Dementia Caregiver Cafés: forum for ongoing education, support and innovation sharing Unpublished article 17Jul07 © Gemma MM Jones
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Summary

Dementia Caregiver Cafés (DCC) are a new way of providing 'ongoing dementia education intervention' in the Netherlands. They have been developed along parallel lines to Alzheimer Cafes, by Dr. Bère Miesen. This article reports on the structure and content of one DCC meeting, and three year programme of themes, so that the usefulness and applicability of this form of education in the UK can be considered.

What is a Dementia Caregiver Café?

Dementia Caregiver Cafés (DCC) are monthly gatherings for anyone employed in dementia-related work, to provide them with an open, personal, regular update forum to learn, share knowledge, and hold candid discussions around. They are a new type of staff support and dementia education intervention. The goals are to consider specific care issues, to raise the career profile of both the field of dementia care and of those who choose to work in it 'professionally', and to attract interested newcomers to the field.

It is for all those involved in planning, assessing or providing dementia care, in whatever setting; dementia care staff, related professionals and ancillary workers. DCCs are an outgrowth of the Alzheimer Café concept. Both ideas are the inspiration of Dr. Bère Miesen, with whose permission the contents of the session reported here, are shared. (Pseudonyms have been used for the people who were interviewed.)

DCCs run on a three year programme of themes. This article summarizes the content of the final DCC session of the second year. The topic discussed at this DCC was 'the paradox of normality'. This DCC concluded with an invitation to attend a day long National Conference on Dementia Care.

[Note about language and conceptual differences: In the Netherlands DCC cafés are called 'PG Cafés'; PG stands for 'psychogeriatric'. In Dutch, 'psycho', is thought of as 'psychological', and does not have the negative connotations of 'craziness' that it does in the UK. Dementia care does not come under the remit of 'mental health services' in the Netherlands.]

The 'three year' theme layout for DCCs

The content of ten themes per year for three consecutive years will be familiar to those who know the thrust of Miesen's work. (See Miesen, 1999, about 'attachment behaviour and dementia'.) The topics are focussed around a care mandate, care product, core themes, key topics within dementia care. See **Box 1** below. The ten themes are each discussed in relation to 'three types of know-how' and relationships, thus providing the 30 topics contained in the full three-year programme. The hope is that all of these will contribute to a positive, professional conceptualization of good dementia care.

Box 1 The 10 DCC Themes

Over-arching slogan:
Love alone is not enough for good care
(a knowledge base is required).

Slogan for the second year:
Dementia care a special field of work: do you know what makes it special?

Assumption:
'Good care' for people with dementia is always embedded in a 'relational' context.

The care product is:
the quality of our attachment to the person being cared for.

1 From this relational perspective and the primary mandate to provide 'good dementia care', caregivers are challenged to 'grow with' the person with dementia, (alongside the 'consequences of the illness on them).

This endeavour to continue 'growing with' a person with dementia can be described in terms of **three core themes related to the care process**:

2 the increasing loss of a 'shared world'
3 reduced reciprocity in communication
4 attachment and saying goodbye

It also raises questions for caregivers around about **six care-related issues**:

5 intimacy and sexuality
6 aggressive behaviour
7 power and powerlessness
8 truth and truthfulness
9 the paradox of 'normality'
10 adoption, transference and counter-transference

The 10 topics in the left column can be elaborated in terms of what **good dementia care requires**:

. three types of 'know-how' and expertise
  ~ head - the knowledge required
  ~ heart - the attitude and experience
  ~ hands - the skills

. consideration of the **relationships between and viewpoints of four stakeholders**

- the person with dementia
- family carer or partner
- oneself, with a specific role/function
- representatives of any other organizations involved in/with care

Where to hold a DCC; setting and timing

Any setting that has easy public access and appropriate facilities for setting up a sound system in a roomful of tables, and offering refreshments is suitable for holding a DCC.

The DCC described in this article was held in a brightly coloured, modern university bar/restaurant in ‘the Hague’, in the late afternoon. A good sound system with roving microphones had been set-up beforehand. The guest speakers and discussion leader (Bère Miesen) were seated at a table at the front of the room and had reviewed the theme for the evening and the discussion questions before things got underway.

