

**Alzheimer Café UK**



**All in the same boat**

[www.alzheimercafe.co.uk](http://www.alzheimercafe.co.uk)

## **Introductory Information Pack: to help set up and host an Alzheimer Café**

**prepared by Gemma MM Jones and Kandy Redwood for the:  
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**A copy of the Promotional DVD** showing interviews with professionals and guests at the Farnborough AC is contained within the AC UK conference pack for the 14 May, 2010.  
 (It can be viewed on the AC website, or on [thewidespectrum.co.uk](http://thewidespectrum.co.uk) website.)

<p><b>Contact: the Alzheimer Café UK Charity, <a href="http://www.alzheimercafe.co.uk">www.alzheimercafe.co.uk</a></b></p>
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## Note about this pack

*This pack* has been assembled to help those thinking about setting up an Alzheimer Café (AC).

It provides translations of the original AC handbook, and the 33 quality control criteria for ACs. (A sample 'AC self-evaluation form' is available as separate document on the AC website.)

It includes various items that have been used at the Farnborough AC (survey forms, check lists, evaluations, and sample interview questions).

For more detailed information - such as interviews with professionals and AC guests, and 'answers to commonly asked questions by AC new coordinators and interviewers', see the new book:

***"The Alzheimer Café: why it works"*** (GMM Jones, 2010, 212 pages, The Wide Spectrum Publications, Kingswick House, Sunninghill, Berks, UK, SL5 7BH). Available from the website [www.thewidespectrum.co.uk](http://www.thewidespectrum.co.uk)

Further references to articles about the AC are provided at the end.

Also, please visit the website: [www.alzheimercafe.co.uk](http://www.alzheimercafe.co.uk)

## Item 1 - The Alzheimer Café: a guideline manual for setting one up

*(Original document entitled, 'Handleiding Alzheimer Café' by Bère Miesen and Marco Blom)  
(Translated and adapted from the 'Alzheimer Nederland' document - by Gemma Jones; with special thanks to Ray and Elspeth Moran, April, 2001)*

### 1. How it started

On September 15th, 1997, the first Alzheimer Café opened its doors. The long-brewing idea of Dr. Bère Miesen, Clinical Old Age psychologist at the specialist geriatric research centre for, 'Mariënhaven', in Warmond, the Netherlands, had become a reality. After several months of preparation, together with the Alzheimer Association in northern 'Zuid-Holland', he succeeded in launching something, which is now being increasingly replicated.

In his contacts with people with dementia and their families, Miesen had noticed that talking about the illness, even between partners or within a family was often taboo. He was not alone in noticing this. Knowing that **making dementia 'discussable', and providing information about it and its consequences is very important for the acceptance of the illness**, Miesen thought that it would be good if all those involved could meet each other in a 'relaxed forum' to exchange experiences and to talk about dementia. There would then be a place where people could share their experiences [successes and sorrows].

#### **Quotes from Bère Miesen**

*"Dementia is a complete catastrophe. Both the person with dementia and their family deserve to be well supported. The recognition and admission of mental [psychological] suffering can make life live-able again".*

*From: De Telegraaf, September 1999*

*"In the outside world there is little recognition of the fact that both the person with dementia and those close to them are going through a grieving process."*

*From: VWS Bulletin, June 1999*

#### **What is understood by the word "Café"?**

How could such a 'relaxed atmosphere' be better described than with the word 'café'?

Miesen's idea of an Alzheimer Café first became reality in a lecture room of Leiden University. About 20 people attended the first meeting. A month later there were 35, a month later the number had risen to 54, and after 3 months the lecture room contained 80 people. It was clear that the initiative met a real need.

People from the whole country started coming. It appeared that there was a great need for a place where persons with dementia and those involved with them, could talk calmly about the disease. People left the meetings feeling more resilient and also, importantly, with tips on how to assist people with dementia. There was also interest from the national media. The fame of the “Alzheimer Café” also grew as a result of the seven, half-hour, television broadcasts in the series “Living with dementia”- which were recorded by Teleac/NOT in the Alzheimer Café in Leiden.

### **Good Examples Will Be Followed**

Enthusiasm about the Alzheimer café grew; soon, an average more than a hundred people were visiting it. A new venue was found at a hotel in Leiden. Amongst the regular visitors were representatives of other branches of the Alzheimer Association. They also decided to start Cafés in their regions.... Delft and Utrecht were next.

This wide interest resulted in a meeting about ‘How to Establish an Alzheimer Café’, organized by Alzheimer Nederland (Dutch Alzheimer Society). People from more than 15 districts took part. Several specialist Nursing Homes and Care Centres were also keen to use this concept. This led to similar initiatives [elsewhere]. (To see where Alzheimer Cafés are held, see the Alzheimer Nederland site, <http://www.alzheimer-ned.nl>)

### **Variations On A Theme**

To avoid reinventing the wheel, many other AC initiators have made contact with the original founders or have made orientation visits to one or more Alzheimer Cafés. *[This article was prepared before there were two-day courses available for AC coordinators and interviewers.]*

Nevertheless people are also looking for ways to make the idea more applicable to regional needs: different starting times, different locations or even another name, because the term ‘Café’ might be too restrictive. What remains important however is keeping to the original concept, which has turned out to be so successful.

This is one reason for putting the existing experiences with cafes down on paper ... [so those initiators interested in starting a cafe] can make a considered choice before starting a Café. They can benefit from the practical information... and devote their energies to hosting the AC meetings rather than reinventing the wheel. If we think of all those having dementia, and their carers, we realise that the quality of support can never be *good enough*.

In a brief outline such as this, it is difficult to *fully* describe the fundamental principles, theoretical starting points and underlying vision of an Alzheimer Café. To best understand this, it is really helpful to attend one of the first meetings [of the thematic presentations] of an Alzheimer Café annual programme, and be closely involved with it for a longer while.

We have been helped by several articles by Bère Miesen, which started off the development of an overview of the Alzheimer Café phenomenon. The core of his vision can be found in the following passage from the introduction to his book “Living with Dementia” (Leven met Dementie).

### **Underlying Vision**

“The Title ‘Living with Dementia’ can be explained in two ways. On the one hand, it indicates the bewilderment, which starts when it becomes clear that a catastrophe is about to descend on the lives of the persons with dementia and their family. ‘How do I handle an illness that threatens my life irreversibly?’ The illness, either your own, or that of someone close to you, suddenly gets full attention. On the other hand, the title indicates that the moment that persons with dementia and their families have more or less accepted that a catastrophe has occurred, they can ask a new question, ‘How do I lead as normal a life as possible, despite the illness?’ Now, it is no longer the illness, but someone’s life that is the focus of attention. The illness has, despite everything, been faced up to. This is the more positive approach to a process, which is often a long one, with a distinct beginning and an end.

