

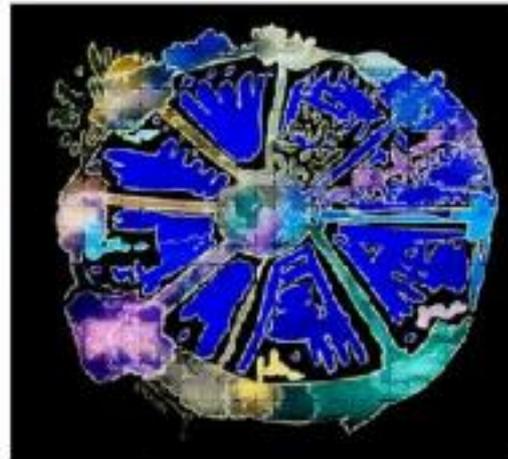
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## TAD (Thoughts About Dementia) Newsletter



12 July, 2011

### Alzheimer Cafés and other 'café models'

#### Related ideas for observations and research:

- Are you in a position to volunteer or help with a café locally?
- Do you know which model of café is being used, and why it was selected?
- Does the selected model suit your needs and objectives?

Dear Reader,

#### Background

For those not familiar with one, the Alzheimer Café (AC) is a recent form of 'post-diagnostic group-support intervention' - in the form of monthly gatherings in a café-like atmosphere - for people with dementia, their family/friend carers, and all others interested in dementia. At AC gatherings, there is music, refreshments, information and education about dementia. They are free-of-charge and people can attend for as long as they are comfortable doing so. (Sometimes, whole family units attend. Many guests have attended for years; some have become not only 'core family members', but also volunteers.)

An AC is organized and hosted by a steering committee in conjunction with an AC coordinator, interviewer/discussion leader, health and social care professionals, and volunteers - including a representative from the local Alzheimer's (Society or other) support group. More detail about the workings of ACs is available from the [alzheimercafe.co.uk](http://alzheimercafe.co.uk) website, books and articles 1 - 13.

Contrary to what the name suggests, an AC is much more than a social gathering. Its purpose is to reduce the stigma surrounding dementia by facilitating social contact and providing education about dementia, for everyone affected by and interested in all types of dementia – not only Alzheimer's disease.

(The name 'Alzheimer Café' was chosen to be in keeping with the name that was most familiar to people. Most national organizations are called 'Alzheimer Societies'...although they are also the 'support umbrella' for all types of dementing illnesses and related disorders.)

### **The first ACs**

The first AC was conceived of, and started by Dutch clinical psychologist Dr. Bère Miesen, in Leiden in 1997.

His key message was:

*"Do not hide away - come and participate with us, in this safe [AC] space, and in society and life as much as you can. You did not ask to get dementia, and it could happen to any of us. Here we understand - and want to talk about it and learn to live with it."*

### **Purpose of the AC**

The AC is intended to supplement - not compete with, reproduce, or replace - other forms of support or information. The first AC in the UK started in 2000 – at last count there were twenty-eight. ACs have spread to over a dozen countries - most recently, Canada <sup>13e, 14</sup>.

With various new initiatives and the increasing calls for 'inclusion and openness' of the past decade, it's hard for newcomers to the dementia-care field to appreciate what was so unusual and helpful about the first ACs. At the time ACs started the predominant type of support available was in the form of 'Support Groups for family/friend carers'. Local groups - often Alzheimer's Society Branches - organized them, and there was no standardized content or information. The groups were for the carers (though sometimes parallel activities were held for people with dementia separately.) Carers who could not make arrangements to leave the person with dementia to attend a meeting, could not benefit from such support groups.

### **Alzheimer Cafes and other café models**

Reducing stigma: 'naming the pain' and discussing core themes

Bère Miesen started the AC to create a 'safe place' - for everyone together. Besides the socializing, topics relating to dementia (but ones which are rarely spoken about) are presented and discussed knowledgeably, sensitively and openly with people with dementia their carers/caregivers – with the help of professionals and volunteers. He believes that increased understanding of dementia and 'naming the pain', can reduce stigma and help people to:

- break through the pain of receiving a diagnosis (and also of any denial)
- stay connected and face the uncertain future – together, better
- role-model positive attitudes and communication.

This was intended to replace the 'whispering behind a person's back', that happens when those around the person with dementia are not comfortable, or do not know how to speak with them about dementia.

