

Dementia care: involving people in Alzheimer's cafes

An Alzheimer's Cafe is more than just a 'social outing', which the name can suggest. An Alzheimer's Cafe is a monthly post-diagnostic group intervention that provides education and information about dementing illnesses and various types of support. Alzheimer's Cafes are a social gathering where anyone interested in dementia, especially people with dementia and their family carers/friends, meet.

Alzheimer's Cafes are hosted by professionals, caregivers, volunteers and representatives of local dementia support groups (e.g. Alzheimer's Society). It is referred to as 'low threshold' support, because the atmosphere is cafe-like and therefore fairly easy to join. Although it may not seem unusual to have people with dementia and their family openly discussing topics around dementia, the Alzheimer's Cafe was the first support intervention to do this. Prior to that, there were only separate support groups for people with dementia and family carers. The Alzheimer's Cafe is also a practical effort to help reduce stigma about having or talking about dementia.

This article explains how Alzheimer's Cafes are hosted, and gives inspiring examples of how care home residents, relatives, managers and staff are involved with them.

The start of the Alzheimer's Cafe

Necessity is said to be the mother of all invention, and so it was with the Alzheimer's Cafe. Dr Bère Miesen, a Dutch clinical psychologist-gerontologist who specialized in dementia, came up with the idea and



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Alzheimer's Cafes support people with dementia and their significant others in a safe, social café-like setting. This article explains how they are hosted, and how care staff are involved with them.

started the first Alzheimer's Cafe in 1997. He was frustrated that health and social care students were not taught more about the emotional aspects of having and living with dementia. Emotions include fear, anger, helplessness from stress, long-term grieving, guilt, adapting coping and communication, and difficulties admitting to the need for and asking for help. That meant that people received some types of help, but were missing out on support for essential issues. The rapidly increasing attendance affirmed that a genuine need was being met.

Various levels of support are available:

- The role-modelling of positive language, accurate concepts, an accepting attitude, sensitive communication, and warm interactions
- Discussion of dementia grounded in a philosophy and vision of dementia care that values people and promotes their inclusion and participation in life, including the expression of emotion/s
- The presence of a variety of knowledgeable health and social care professionals
- 'Core families'—who are experienced in attending the Alzheimer's Cafe and can talk about dementia openly
- The presence of regular volunteers, and representatives who can identify familiar guests and newcomers, and introduce them to other guests
- Information leaflets about local services
- Relevant literature.

The first Alzheimer's Cafe in the UK took place in 2000. There are now 27 in the UK, and more are being planned. This article refers to the original Alzheimer's Cafe model but other versions of 'cafe model' are in use in the UK.

What happens at an Alzheimer's Cafe?

Alzheimer's Cafes follow a set routine (see Box 1) and are structured around an annual programme of themed topics. Themes broadly follow the course of a dementing illness and explore issues relating to the emotional aspects of having dementia and caring for a person with dementia. They are the psychological education part of an Alzheimer's Cafe. A topic is presented as an interview or interactive talk, or video (see Box 2).

During the discussions, it is publicly acknowledged that dementia represents a major catastrophe in the lives of all involved, that it is unasked for and could happen to anyone; the various types of pain associated with it include powerlessness, dislocation and distress. Discussions also acknowledge that receiving support, meeting others, and participating in life as much as possible is preferable to hiding away.

Box 1: what happens at Alzheimer's Cafes?

- Most groups hold Alzheimer's Cafes gatherings ten or 11 times year
- Alzheimer's Cafes gatherings are often held in the evenings and last about 2 hours:
- Half an hour of socializing with refreshments and snacks, music
- interview, interactive talk or video-clip relating to a theme
- A short break preceding 'questions and answers', with music
- Question and answer session
- More socializing and refreshments
- 'Purely social' gatherings are sometimes held in December and July, often with live music and perhaps a barbecue.

Alzheimer's Cafe gatherings are held in a friendly, social, cafe-like atmosphere, where people can converse, listen to themed talks or interviews, enjoy refreshments and music, and come and go freely. Alzheimer's Cafes are free of charge. People may start attending Alzheimer's Cafes from the time of diagnosis for as long as they wish or are able to (Miesen, 2002; Miesen and Jones, 2004).

Benefits of attendance

The overall atmosphere of an Alzheimer's Cafe is one of safety, in the presence of others who understand about dementia, so that no one need be embarrassed. Feelings of safety can be facilitated by: good role-modeling, a pleasant social environment, familiarity, appropriate humour, constancy and predictability (e.g. through the timing-structure and routines at Alzheimer's Cafes).