The Alzheimer Café, a meeting place for persons with dementia, family, carers and other interested parties, helps with this process: to get from one point to the other, with as much support as possible. In short, the Alzheimer Café can be regarded as an intervention with aspects of both education and support. All the advantages of having a ‘low threshold’ (all inclusive), informal advice and consultation and ‘self-help group type contact’ with ‘companions in distress’ - are offered/combined in a relaxed atmosphere. The term ‘companions in distress’, also applies to people with dementia themselves. However, we don’t hide from the facts; dementia represents a major catastrophe in their lives of all involved; it usually occurs unexpectedly. **The mental pain, the powerlessness, the dislocation and the distress of the person with dementia and those close to them, therefore, form the starting points for discussions.** How each person copes with the pain is very different and individual.

If someone visits the Alzheimer Café he/she admits his/her sorrow and faces up to it. It is clear, that [hereafter], a person can progress further [and learn to live with dementia].

Dementia is a chronic brain disorder that can lead to psychological trauma, and for some reopens ‘old wounds’. That is to say that each person has to work through the reality that he/she is losing the control over his/her life. And for some, earlier feelings, which arose in a comparable situation of distress, can re-surface again. *For example: emotional memories of powerlessness in situations of incest, POW camps, and violence in war, being deserted, or other traumatic experiences can be triggered again. The suffering is then doubled.*

The person with dementia is more aware of the illness and the situation than it would appear on the surface, even if he denies the illness and will not talk about it. The emotional situation of the family is also difficult, because it concerns an 'intangible loss'. Relatives face a complicated grieving process. The family starts to lose someone, while he or she remains 'visibly' with them for a long time.

It is important to gain certainty about the diagnosis as quickly as possible, and to lose as little time as possible in denying what is going on. This ... helps someone to take hold of their own life again, and to take the steps or decisions which are necessary. This allows a person to take control, not only of his own life again, but also to restore mutual contacts, albeit not necessarily in the same way as previously."

### **Some starting points**

#### For the person with dementia

*Some things may be going wrong, or be difficult for you to do, but you are not 'crazy'. Try to [explain] the changes that you notice happening in yourself, to those around you. Have your difficulties assessed by a doctor; nothing is worse than anxiety and uncertainty.*

#### For the family

*It is good to think of your own interests. Draw attention to the grieving process that you are going through. Seek emotional support from people you trust or your 'fellow companions in adversity'. Sometimes that can be a professional or caregiver who is more distanced from your situation. The attention you give yourself can also benefit the person with dementia. Seek help early for the practical problems; get enough sleep.*

#### For others close to the person with dementia and their family

*If you suspect or know that someone has dementia, don't be too quick to assume that the person 'doesn't want to speak about it'. Such a discussion might be easier than you think; often all you have to do is listen. Don't forget to ask the partner or children what the illness means to them; their problems are often greater than one realizes at first sight.*

#### For professional caregivers

*Try to make sure the diagnosis is established as soon as possible. Inform the person with dementia and the family about the meaning of the diagnosis. Inform them about how and where they can get help. Make sure the person with dementia and their spouse/partner get help, as a couple. That way they can try to share their pain, reduce their feelings of loneliness, and be stimulated to work through their grieving and feelings of loss. (From: *Mijn Lief, Mijn leed*, 2000, Kosmos, Utrecht, English version *Dementia in Close Up*, Routledge Tavistock, 1999 - see reference list at the end)*

## **2. What is an Alzheimer Café?**

By talking about the problems that having dementia brings, persons and families can better manage their own situations. Making the illness 'discussable' gives the person with dementia the feeling of being able to influence his situation. He/she also meets people 'in the same boat' as him or herself. The family see that they are not the only ones with the feelings of powerlessness, dislocation and distress. With the coming of the Alzheimer Café, there is a place where they can go together and find out how others deal with the illness and its consequences. The visitors feel they belong and find recognition and acceptance. That in itself is unique. Furthermore, the Alzheimer Café brings together various aspects that the usual 'carer support and information evenings' lack. Although the AC meetings are partly therapeutic and have a strong educational side, a part of the evening is specifically for making informal contacts. In addition, its low threshold environment is unique. The range of people that visit a Café is great. Besides people with dementia and relatives, friends, professional carers and students, others interested - such as journalists and representatives of the regional and national media and even policy makers sometimes attend.

### ***Aims***

The Alzheimer Café has three main aims. First, information is provided about dementia and the psycho-social aspects of dementia. Secondly, it emphasizes the importance about speaking openly about problems. Recognition and (social) acceptance are essential to this. Thirdly, the Café promotes the emancipation of persons with dementia and their families, by helping to prevent their becoming isolated.

This all sounds rather therapeutic. However, as mentioned earlier, that is not to say that the course of an Alzheimer Café evening is as therapeutic as this sound on paper. It is of prime importance that visitors can talk to each other informally and without interruption, exchanging experiences for example, or informally consulting carers and specialists. It is precisely this relaxed atmosphere, which breaks down [stigma] the taboos and gives people the important feeling of belonging...the acceptance, acknowledgement and recognition mentioned earlier.

### ***Changing Themes***

A different theme is discussed at each AC gathering, but the timing of the evening follows a fixed structure. After the welcome with coffee/tea, comes a half hour of information. This could be via live interviews with persons with dementia and their family members, or videos of discussions with others who have visited the café. Often there is a lecture or a specialist is interviewed before a video is shown. It will be evident that this is dependent on what the organisers and/or the guests prefer. After a break, those present can discuss the evening's theme or bring up other topics. Hereafter, the meeting closes with more informal socializing and refreshments.

The order of the themes or topics is not fixed, but a certain 'thread' to the [annual programme]. That is...the topics tend to follow the chronological course of the illness.

Very often, after a theme has been discussed, there are comments made, questions asked, and personal reactions given. The interviewer leads this discussion with the visitors. Those attending (including the professionals) are there as a sort of 'living example and resource' from which to draw further responses and concrete information.

The themes include:

- . What is dementia? How is it diagnosed?
- . What happens to memory and other abilities?
- . It's getting too much: understanding changing abilities and emotional responses
- . What help is available; why is it difficult to ask for help
- . Adapting communication
- . How to carry on?

### ***Frequency and Starting Time***

Meetings are held monthly, always on a fixed day or date; for example every first Monday in the month. The time and length of the meetings are also fixed. In general, gatherings are organised 10 times a year, avoiding the holiday seasons. The times of the existing Cafés vary somewhat. Some operate in the evenings, others during the day. Both have advantages and disadvantages.

