementia? What if you could admit it's a possibility, and talk about it with your family, like we're doing now?

G – [is attentive but silent]

[G and P face the wife and son.]

P – Would you like to try?

G – Yes.

P – Shall we try a practice right now?

G – Yes.

P – OK. Pretend you don't know me. Introduce yourself to me; tell me that you think you might have dementia.

G – [He faces P, shakes hands, and says, "I'm [his name] and the doctor thinks I might have d...d...dem... [he stops.]

P – That's good.... almost there. Do you want to try once more?

G – [Nods.] "I'm [his name] and I might have dementia."

P – Hello [name]. Thank you for finding the courage to say that.

[G's wife and son hug him and speak with him.]

P - How difficult was that?

G – Not so much.

P - Do you think you could stand one more introduction?

G - OK

P - This time you don't have to say anything - I'll do the introduction. I'd like to

re-introduce you to your family, who obviously care for you very much.

G – Fine.

P – [Facing the wife and son, says] I'd like to re-introduce your husband and father to you – in a new way. He thinks he might have dementia. It's a difficult thing for him to consider and he's very upset about it. The discussion here tonight, made him think about it and want to talk about it. [The wife and son shake his hand, like in a formal introduction.]

[Then P says to G] Here are your wife and son. They look like they want to talk to you and stay close to you and to help you, whatever is the matter – dementia or not. Is that right?

[Many nods; tears well up, and they hug each other for a long while, speechless.]

P – Does that feel better now?

G – Much, much better – I can't tell you.

[They talk together.]

P - Please come to the Café alone or together, whenever you wish. You're always welcome, and the people here understand about these things.

This family left the Alzheimer Café very happy. Before leaving they shared their story with others, which would have further have reinforced this gentleman's achievement. This gentleman's denial may return, but if so, it is likely to only to be fleeting. He was very aware of his difficulties.

### **Related ideas for observations and research:**

- . Have you noticed the types of denial, awareness and lack-of-awareness mentioned?
- . Did you notice that the gentleman in Example 4 did not deny his difficulties, just the diagnosis? That he initiated the conversation? And, that the presenter was picking up on information from both him and his family, before replying?
- . Have you ever had the chance to speak with someone about their dementia - although others were not able to discuss it with them? Was it difficult?
- . Did you notice during the [role-play of the introductions], that it took the gentleman two attempts to say aloud that he *might* have dementia?
- . Have you thought how difficult it might be to start speaking about your difficulties, if you had been denying them for a long while, and no one helped you try to do so?

Best Regards,  
Gemma

### **References-**

- 1 Jones G (2010) The Alzheimer Café: why it works. The Wide Spectrum Pubs., Berks. UK, SL5 7BH [thewidespectrum.co.uk](http://thewidespectrum.co.uk)
- 2 Miesen B (1999) Dementia in Close-up. Routledge, London.
- 3 Feher EP, Mahurin RK.; Inbody SB.; Crook TH, et al (1991) Anosognosia in Alzheimer's disease.

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4 Two-day course by GMM Jones. "How to host an Alzheimer Café: for coordinators and interviewers". See Alzheimercafe.co.uk; thewidespectrum.co.uk

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