The guests, about 45, started trickling in, had a drink together and mingled at the various tables to catch up with one another. They came from a surprising range of settings and health care disciplines; care assistants, nurses, psychologists, a social worker, a home care co-ordinator, a lecturer in psychogeriatrics, a care manager of a facility for older persons with learning disabilities. They represented nursing homes, the community care sector, specialist dementia care homes, and a local hospital.

	
Dr. Bère Miesen seated with interviewees	DCC guests who work in dementia care

The DCC has the same recommended timing structure as that used in the original Alzheimer Cafés; five separable slots of 30 minutes each.

Time Block A- 30 minutes for socializing
Time Block B - 30 minutes to hold the interviews
Time Block C - 30 minutes to listen to (live preferably) music and discuss the content with others
Time Block D - 30 minutes for audience participation in the theme and questioning the speakers
Time Block E - 30 minutes for socializing

Time Block B - Opening discussion with the interviewees

Yvette, in her mid-thirties, is a senior caregiver who works at a large specialist care home. Penny, in her mid-forties, is a nurse tutor who teaches courses about dementia care to staff in three care homes; she has also worked in dementia care. (The care homes are large by UK standards; totalling 700 residents). Bère Miesen is the interviewer and discussion facilitator.

Bère welcomes the guests, introducing the interviewees, and describing the theme for the evening. He reads a list of behaviours out to those present, and asks whether the guests consider this 'normal' or 'abnormal' behaviour. A show of hands is given for each. (The audience has mixed opinions to some of the statements.)

The statements are:

1. Mr. Smith asks the same thing 100 times a day.
2. Whenever Mr. Wilson sees a particular gentleman, he always becomes angry and swears at him.
3. In two years I've never yet managed to get a friendly word out of Mrs. Jaimond.
4. Mrs. Phelps treats me like her servant.
5. Mr. Anton is constantly touching me when I'm near him.
6. Mrs. Tucker always follows me around- or her husband when he's around.

Both interviewees agree that these behaviours are 'not normal'. They would likely be unfamiliar and easily misunderstood by those who did not know about behaviour changes in people with dementia.

Yvette and Penny are then asked to respond to a series of questions about their work and experience.

Which behaviours of persons with dementia upset them most?

Yvette: withdrawn behaviour upsets her most. She has observed that it sometimes occurs when she is unable to get 'real contact' with people with dementia, and they seems to withdraw further (deliberately, she wonders?). Aggressive and potentially 'sexual' behaviour can also be difficult to deal with.

Penny says that seeing people behave in an obviously sad and forlorn way bothers her most.

How do you manage specific behaviours, for example, people who are anxious, 'panicy', or constantly trying to secure the presence of another [attachment behaviour]?

Yvette says she tries to be professional; she knows there's a reason for such 'claiming behaviour' and she tries to understand and help the person.

Penny says that this is a difficult question because each person's boundaries with specific others are different.

Bère continues: at home, one wouldn't likely accept the above behaviours from those around, so how does a caregiver 'learn' to accept such things from the residents in their care? His point is that caregivers don't have 'instant tools' to deal with this, and it requires a lot of understanding of the fears of persons with dementia to allow and even encourage the prolonged close proximity of residents as part of one's work.

What do you do if you get hit by someone?
Yvette: I becomes calm and waits for my 'impulse to react' to change. She explains that she 'withdraws a part of herself', but tries to stay with the person. It is easier to deal with such a happening if you understand that there's a reason for the person's anger, if you can find out what the trigger was. Sometimes you don't have enough background information for that. She is concerned that some of the young care assistants haven't been taught about this before starting their work. When you accept such behaviour, because of a person's situation, you move your normal boundaries, temporarily.

Penny: In order to accept such behaviour, instead of becoming reactive to it, you need knowledge and skills and insight into how you deal with aggression from others in your home setting and other personal relationships. You need to understand what kind of boundaries you have normally, and also, how in dementia care settings, things may be different than in other relationships because of a person's age, condition, personality and the immediate circumstances and misunderstandings.

Yvette recounts an example:
A gentleman became angry with her when she was giving him a perineal wash before helping him into his wheelchair. He would hit and kick. The first time it happened she left him alone for half an hour, before returning to finish his morning care- she didn't know what else to do. When she returned, he offered his apology, which puzzled her further, because she thought that, with his dementia, he wouldn't be able to remember what had happened. On hearing about this incident, the care supervisor thereafter sent caregivers to help this gentleman in pairs. This helped. (He had different boundaries with two people than alone with one female.)