Evening Cafés attract more people, because family members and professionals are home from work then. However, it can be that some people don't come because they don't want to go out in the evenings. This is especially so in winter. If you plan to hold your café in the afternoon, the reverse is the case. Working people, such as the children of the persons with dementia and the professionals often find it hard to get time off. Therefore, consider carefully who form your target group and participants and adapt your opening hours accordingly.

### ***Type of Location***

The choice of location is important because the character of an Alzheimer Café is a 'low threshold' one, appealing to as many persons as possible. Although care home and nursing home settings are not recommended, nevertheless, some districts have chosen to hold their AC gatherings there. (The cost of renting accommodation and the desire of a care home to have a greater public profile can influence the choice of location for an AC.)

In Utrecht, the large café room of a Care Centre is used; in 'The Hague' the café is held in the City Hall. Regardless of which organisations want to work to set up and host a café, it is important that they work towards the same objectives. It is essential that person with dementia and family (especially if persons have only been recently diagnosed), feel comfortable visiting a Alzheimer Café. Since the AC gatherings are generally directed at persons in the earlier stages of dementia, it is usually better not to automatically choose a nursing home as a location.

### ***Any results???***

... there surely are. Although the expected attendance at the first meeting of a new Café must not be pitched too high, practice shows that the second meeting (generally through word of mouth publicity) attracts a bigger attendance. When someone has visited a Café once, he or she often comes back. Such a person we call 'a regular' (Core person). Families who come back together are called 'Core families'. Their presence is essential to help other newcomers feel supported. At subsequent meetings the number of 'regulars' grows and new participants join.

### ***Some Quotes***

*'First I find it very informative and secondly it is good that you are not the only one with problems.'*

*'In short? Penetrating, emotionally gripping and very recognizable'*

*'Initially I did not want to admit that I had it. But here it is accepted and that has helped me'*

The findings of a survey by northern 'Zuid-Holland', showed that the Alzheimer Café formula was well liked. Exchanging information through informal conversations was much appreciated. Visitors thought that the aims of the Café were being achieved. Communication was good, everyone was involved and many people found their desired recognition and acceptance at such meetings.

### ***Café Lay-Out and Ambiance***

There are various ways to lay-out a Café. The lay-out partly determines the Café's ambiance. For example, during the discussion time, you can let the leader of the discussion to wander amongst the audience with a microphone. This ensures people's involvement and contributes to the low threshold feeling. Other Cafés provide a podium on which the Chairman and his guest speakers sit. Questions are posed and answered directly from the podium. With this form of presentation the emphasis is more on the expertise of the speakers. Placing them on the podium does create a greater distance though. It is of course nice to give an Alzheimer Café a 'café-like' appearance to get the right atmosphere. Don't go to too much trouble though: tablecloths and candles on the tables add a nice touch.

### ***Music***

As you know music is important for the atmosphere. To create the right ambiance in the Café, light café-type music works often. It is a good idea to organise live music if that is possible. For example, some cafés have found having that a pianist goes down well. Naturally this depends on the venue [and culture]. Of course, you can bring in other forms of live music. Be careful that the musical content of the meeting does not come to predominate so that the aim of the Café is changed.

### ***Information and questions after the talk***

Providing an 'Information Stand' is a useful addition to a Café. Visitors can look at information material or even take it with them. If you have chosen the theme 'Dementia at a young age' it is a good idea to adapt the brochures and folders to fit this theme. It is guaranteed that some people will want to read the material through quietly at home. In order to offer a broader range of material you can for example make contact with the local library. It may have some useful books to place on your stand for people to look at.

After an evening at the Alzheimer Café people sometimes still have questions that could not be answered during the evening. It is important therefore that help is available. It is preferable if this can be through your own staff or volunteers [Core Professionals]. Any other professionals present can also fulfill this function. It is important for the visitors that they can question the professionals informally. We have seen that is useful to have a 'local contact address list' available. People can also be directed to the local and national Alzheimer's Society Helplines.

### **3. How is an Alzheimer Café Meeting run?**

Although we have already described how Alzheimer Cafés work in general, in this next section we explain this in greater detail. What elements are important for a successful Alzheimer Café evening [gathering]? What are the most important things to consider? We will look at several practical issues in the course of a programme. We will also discuss the role of the interviewer or discussion leader, who is the equivalent of the 'spider in the web' [drawing everyone in to participate].

#### ***Programme Planning***

The programme can be roughly divided into four fixed parts; the 'arrival and introduction', 'the presentation of a video or the talk in the form of an interview', 'the discussion' and 'the informal get-together' after the formal part of the meeting. Although you don't have to stick strictly to the times, practice shows that the discussion leader must ensure that the formal part of the meeting gets enough time. Arrival, the interval and the conclusion must not take up too much time. The official educational part of a Café, on average, lasts up to one hour. Arrival and departure and socialization are in addition to this. Each of these can take up half an hour. This is shown next.

- 0.00 Arrivals with coffee and tea
- 0.30 Start, with introduction, video and/or interview/s
- 1.00 Interval with music and drinks
- 1.30 Discussion
- 2.00 End formal meeting
- 2.30 Informal Session and Departure

### ***Arrival/reception***

An ordinary café may fill up slowly. This is also true of an Alzheimer Café. The visitors like to have the time to find a seat and get something to drink. About half an hour is allowed for this, after which the 'topic part' can begin in a relaxed way. Experience shows that especially the regular guests (Core members) use this time to catch up with each other and make arrangements. However, some people will arrive just as the talk or interview is about start. If the Alzheimer Café has just started and perhaps the numbers attending are not very high, it is important to lay-out the room so that people don't sit too far apart. It is better to keep some chairs aside, which can be put out in the case of a higher turnout. It is important for the organisers personally to welcome newcomers, to put them at their ease if necessary. They can be accompanied to a table in the room, with regular/Core family members and professionals to prevent them sitting right at the back, or alone.

### ***Introduction, video or interview***

The formal part of the meeting begins with a welcome and introduction of the theme and speakers, the presentation/video and/or the interview/s. Half an hour is planned for this. Providing information on the theme is key. Usually, an expert is invited to give a lecture and be interviewed. This can be a monologue, a discussion between the lecturer and the interviewer/discussion leader (with or without a person with dementia or a relative), or, an interview with a [professional], family member and/or a person with dementia. A conversation or interview can, for example, take the form of a question and answer session. When choosing an expert, it helps to know if he or she is an experienced speaker. A good presentation encourages people to ask questions.

Another way of presenting information about a topic is to show a video. This could also be part of the lecture. (For example, The TV series 'Living with Dementia' is suitable for use in a Dutch cafés, because they were recorded in a café setting.) It is also possible, to make a recording of an interview with someone with dementia and their carer in their home environment, and to show this during the meeting. This has been done at the café in Den Bosch. The person with dementia and her daughter were present at the café on the evening it was shown. Of course, permission for this has to be obtained.