The Alzheimer's Cafe helps to reduce the stigma of dementia by giving recognition, status and attention to people with the condition, their carers, and the illness. This is done by providing psychological education, information about local services, practical support, and opportunities for questions, sharing experiences and social interactions.

The Alzheimer's Cafe offers people an increased sense of control, through education, information and access to professionals.

The resources available at an Alzheimer's Cafe enable people and their families to get rid of their fear and denial of the disease by exploring the condition and its consequences. This may also help them better accept their changing role or work through to the next stage of their grieving process. Attendees overwhelmingly say they want to know 'the truth'; they do not want to be told fairy tales and platitudes about dementia. Invariably Alzheimer's Cafe guests share and compare their stories, such as disappointments/successes; how easy/difficult it was to get a diagnosis; and how easy/difficult it is to forgive oneself/another for losing patience.

For some guests, attending an Alzheimer's Cafe is their only monthly outing, and the only time they have seen a health or social care professional outside of an assessment or crisis situation. Here, they can ask professionals questions informally over refreshments. Some guests feel better when they've spoken to a professional, volunteer, or another carer, or found useful literature, or suggestions about how to locate additional

assistance. It may be that what was helpful to them was not only the guidance, but also the interest shown in them at the following Alzheimer's Cafe. Sometimes, a professional from the Alzheimer's Cafe has phoned them the next day to see how they are doing.

Some GPs, pastoral-care workers, outreach workers, and day care staff attend the Alzheimer's Cafe because it quickly allows them to see how people are doing in a relaxed social setting. Since formal dementia education can still be difficult to access, staff and students in contact with people with dementia have attended Alzheimer's Cafes to supplement their education.

It is hoped that the Alzheimer's Cafe model may be a way to offer dementia support to ethnic communities that have been hesitant to engage with traditional support provision. Research is being undertaken to find out who avoids attending Alzheimer's Cafes and other forms of traditional support, so that new adaptations and interventions can be developed to reach and assist them.

is this education helpful?

Dementing illnesses are still incurable chronic illnesses, which can be psychologically traumatic in different ways. Each person has to work through the reality that he or she is losing control of their life and abilities. It is now generally accepted that people with dementia are more 'aware' of their illness and the resulting difficulties than previously thought (Miesen, 1999; Clare, 2006). Denial of the illness and refusal to talk about it is strong evidence for such awareness.

Dementia can also be traumatic because some people experience fear and difficulties from the re-surfacing of old wounds. These can include earlier uncomfortable feelings from a distressing situation (Jones and Burns, 2002; Miesen and Jones, 2002).

For the family and friends, it is also emotionally distressing. Their loss is 'intangible' because the person is physically present and may appear fine, yet they are changing. Relatives often experience long, complex grieving processes, which usually start at the time of the suspected diagnosis. People with dementia may also be grieving for the changes and losses they are experiencing.

Care home staff links

The role-modeling of good communication and attentive interactions can make guests

Box 2: themes for interviews and talks in an Alzheimer's Cafe annual programme

- 1 What is dementia?
- 2 What happens to different types of memory and other cognitive abilities? What simple, accurate ways are there to describe the changes? (factual, emotional, and sensory memory (Jones, 2004)) What are the benefits of learning to talk about difficulties and explain them to others?
- 3 The range of human emotions: what is their purpose? Which ones are most uncomfortable? How do people respond emotionally to chronic illness before and after a diagnosis is made?
- 4 Understanding fear and anger: they often occur together—which comes first? What are people afraid of? What is the purpose of 'attachment behaviour' in people with dementia (Miesen, 1999; 1997). Listening to a person's story (life as they experience and understand it) as a first step in dealing with anger
- 5 What help is available?
- 6 Communication
- 7 Stress
- 8 Understanding grieving and guilt
- 9 Learning to live with dementia: hitting and overcoming brick walls in life: How have you (and others) overcome difficult times in the past? How you have learned to adjust? Which role-models and examples have helped?

Other topics, used depending on the comfort of the interviewer and interviewee, include:

- Daily ethical dilemmas: e.g. to lie or not to lie; to help or let a person struggle a bit; whether or not to encourage/prompt/force
- Behaviour changes and the variety of reasons for it
- Explaining visuoperceptual changes in dementia
- Breaking through denial: what can help?
- Intimacy
- Does receiving a diagnosis of dementia help you to 'move on'?
- How do you explain to others you have dementia?
- What is known about carers, and how to emancipate them?
- What makes a 'good' care home? (AC Nederland, 2011)



The ambiance at the Alzheimer's Cafe comes from the good company, refreshments, nibbles, the music and support of volunteers and professionals



These volunteers, who also work in care homes, are preparing refreshments. They wear bright T-shirts for easy identification by guests

comfortable and can help to educate them. A positive spin-off from this is that it can be the best form of advertising for care homes and day centres. If their staff members attend Alzheimer's Cafes often enough to become familiar with guests, or if their professionals are interviewed, it will likely influence the choice of care setting when one is needed.