What is it like to accept affectionate, positive behaviour, like hugs, kisses or people hanging on to you?
Penny: It's easier to accept such positive behaviours, than kicking or hitting. However, you still need to understand your own boundaries in order to work well with it. You need to appreciate that a person with dementia can mistake your identity for someone else in their past, and hence behave with so much familiarity towards you'.

Some residents receive more attention than others, don't they?
Penny: 'For sure!' It's not supposed to happen, but it does. The residents who receive least attention from caregiving staff are those who call out often, are aggressive, physically very claiming, and those who are withdrawn, who seem to send out a message that says 'just let me be'.

What pitfalls are there to understanding behaviour changes in dementia?
Penny: Stereotyping a person is a large pitfall. The warning signs can already be heard in caregiver comments like: "There he goes again." Staff members often work out of their own feelings or intuitions; these can be focussed, or scattered unless they have had good education and good experiences.

Yvette: My heart and feelings go out most to another person whenever they seem to be uncomfortable 'inside themselves' for reasons that sometimes I cannot find out about.

Such uncertainties can make caregivers very vulnerable, isn't it so?
Yvette: In this line of work, where there is a chronic shortage of trained personnel; management can't be too choosy in who is employed, so the reality is that some staff are good at their work, understand it and like it, and some are doing it for other reasons. They are the most vulnerable it seems.

The question remains; why and how do we accept behaviours that are difficult to work with in our field?
Yvette: It's part of professionalism to understand and accept.

Penny asks her what her professional knowledge and experience include primarily; knowledge about the person's background, or, knowledge about their illness?

Yvette: Says 'both', but explains that her ability to respond professionally comes mostly from understanding that behaviours that are difficult to work with, are not directed 'knowingly, personally' against her. That makes all the difference.

How do you learn 'not to take it personally'?
Yvette: It's more difficult than I made it sound just now. There's a big difference between how you work at the beginning versus the end of a week. What's happening in your private life also influences how you behave at work. It is more difficult to admit that there are things about us that influence the behaviour of others too.

Block C
Musical interlude by a guitarist-singer: 30 minutes
Most people get a drink and the discussion continues informally.

Time block D - questions and comments sought from others present

Who has a question? [None immediately arise, so Bère Miesen asks the following questions of those present]

What do you do when someone hits you? What are your terms of reference for such behaviour? What kind of personal baggage are you carrying around in your own backpack?

Response from a male caregiver: You need to learn not to act out of your own personal baggage in your work setting.

But what do you do with this baggage…it is still there, somewhere, while you work?

Female care assistant: Where we work, each new member of staff is given a 'buddy' to work with for one year. Such mentorship and role modelling helps a lot; it gives you time to reflect on how someone else is dealing with given situations, versus the reactions that you would be inclined to have automatically, if you weren't in such a work setting. It was a very helpful way for me to learn.

A lecturer in children in the field of learning difficulties:
In our field, there is a **standard course** taught to caregivers, about how to work with aggressive behaviour; **how to work with it 'anti-aggressively'.** It is mandatory, by law, that all caregivers in our field of work take this course. She asks of the others guests present- **Is there no equivalent course for caregivers of persons with dementia?**

Response (person of unknown profession): No. Home carers get a course that includes information about manual handling and knowing your own limits. More teaching is needed, including information specifically about 'understanding behaviour' and 'helping techniques', not just about 'aggression'; that's too vague a topic .

You might be taught things, but at the moment something occurs, you can still be left unnerved, standing with a mouth full of teeth, not knowing what to do, isn't it?
Response from tutor for Homecare services: Yes, and that's why support needs to be structural, built into the care system, not just from the initial education given at the start of a new job or on an ad hoc basis. For example, **'Reflecting On Care mini-meetings'** don't need to take much time. It can be enormously helpful if, after the 'hand-over reporting' at shift-change, the team spends five minutes together, giving real attention for supporting each other.

Another response: But the 'old guard' staff members are not likely to take the time to do this, so how does one get such an idea introduced?

Another response: I had a good experience where I work. After handover, just one extra question was asked of each staff member, **"How was your day/shift"?** This allowed not just the negative things to come out, but also the fun and humourous things, and good ideas came out of this brief exchange, as well as increased understanding of each other.