Whether it is a lecture, a video or an interview, it is important that the guests/audience can recognize themselves (their own situation), in the material that is presented. In a lecture format this can be achieved through making it interactive by eliciting comments throughout the talk, to make it interactive. If a video is used, guests can be asked to observe what they recognize or have experienced themselves.

### ***The Interval***

Contrary to what the name implies, 'the interval' is a very active part of the meeting for the organisers. They will be answering questions that people do not want to ask in public, or, they join in at a table where people are talking, whether it is about the evening's theme or not. They can use this time to collect questions and points for

discussion to bring up after the interval. It is important that they know what the concerns and queries of the guests are.

The **information stand** is often visited during the interval. Staff who are manning the stand can also expect to be asked all sorts of questions. People who have very specific questions also often approach professionals present. It is important to have antennae for questions that go beyond the individual and that relate to the theme of the meeting. Instead of answering the question immediately, encourage the person asking it to raise the question during the discussion.

### ***Discussion***

After the interval it is time for the discussion [or question and answer session]. The people in the room may react to what was presented before the break. This can range from questions for clarification, to a personal response lasting several minutes. For a good discussion it is important that the discussion leader keeps control [and focus on the topic]. Ideally, there are questions and answers, or, discussion between the visitors [but sometimes this needs to be stimulated]. Moreover, the limited time must be properly divided between all the people who want to contribute, including those who don't push themselves forward.

[Some groups and sessions can be very talkative.] To keep the discussion 'on track' it is sometimes necessary to agree to some rules with the audience. [I.e. only ask questions that you think would be of benefit to others in the room also.] Then, everyone knows what's allowed and not. This makes asking questions and the discussion simpler. If someone repeatedly dominates with many questions, or always wants to ask their question first, or give their opinion on everything said; it will be appropriate to remind them politely that others also want to have a turn. Sometimes, other visitors will point this out. In this way the Alzheimer Café is like a real café.

### ***Informal socialization time, ending the café, and evaluations***

The rounding off of the discussion is also the end of the formal part of the meeting. Some of the visitors will leave almost at once. Experience shows that others will want to go on talking with each other while having a drink just to recover from all the information and listening to other people's stories; the café atmosphere again takes over. In some Alzheimer Cafés, there is dancing or singing afterwards. It is difficult to say exactly how long it takes for people to leave, but it is often about half an hour.

If they wish, the organisers of the Alzheimer Café can use the informal get-together to discuss subjects for future meetings with some of the visitors. In Delft, they have the custom to ask one of the visitors beforehand, if they want to record their impressions of the café in a logbook. At the end of the meeting the visitor can fill in the logbook and, if necessary, discuss their impressions with an organizer. Other ways of evaluating the cafés have also been used. In Utrecht, people were asked their opinion

via a questionnaire. In other places, candid responses made to the organizers during and after the café are recorded, dated and saved.

[Most Café organizers also record the impressions of the volunteers and organizers of each AC in separate book for their own records.]

Whether it is the first meeting or the hundredth, it is wise to evaluate every meeting. What went well? What went wrong? What could/must be improved? Show this evaluation regularly to the consultation group. Together you can ensure a good programme of meetings. Put the evaluation in writing. You or others may benefit from this in future.

### ***Interviewers/Discussion Leaders***

Most Cafes work with a 'duo', who function either jointly or alternately as an 'MC coordinator' and/or an 'interview/discussion leader'

The discussion leaders play a crucial role in the planning of the Café. They are responsible for the smooth running of the meeting and determine to a great extent, what the participants get out of it. Ensure therefore that you appoint a discussion leader who can be relied upon to do all this. So far we have identified two variants of the discussion leader's role, the 'expert' or the 'presenter'.

The 'expert-type' interviewer can answer questions from the audience or otherwise give his/her opinion in the discussion. It is important that he or she is practicing as a professional and knows the professional circuit. Sometimes he/she will know the visitors through his/her work. Normally this gives a trusting relationship and can increase the public's feeling of openness and security. A pitfall for the expert is that he or she answers all the questions and does not leave any space for the mutual exchange of experiences.

The 'presenter-type' interviewer ensures that everyone who wants to speak during the discussion gets the chance to do so. He leaves technical questions to be answered by the experts who are present. It is recommended in this case, to operate with a fixed team of experts present at the café. It is helpful if the presenter can discourage the experts from using jargon and create a good relationship with the audience. A good presenter makes use of his/her own ignorance to ask more questions [on behalf of the guests].

The *perfect* discussion leader does not exist. However, it is possible to list certain qualities that the 'ideal' leader would possess. These are listed just below. The following qualities are important:

- . knowledge of the different forms of dementia and of interacting with persons with dementia and family carers;
- . experience with the problems of partners and family of the person with dementia;
- . experience in leading group discussions;

- . a relaxed manner of presentation,
- . and a trustworthy personality.

### **Qualities of the Discussion Leader/Interviewer**

- . complete respect for the questions and the persons asking the questions
- . the ability to perceive and react well to signals from the audience
- . the ability to pass on and paraphrase questions from the audience
- . to be able to hold a 'companion' type of relationship with the visitors
- . to be able to encourage open conversation, also in a way that could also break through taboo subjects

Perhaps you will feel from this description that an experienced psychologist would be the ideal discussion leader. This is indeed a good option, but of course not a strict necessity, especially if you choose to use two leaders or an experienced presenter in combination with a team of experts.

Whatever your choice, it is a good idea to realise in advance that it is a difficult job and that you should regularly review whether the discussion leader is carrying out his/her role well and with enthusiasm. The leader must react well to signals from the audience. People with annoying questions, tears and laughter, moving stories, and insoluble problems can all be present at a café.

## **4. How to set up an Alzheimer Café**

If you decide to organize an Alzheimer Café in your area, you would be wise to form a **working party/ steering group**. A working party usually comprises 3 or 4 people from the organising institution(s). It is easiest to divide the tasks amongst the members of the working party and to agree who will stand in for whom, in cases of absence.

Once the Café is in existence, the working party need not be disbanded. Members can help with preparing the room, looking after refreshments, and manning the information stand. And of course, they can take a role in setting the themes and the programme of the Café.

There can be a considerable time between the decision to start an Alzheimer Café and the first meeting. The average preparation time is between 3 and 6 months. The opening of an Alzheimer Café [in the Netherlands] often takes place on or near World Alzheimer Day, the 21st of September.

### ***Manual***

To monitor the progress of the activities consider preparing a manual. A small job-list can be drawn up for each area of work that comes up during the preparations. The list

shows who will do what and when. At working party meetings the manual with the job lists can be regularly brought up to date.