Some caregivers and care home managers bring residents who they think will benefit the Alzheimer's Cafe. However, as Alzheimer's Cafes are a form of post-diagnostic support, the residents obviously have to have been diagnosed and told their diagnosis.

Caregiving staff have been good advocates for the Alzheimer's Cafe and have told family visitors about it, and what the talks were about. A number of care homes have 'Alzheimer's Cafe posters' on their information bulletin boards. In this way, some family members have been steered and encour-

aged to attend the Alzheimer's Cafe, with or without the person with dementia.

As one care home manager recently said:

'Having my staff volunteer at the Alzheimer's Cafe has actually helped change their practice - especially the caregivers—as they learn more about the effect of dementia on families and friends.'

Do guests tire of the themes?

Many guests who have attended for over 10 years say that, although the themes are repeated annually, there is always variation in the interviewees and the talks. They also hear different things each time, as their situation, experiences or thoughts change. Since themes are announced beforehand, guests can choose whether to attend or not.

Who coordinates and interviews?

A wide variety of people experienced in dementia care have become Alzheimer's Cafe coordinators and interviewers. To date they include the professionals involved in dementia care who include care home managers. Alzheimer's Cafe coordinators attend a 2 day training course for this role.

The location of Alzheimer's Cafes

Alzheimer's Cafes have been held in a wide variety of places, such as town halls or churches. Although some are held in care homes and day care centres, these are not

ideal because people with newly diagnosed dementia may be in denial and wary or fearful of such settings.

Inspiring examples

After visiting the Farnborough Alzheimer's Cafe, the first in the UK, Chair of the Isle of Wight Registered Care Homes Association Maggie Bennett was determined to set one up. Others were also interested, so they formed a steering committee and opened the Newport Alzheimer's Cafe in 2009. This Alzheimer's Cafe runs with major input from staff from several residential care homes, and even some volunteers who are residents! It has been so popular that another Alzheimer's Cafe is being planned on the island. Volunteers may help with refreshments, setting up the venue, welcoming guests, manning the information table, and organizing extra events, such as BBQs.

How long can people attend?

People with dementia can attend for as long as they feel safe, engaged and comfortable there. Some people can follow things better if they are seated close to the speaker versus at the back of a hall. Family carers usually judge when the Alzheimer's Cafe is no longer suitable for the person with dementia. Some people continue to attend with their family members after moving to a care home (Jones, 2010).

Some new Alzheimer's Cafe coordinators have been concerned about what to do if

people with dementia become uncomfortable, bored, distracted or disruptive to others at an Alzheimer's Cafe. That shouldn't be a concern because there will be enough expertise present to help out. Volunteers may accompany someone to the toilet and talk to them to give their family carer a chance to speak to others, or help them leave if they or their carer wish.

Conclusion

Alzheimer's Cafes are increasingly recognized as an economical form of post-diagnostic support, and an integral part of some dementia care pathways (Thompson, 2006; Jones and van der Eerden, 2010; Nuffield Council on Bioethics, 2009).

The *Dementia 2010 report* (Alzheimer's Research Trust/University of Oxford, 2010) showed that 69% of people with dementia are unknown to their GPs. This includes people from ethnic minority groups, those who have limited or no social networks, and those who live alone and in rural community, in sheltered housing, residential and nursing homes (undiagnosed). It also includes those who have been displaced and/or marginalized, such as people with mental health illnesses, older homeless people and those with addictions.

It is hoped that the Alzheimer's Cafe model may be a way to bring support into those communities that have been mistrustful of, or hesitant to engage with, support services provided by 'health and social services'.

There clearly is a need and scope for additional Alzheimer's Cafes and other forms of practical, ongoing support. Perhaps your residential or care home management and staff are in a position to consider contributing or accompanying residents who wish to attend.

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Key points

- **Alzheimer's Cafes give people with dementia and their carers a safe, supportive way of obtaining information and education about the condition**
- **Attendees learn about the consequences of, and the emotional responses to, dementia from other participants, knowledgeable professionals, and volunteers**
- **Everyone interested in dementia is welcome to Alzheimer's Cafes, but since supporting people with dementia is the main reason for the café, they are central to it**
- **Managers and staff from care homes assist at Alzheimer's Cafes as coordinators, interviewers, volunteers and learners**
- **Participation at an Alzheimer's Cafes can be good advertising for a care home or service.**