Response from a student: Observe behaviour- it's 'influenceable' and changeable; so is the environment, and this is so basic important. If residents sit all day in a room together where one person is calling out constantly, all day, they all react to the person calling out but, also increasingly towards each other's comments.

Bère Miesen responds: That certainly is true and it will be a main focus for discussion in another session, but not today. And- understanding the interactions between residents isn't all there is to it, one also has to keep the 'bigger picture' in view to work well. There also has to be **'some space' in the workplace setting for**

acknowledging and dealing with the imperfections and deficiencies of fellow staff members sometimes. Some of this can be dealt with by the 'care team' collectively. For example, it should be possible to admit to each other: 'I can't manage this gentleman right now', or, 'I need a bit of distance from this lady today'.
It may be that you resemble someone in the resident's life and the association is positive; your care relationship works well. But it can also be that the association the lady makes with you is a negative one, and it doesn't allow for you to work well with her- maybe only temporarily. However, it may not be difficult for other team members to work with this lady. It can be a relief to think that such understanding from team members is at hand, without hiding behind 'work platitudes' as was often done in the past, that, 'every staff member has to work equally well with every resident'.

Response from a Caregiver who works in a new 'small group living project':
She says she is with 7 residents 8 hours a day. There are 9 such **'small living groups', called 'houses'**, each with a single member of staff. The way these projects were 'intended to work', was that residents would have a fixed caregiver and continuity. However, in reality, they do not allow for the type of team backup support just mentioned. When staff sometimes can't handle things anymore they ask each other 'Can I swap houses with you'? She accepts that 'knowing one's limitations' is part of professional behaviour but there is need for some 'scope for change' too. You can't be with the same seven people all day, all week, week after week, and necessarily behave 'professionally' all the time.

Response from a care team leader: It's difficult to create such 'terms and conditions' for staff if you don't understand them or haven't experienced them yourself. You tend to think that others, like you did, should 'just get on with it without being soft and winging'. To change, you have to *learn* to say 'I can't manage this, or at least, I can't manage it right now'. The longer one is in a job it seems, the harder it is to ask for help and things for oneself. In the new education programmes students are taught to make 'reflection journals' and think about their work differently; that wasn't so in the old education methods.

Response from someone at the back of the room: **Maybe old caregivers are too old to learn this?**

An old caregiver responds back: I've done my work for 37 years and I'm not rusted-up so badly yet that I can't change or move.

Another older caregiver: I've worked in care for over 17 years. I understand what my own 'self image' is by now, and I certainly think it is possible to say to oneself, 'I'd like to learn this new thing', or 'What on earth have I been doing'?

Bère Miesen addresses the previous caregiver: Are you part of the old or new guard?
Response: I'm 45, just on the boundary!

Bère Miesen: Where is that boundary? Does anyone dare say?
Laughter and this part of the DCC closes. Music starts and the discussion continues informally in the room.

Conclusions

Normal behaviour is a paradox. To understand the behaviour changes of some persons with dementia requires knowledge of life history, which abilities are affected by the illness, and insight into one's own responses to the aggression and closeness of others. Long-term mentoring, and the good role-modelling of colleagues is a valuable way to learn how to interact helpfully, rather than simply out of one's own automatic response patterns to having 'buttons pushed' by those in our home settings.

The value of such a DCC gathering was obvious, not only from interview content and discussion, but also from the reluctance to leave when the DCC was finished. The social setting for such education made a pleasant occasion for such learning. The presence of persons coming from such a variety of dementia care jobs, greatly helped the breadth of the discussions.

The effectiveness of the original DCC concept, 'to educate and support those involved in dementia care', is inextricably linked with the skills and experience of the 'Interviewer', and the mixture of expertise of those present in the gathering. This intervention could presumably have turned into a 'disgruntled, complaining session' in less skilled hands, and with a less clear vision of good dementia care.

The DCC seems to have the potential to be as cost-effective a 'support and educational intervention' as the Alzheimer Cafes, …once we are prepared to acknowledge out loud that ongoing staff support and education and amongst the key needs to develop dementia care as a professional specialization in its own right.

It would be interesting to know if readers in the UK like the sound of this idea.
It would be equally interesting to know whether setting up such a service for staff would have an eventual impact on job satisfaction and 'high staff turnover rates' in this field.

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