Sample manual content

- setting up [steering] consultation group
- choice of location
- choice of discussion leader
- setting date and time
- themes and introductions
- publicity plan
- regular evaluation
- budget

Using a manual can be more practical than just relying on everyone's memory. It is also convenient for new volunteers. There is no 'standard type' of manual because there are too many regional differences.

### ***A Consultation / Advisory Group to the Work group / Steering committee***

Most Cafés start up with the aid of a 'consultation group'. The consultation group is a constructive, critical group of people who together act as a 'think tank' and an 'advisory group' for the working party. In practice this group meets every 2 to 3 months. In the beginning, this can be more often.

The members come mostly from the regional care sector, not just from one town or institution. This is the most practical arrangement because it provides broad support. The members can also play an important role in telling persons with dementia and families about the Alzheimer Café. They are the ideal group to tell others about the Café. Ensure therefore that professional caregivers from all sectors are represented.

### ***Choice of café location***

For an Alzheimer Café the choice of location and ambiance are very important. Try to choose both a good psychological and physical location. By a 'psychologically good location', we mean that the guests feel comfortable, at home, in the Café. Take the example we referred to earlier, a nursing home might be a perfect place to hold a Café, except that it can be threatening to people who have just been diagnosed. Sometimes they don't want to be confronted in any way with people in the later stages of dementia.

A physically good location has characteristics such as safety, ease of access, access for disabled, sufficient parking and so on. Is the entrance in a dark alley, where people will feel unsafe? Is there a good transport connection from the station? Apart from the building, the room must meet certain requirements. The most important question is whether the room is right to create a convivial atmosphere.

Apart from the practical requirements that the room must meet, (see below) certain facilities are essential. These can vary from meeting to meeting. For example, for the discussion you can best use a *mobile (roving) microphone*, so that all participants are audible. A good sound-system installation will be required and perhaps a video screen. Think about what what equipment will be needed. For convenience make a checklist.

#### Practical requirements

- . Room size: is the room too big? Can it be subdivided?
- . Can tables and chairs be set out sensibly?
- . Can people see properly? Can the lights be operated independently?
- . Can everyone be heard? Is there noise from outside?

#### ***Offering refreshments?***

There is no question about this: refreshments must be available. It is usually best to arrange this with the manager of the location. Decide which drinks are always to be provided; only coffee and tea, or also juices, soft and alcoholic drinks? Are you going to provide the drinks yourself or use the on-site catering? This affects the costs. Are you going to let the visitors pay for any/all of the refreshments, or, only for alcoholic drinks? Will there be nibbles provided for table?

#### ***Planning the Meetings***

In the preparation phase, it is wise to agree the topics for at least the first three or four meetings. The speakers can be invited as early as possible, and any videos can be organized. Usually the speakers are prepared to appear, as a favour, or, for expenses only. Confirm everything in writing, and provide practical information such as the route to the Alzheimer Café and where to park.

Sometimes the opening of an Alzheimer Café is enhanced by a regional symposium or an information campaign about dementia for the wider public. Ensure that the date, time and location are the same as the regular meetings. It is then more likely that your guests will be able to come at this time in the future and it will avoid unnecessary confusion.

#### ***Contacts with the Press***

You will want the Café to become well known so that people come to it. Therefore it is wise to inform the local press about your plans at an early stage. Ask all the media for lists of copy deadlines. It can also be helpful to ring a newspaper and invite the editors to the first meetings of your Café.

Once you have made contact with the Press, they'll be more receptive when you inform them about another meeting. This can be important for free publicity. You can announce the meetings in regional and local papers, free newspapers, on cable TV,

or via regional television. You can also put up posters at the chemists, health centres, supermarkets and mobile shops.

### ***Becoming known to Care Organizations***

Care organizations, especially the local Alzheimer's Society and/or other dementia support groups, are important for referring people to your Alzheimer Café. Tell them about your existence. Apart from those mentioned above, also contact GP's, hospitals, social workers, church organizations and women's groups etc.

Send them a press notice or brochures, offer to talk to them or send them an article for their house magazine. If you know people personally, invite them directly to visit the Alzheimer Café.

### ***Acquiring new Café visitors or guests***

Press publicity and the contacts with the institutions increase the potential number of visitors. Even if people know of the existence of the Alzheimer Café, that does not mean that they will also come. Some come straightaway; others need coaxing.

First-time visitors often have a watchful approach. Sometimes their partner or carer comes alone to have a first look to taste the atmosphere, see whether it is of any interest for them and whether the person with dementia will feel at ease. In this context every meeting of an Alzheimer Café must prove itself anew. Staff at the Café give newcomers a special welcome and explain to them what happens.

They can explain that visitors are free to come and go. Ask them afterwards what they thought of the meeting, and to invite them for the next time.

### ***Word-of-Mouth Publicity***

Don't expect 80 visitors for the first meeting. Assume that not everyone knows about the existence of the Alzheimer Café. Publicity needs time to take effect. Knowledge of the Café will grow slowly. Keep contact with persons who have the potential to refer the café to others and try to get regular publicity. Once the Alzheimer Café is on the go, numbers will rise. Many people with dementia and carers who come to a meeting for the first time, do so on the recommendation of regulars or other frequent visitors of the Alzheimer Café. Professionals who are enthusiastic also encourage people to take part.

The best advertisement therefore, is happy customers. You can make use of this by including the experiences of visitors in the brochure, press release or flyer. And if you can use your local radio station, don't hesitate to invite 'a regular attendee' to tell his story. This usually generates plenty of response from the listeners. The internet is another medium to become known by.

## **5. The Alzheimer Café – learning along the way**

In this guideline manual a number of frequently raised topics have been covered which may be useful to those interested in starting an Alzheimer Café. Much more could be said - some of it anecdotal, some very practical. To have this on record, we regularly gather all sorts of ideas, cries from the heart, and pitfalls. We make this information available to interested parties. Hopefully this generates more reactions. In this way we continue to discuss and develop the concept. Some of the comments received to date include:

### ***1 Getting people with dementia to attend the Café***

It is not always easy to attract people with dementia to the Café, initially. We found it difficult to reach them. We went to the neurologist at the Memory Clinic and to several staff at a Day Centre and asked for their co-operation. They are in close regular contact with people in the earlier stages. We should have thought of going to these contacts earlier.

### ***2 Keep the Music Volume Down***

Have you ever been somewhere where the music was so loud that you could not hear yourself speak, or to a lecture that you could not hear because the microphone or sound-system was inadequate? It is also very irritating in an Alzheimer Café if the music is so loud that people find it hard to hear each other. For people with a hearing aid it is a problem anyway. Music is fine, but keep it in the background so it does not obstruct conversation.