(Such avoidance and stigma was also the norm with people with cancer about 30 years ago.)

The discussion topics that Miesen taught for years, and piloted at the AC, became part of a set of core themes from which the annual AC programme is prepared. The themes reflect the (emotional) issues that are encountered

in the dementia process – e.g. what is/isn't dementia, how a diagnosis is made, understanding what happens to memory, breaking through denial and learning to adapt and live with dementia, what support is available, issues around asking for support, understanding emotions, stress, adapting communication, grieving and guilt. The AC approach inspires new openness for other forms of dementia education and support.

Choose the type of café model with your aims and objectives in mind

Since ACs started, this café style of gathering has proven popular. Alternate types of 'café models' have also developed subsequently – for example there are now cafes called 'memory cafés', 'dementia cafés', and cafés with various other names.

All cafés offer opportunities for social contact and are valuable for that, but there are also significant differences between them - in terms of whether their focus is on dementia education, primarily social contact, providing an activity, or offering a point of contact with professionals.

If you're interested in setting up some sort of café, the model you select to use will depend on your aims.

**For example:**

- some cafés hold 'general information talks' but not necessarily about themes related to dementia
- some cafés do not have health or social care professionals present for talks or interviews, subsequent discussion and queries from AC guests
- some café- style services are functioning like informal drop-in centres - places to have refreshments and speak with a professional [e.g. a nurse]
- some cafés provide activities like painting and music for people with dementia for brief intervals

*[Though there are obvious benefits to providing activities - some professionals are concerned that such cafés may come to function like 'mini-day care sessions', and be used as substitutes for the provision of more comprehensive day care services, which are the bedrock on which the vision of 'care in the community' in the UK depends.]*

Dr. Marco Blom, gerontologist and director of Alzheimer Nederland (AN), has reflected that the AC has been an exceptional support service and that AN is eager to increase the number of ACs and to help maintain their quality (Blom, personal communication). AN funded the research and collaboration that went into developing the quality control criteria (QCC) for ACs, in 2006 <sup>8</sup>.

**If you wish to start an AC**

Anyone wishing to start an AC is encouraged to, and free to do so, if it meets their aims and they are guided by the QCC15, 16. There is not cost to do this. The AC UK Charity promotes new ACs, providing them with artwork, logos, practical suggestions, hosting AC conferences, and the courses mentioned below. *[Patents on ACs are held by Bère Miesen, AN, and me.]* Information about how to start an AC is available from a variety of sources <sup>1, 4</sup>



Caption: April, 13 - 14, 2011 – Course participants of "How to host an Alzheimer Café course: for coordinators and interviewers", Lymington, Hampshire, UK

**Upcoming courses?**

The next AC course is planned for Nov. 9 - 10, 2011, in Leicester, UK.

Details of this course and others are posted on thewidespectrum.com website.

Conclusion:

The AC is meeting a variety of needs, and many people are attending them as an additional form of support in their community.

Best Regards,  
Gemma

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**Box 1 - The AC Course content**

The AC course I've developed, in English, is based on the version that Dr. Miesen teaches in the Netherlands. (Alzheimer Nederland provides it for the coordinators and interviewers of their new AC, and for those who want a refresher and to network with others hosting ACs<sup>20</sup>, <sup>21</sup>.) I filmed him teaching his AC course two years ago, and attended the instruction sessions for those who will be taking over for him - as he is planning to retire this autumn.

Since AC coordinators and interviewers are present at ACs as leader figures who have expertise in dementia (a knowledge-base, accurate vocabulary, and the experience of dementia to role-model good communication skills), the course topics reflect this and include:

- history of the AC, and role descriptions for coordinators and interviewers
- stigma, demographics and public perception of dementia
- the start and progression of dementing illnesses (changes in: cognitive abilities, behaviour, and family carer responses)
- key concepts: trauma, powerlessness, awareness, denial and control
- 'attachment and dementia': behaviour, figures, Miesen's POPFid theory
- communication
- different patterns: coping, grieving, and guilt
- working with the AC themes
- considering the parts of an interview
- the 33 quality control criteria for ACs
- hosting ACs: examples, queries and trouble-shooting (more details on these topics are available \*, \*\*)

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  - c TAD 27: 10 February 2011 Doctors, dementia assessment, support and concerns about driving
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