### ***3 Starting new Alzheimer Cafes in a region***

People ask us regularly if we will set up an Alzheimer Café in other places in their region. This can happen sometimes, even if one Café has a regional role. How do we deal with this? [We explain that] the existing organization already requires a lot of energy and resources. [When there is enough demand and resources for another café, it can be set up.]

## **Conclusion**

### ***People with Dementia . . . .***

are at the centre of the Alzheimer Café. We have to try to remember this constantly and consistently.

It is our aim to include people with dementia in every way possible, in addition to them enjoying the time they spend at the café. If they have special opinions, skills or talents, plan on using them. For example, exhibiting someone's art work or letting them playing the piano at a café, or reciting a closing poem. Try to be conscious of valuing people. The challenge lies in always remaining conscious of this.

## Item 2 - Local survey/feedback form: pre-Alzheimer Café start

Name:  
 Address:  
 Telephone No.

Email:

	Yes	No
Do you like the idea of an Alzheimer Café?	_____	_____
Are you interested in attending as a:-		
core-member?	_____	_____
core-family?	_____	_____
coordinator or interviewer?	_____	_____
steering group member?	_____	_____
volunteer?	_____	_____

If 'volunteer', please indicate your first, second and third choices, thank you.

	First Choice	Second Choice	Third Choice
Organizing transport or being a Driver	_____	_____	_____
Venue Booking or standby care assistant	_____	_____	_____
Catering/ kitchen arrangements	_____	_____	_____
Technical Matters: Sound system/ computer	_____	_____	_____
Welcoming and Registration	_____	_____	_____
Socializing with new guests	_____	_____	_____
Setting up, and Clearing up	_____	_____	_____
Publicity, fundraising, advertising	_____	_____	_____
Other?	_____	_____	_____

Do you have suggestions for a venue with good accessibility and parking?

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Please make any other suggestions for starting a new Alzheimer Café

*Thank you for your participation, your responses are valuable to us.*

### **Item 3 - Organizational details for hosting an Alzheimer Café**

#### **To start with:**

- . Form a group of people interested in starting an Alzheimer Café (AC)
- . Survey the local area to see what interest there is (and relevant suggestions)
- . Form a steering group (of a size to be able to be productive)
- . Prepare a project plan and costings; seek funding and community support
- . Select fixed time for the AC (e.g. second Thursday of each month)
- . Select/book a venue (consider parking arrangements, disabled facilities, kitchen facilities, lighting, sound system etc.)
- . Meet with volunteers; give them any appropriate information or education or form volunteer groups - for example:
  - Transport and Drivers
  - Catering Arrangements (\*)
  - Venue Booking and Technical Matters
  - Publicity and Advertising
  - Setting up, welcoming and clearing up
  - Music and sound system, including microphones
  - Manning the information table and/or lending library
- . Choose suitable music (CD's, cassettes or 'live')
- . Meet with and prepare the Volunteers (perhaps also with a dementia course)
- . Prepare an annual programme of topics for presentations / interviews (with ideas for dates, speakers)
- . make arrangements for storing supplies (eg sign, tablecloths, candlesticks)

#### **For each meeting:**

- . make the required preparations for the interview or talk
- . arrange transport for guests requesting it
- . bring supplies needed (e.g. sign-in book, name labels, tablecloths, sign)
- . set up the venue
- . set out the literature table (well stocked and up-to-date)
- . set out the registration and comments books
- . coordinator or MC introduces the topic and speakers
- . speak with the speaker/interviewee afterwards
- . speak with volunteers afterwards
- . do a brief evaluation of the gathering
- . tidy the venue/ store supplies
  
- . make any extra preparations for the twice-yearly social gathering (e.g. live bands, musicians, performers, arrangements for a BBQ)

*\* Kitchen staff may require Hygiene and or Food Safety Certificates – some halls run their own courses.*

## Item 4 – Samples of ‘Annual AC programme of topics’

<b>Date</b>	<b>Topic</b>	<b>Speaker/interviewee</b>
Sept.	What is dementia/ how is it diagnosed	Doctor
Oct.	What happens to memory	Psychologist
Nov.	What happens at a Day Hospital	Day Hospital Manager
Dec.	Christmas social	Dance Band
Jan.	The range of emotions – what they’re for	Family therapist
Feb.	Fear and Anger	CPN
March	Communication	Interview family Carer
April	Stress	Interview family Carer
May	Hitting brick walls: Living with dementia	GP
June	Grieving and Guilt	Pastoral Care Worker
July	Summer social	Potluck set to Classical quintet
Aug.	break	-

<b>Date</b>	<b>Topic</b>	<b>Speaker/interviewee</b>
Sept.	What is dementia/ how is it diagnosed	Old Age Psychiatrist
Oct.	What happens to memory and other abilities	Admiral Nurse
Nov.	Breaking through denial	Panel of Family Carers
Dec.	Christmas social	Musician / Accordionist
Jan.	What help is available	Alzheimer Society representative
Feb.	Adjusting communication	Family Carer
March	Role of the GP in providing ongoing support	GP
April	Learning to talk about it to friends	Interview family Carer
May	Extra needs of people with dementia in hospital	Social worker
June	Grieving and Guilt	Bereavement counselor
July	Summer social	Musicians
Aug	break	-

<b>Date</b>	<b>Topic</b>	<b>Speaker/interviewee</b>
Sept.	What is dementia/ how is it diagnosed	GP
Oct.	What happens to memory and attention	Memory Clinic nurse
Nov.	What help is available	Outreach worker
Dec.	Christmas social	Dance Band
Jan.	Why is it so difficult to ask for/accept help?	Family therapist
Feb.	Emotions – especially Fear and Anger	CPN
March	Adapting vacations so they really are vacations	Dementia Vacation Specialist
April	What happens at the local Day Care Centre	Activities Therapist
May	Grieving and Guilt	Interview family member
June	How sensory perceptual difficulties affect behaviour and ideas to help compensate	Occupational Therapist
July	Social	BBQ
Aug	break	-

## Item 5 - Catering list: stock taking and order form (Sample)

To purchase for (Date) \_\_\_\_\_

Cater for (estimate number) \_\_\_\_\_ people

Item	number required	person responsible	other reminder
Biscuits			
Sandwiches			
Crisps / nibbles			
Other food items			
Fruit bowl			
Warm drinks			
tea			
coffee			
milk			
sugar			
Cold drinks/Juices			
soft drinks			
Alcohol			
Other			
Candles			
Serviettes			
Gifts E.g. Flowers . for speaker . interviewee . volunteer/s			
Items for special occasions:	Christmas decorations and seasonal snacks		

## Item 6 - Signing in sheet for guests (sample)

<b>Guest Book Form</b> Welcome to the Alzheimer Café UK, Farnborough, Date _____			
Name	Address	Tel No.	Role

## Comment book (sample)

<b>Your comments or impressions about the Café</b>	Date _____
We're interested in any of your thoughts or responses to attending the Café.	
Please note any comments and / or impressions:	
.....	
.....	
You may wish to remain anonymous, or give your name and contact information)	
.....	
<b>(name and contact information)</b>	

## Item 7 - Monthly AC Evaluation form (Sample)

**Alzheimer Café UK- monthly evaluation form Date:**

**Topic/theme:**

**Speaker:**

**Attendance information:**

C = Carers

FC = Former Carers

PWD = People with Dementia

V = Volunteer

P = Professionals

IO = Interested Others

N = Newcomers

Month	Total number	C	FC	PWD	V	P	IO	N

*(Numbers may not tally since some Former Carers act in the capacity of Volunteers)*

Any unexpected absences indicating that a person may need to be checked up on?

---

**Responses to the topic:**

**Participation in the discussion:**

**Responses from guests to the AC gathering as a whole:**

**Any hiccups / reminders for next time:**

Setting up:

Room layout:

Transport:

Guest speaker/s:

Family interviewed:

Catering:

Sound system:

Volunteer Manpower:

Music:

**Unexpected events** (things that need future planning or referring to others' attention):

**Comments re: improvements from previous sessions:**

**Miscellaneous remarks:**

## Item 8 - Interview questions for professionals (samples)

### Sample interview questions: for a 'Carers Support Worker'

#### **Q1. Can you explain what your job as a Carers Support Worker entails?**

- . listening to the Carers and their own experiences and difficulties at home, especially the things they need to do, but may need some help with
- . information about locally/national help, and how to make time for themselves
- . signposting to other services or groups. E.g., Adult Services and what they can offer, (assessments for the person in need and the Carer, respite care, day care, sitting services, occupational therapy, sensory services, financial assessment and benefits team, referral for meals on wheels, information or help to complete the Dept. of Work and Pension's forms for financial benefits.

#### **Q2. How do most Carers/ families get referred to you?**

- . GP practices via the GP's, District Nurses, Community Psychiatric Nurses and Health Visitors and the social workers or Care Managers. However, anyone can refer directly though to the Carers Support Service including the Carers themselves, and they often do.

#### **Q3. What other types of support exist?**

- . there are types of support specifically for Carers
- . locally there are 'Carers Information days' about topics which have been designed around what Carers ask for; continence advice, benefits, having days for relaxation, moving and handling, legal matters etc.
- . there are various helpline numbers and support groups and there is a good range of literature too
- . there are a variety of groups, like Alzheimer Society groups, and other Charities who offer different types of practical, social, cultural, emotional, and spiritual support.

#### **Q4. What are the most difficult situations you encounter?**

They falls into two groups; Carers who need help but refuse it and Carers who need help and want it but can't get adequate help.

#### **Q5. What advice would you have for a Carer of someone who is newly diagnosed?**

The best guidance I can give to Carers, and families, is to get the information they need, to seek out the help and support they need, to ask questions when unsure, to express their own feelings, and to encourage them to help the person with dementia to express their emotions too. When things are out in the open it more possible to learn from, and support each other.

**Sample interview questions: for a Psychologist**

- Q1. You're a psychologist working for \_\_\_\_\_. Can you tell us what your job entails?
- Q2. How are people referred to you?
- Q3. What are the most common types of difficulties you deal with?
- Q4. What kind of help/advice are you able to offer people?  
(Describe services provided both for the person with dementia and their carers.)
- Q5. What types of circumstances lead people to admit that 'it's getting a bit much'?  
Is there a common thread to the difficulties they're having?
- Q6. Do you observe that most people actually wait until it's way too much for them  
and they're in a crisis?
- Q7. What holds people back from admitting it's getting a bit much?
- Q8. What advice would you have for carers about the best time to ask for help?

**Sample interview questions: for the Head Nurse at a Day Hospital**

- Q1. You work with people of many ages and with many types of illnesses, also  
dementing illnesses. Can you explain what happens at a Day Hospital?
- Q2. What is the difference between a Day Hospital, Day Care and Respite Care?
- Q3. How are people referred to a Day Hospital?
- Q4. What is your specific role there? What other staff work there?
- Q5. What other services, organisations and agencies are you linked with?
- Q6. What is considered 'good care' in your service? What activities do you offer?  
Are family members encouraged to visit people at the Day Hospital to see how  
they are managing in that setting compared to the home setting?
- Q7. What length of time do most people attend the Day Hospital for?

**Sample interview questions : for a Community Psychiatric Nurse**

- Q1. Please explain what your work involves. What do you do in a typical day?
- Q2. How do you come in contact with families and persons with dementia?  
Does it usually require a crisis, or are you asked to visit before a situation becomes serious or unmanageable?
- Q3. How often and how long do you visit most families?
- Q4. Family members and the person with dementia may have different needs.  
How do you balance your time and helping?
- Q5. When you see that a family carer is becoming overwhelmed and run-down by their caring, how do you broach this with them?
- Q6. How do you link with other nurses and professionals if people need help with physical conditions like leg-ulcers and enhanced nutrition?
- Q7. Would your work be different if people were diagnosed earlier and referred to you immediately for regular visits?

**Sample interview questions: family therapist with an assessment service**

- Q1. What does your work entail? What kind of help/ advice can you offer families?
- Q2. How are people referred to you? Can anyone request to see you or is it only for families with particular types of needs, or in a crisis-situation?
- Q3. Do you see many families where a person has early-onset dementia?
- Q4. What are the biggest fears families have about seeing you?
- Q5. What are the most common types of difficulties you deal with?
- Q6. What questions are you asked most often?
- Q7. What are the most difficult situations you encounter?
- Q8. How do you balance the needs of everyone in the family?
- Q9. What advice do you have for families, in general, when one member has dementia?

### **Sample interview questions: for a GP**

- Q1. How many people would you see each year in your practice, with concerns about their memory or thinking ability?
- Q2. Is it usually the person with possible dementia, or their partner/ family member who contacts you?
- Q3. In your experience, do most of people come with their concerns right away, or have they waited a long while, perhaps even for a crisis, to get the courage to come in?
- Q4. How do you start to distinguish between people who are worried about their memories because they are making the kinds of mistakes that we all make, and those who are having genuine ongoing difficulties with their memory?

Some Alzheimer Café guests have related that their family member with dementia was reluctant to go to see the doctor. In desperation, they contacted their GP privately, to explain that they need to find an excuse to bring the person in for an appointment. There are varied responses; some GPs were co-operative, some refused to speak with family members, some were reluctant to have the family members present or to pass on relevant information out of 'privacy' concerns. The Nuffield Council on Bioethics report "Dementia; ethical issues", also raised the lack of GP assistance to family carers as a concern.

- Q5. What is the approach taken in the practice you work for?
- Q6. How do you, and how honestly, talk to a person about difficulties they're having with their memory and cognition? What kind of words and language do you use?
- Q7. What is that most difficult thing for you as a doctor, in doing this initial work with people with dementia?
- Q8. How do you see your role, in terms of offering long-term, supportive care for both people with dementia, their carers and families?
- Q9. Is there anyone at your practise who has a 'special interest in dementia', who you can refer people on to?
- Q10. Do you have any personal family experience of dementia?

## **Item 9 - Use of the Alzheimer Café UK logo**

We encourage any group of people who are able to, to host an Alzheimer Café.

Permission to use the 'Alzheimer Café UK' logo will be given, free of charge, to any group adhering to the original AC philosophy and concept (\*), and who are guided by the published quality control criteria, (as opposed to other types of cafés with similar names, but who are using a café as a social setting or following an alternative model).

For permission to use the AC logo, and other artwork for banners and signs, please contact the AC UK Trustees via, The Alzheimer Café Charity website (see contact information on the front).

*\* The 'Alzheimer Café' concept has European and UK patents.*

### **Neon AC Signs**

AC Signs are not mandatory, but most groups have found them very useful as focal and discussion points about the purpose of the AC, i.e. to 'name the pain' and lose fear of it. Some AC groups have used local sign-posting manufacturers to make their 'AC sign'. More recently, the Trustees have been experimenting with a low-cost version made from the casing of a neon light, and a laser etched plastics that look like real neon signs. If you are interested in purchasing one, please contact the AC charity Trustees via the website.

### **The logo on T-shirts**

T-shirts with the AC logo on it have been useful both for advertising the Alzheimer Café locally, and when worn by volunteers and coordinators at ACs to help guests identify them.

Over the years, as seasons and fashions changes, T-shirts have been printed up in different styles and colours - some with the logo just on the front, others with the logo both on the front and back.

You can usually get a reasonable discount when you purchase T-shirts in bulk and it can be a good idea to link up with another AC local to you to do this to secure an even greater discount.

## Item 10 - The 33 quality control criteria for Alzheimer Cafés

*Translation of 'Kwaliteits criteria for Alzheimer Cafés' (developed in 2005)  
Published by Alzheimer Nederland; translated with permission, by GMM Jones, May, 2007*

### **Abbreviations:**

AC = Alzheimer Café

ACs = Alzheimer Cafés

AN = Alzheimer Nederland = the Dutch Alzheimer Society (national)

QCC = Quality control criteria

SEP = Self evaluation procedure

### **Background to the Quality Control Criteria**

In 2005, a set of 33 Quality Control Criteria (QCC) for ACs were developed as part of the ongoing effort to establish a way of keeping the 'core elements of the AC vision' whilst still allowing given groups to make the adaptations necessary in their own areas.

These criteria were derived after 10 years of experience with a rapidly growing number of ACs, and the help of 250 volunteers who carefully considered the content.

### **The 33 Quality Control Criteria**

#### **A The vision and goals**

An Alzheimer Café is a safe, low threshold, pleasant environment for persons with dementia, their family, friends or neighbours, in the presence of a variety of health care professionals and members of the Alzheimer's Society or other local dementia support group. It offers support and information and works towards achieving more openness about dementia.

#### **B The guests**

1. A minimum of 5% of those present at an AC are persons with dementia.
2. Persons with dementia and their family are visible during AC gatherings.
3. Those present at an AC also include local caregiving professionals with a variety of backgrounds (a minimum of 3 types). They have local-regional area knowledge and social knowledge about the impact of dementia.
4. Caregiving professionals who participate at an AC answer questions and respond to the problems of persons with dementia and their families.

### **C The Leadership for the themed-discussions**

5. The themed discussions are in the hands of a consistent person or 'duo'; to ensure familiarity and consistency for the guests.
6. The themed discussions demonstrate multi-disciplinary care-knowledge about dementia.
7. The themed discussions demonstrate practical experience in the interactions with and the guidance of persons with dementia and their family.
8. The themed discussions are a role model for interacting with and communicating with persons with dementia.

### **D Content of an AC annual programme**

9. The annual programme is already set out, in large measure, at the start of each year.
10. The programme follows a year-cycle wherein the themes reflect the dementia process.
11. During AC meetings, psycho-social aspects pertaining to dementia receive more attention than the medical aspects of dementia.
12. The educational part of the ACs, primarily takes place in the form of interviews with professionals, persons with dementia and their families, conducted by the discussion leader.
13. The discussion of the evening is usually divided into five half- hour blocks.
  - half hour socialization with the AC guests
  - half hour interview or interactive talk
  - half hour interlude with music
  - half hour session for further questions from the guests
  - half hour further socialization
14. At least 70% of the professionals who are used as guest-speakers, must work in the local region.

### **E Organisation of AC meetings**

15. An AC has a minimum of 10 yearly meetings.
16. The meetings are held on a fixed day of each month; e.g. 1st Tues. of each month.
17. There is a good sound-system in the room with microphones for the discussion leader, the person being interviewed, and others in the room in the event they wish to ask questions.
18. During the 'non-discussion parts' of the evening there is music playing.
19. An 'Information Table' is present in the room with a wide assortment of printed information and material [from the Alzheimer's Society and other reputable, known sources], aimed at the average person who would attend an AC.
20. The Information Table is manned by one or more volunteers from the Alzheimer's Society, or other local dementia support group.

21. The room chosen to hold an AC in, is an environment which is as non-threatening as possible (low threshold) for persons in the beginning stages of dementia or memory difficulties. A nursing home is not the most appropriate place.
22. Attending an AC is free-of-charge for guests. No donations are asked for during the AC.
23. Volunteers greet and attend to guests on arrival, on leaving, and if they are sad, restless, or don't know what to do with the information communicated.
24. An AC is organised together with the local division of the Alzheimer's Society or other local dementia support group, and volunteers from a minimum of 3 different professional sectors (e.g. care assistants, nurses, supportive family carers, pastoral care workers, carer support workers, social workers, occupational therapists, physiotherapists, speech and language therapists, psychologists, doctors).
25. An AC is organised by a steering committee or workgroup, wherein all persons, specified in point 24, actively participate. [This committee comprises of a fixed number of persons who organise the meetings.]
26. A designated contact person at the Alzheimer's Society Branch or other local dementia support group will be responsible to appoint a fixed contact person, local to an AC, on behalf of the group, to the steering committee.
27. The steering committee of an AC is responsible for the quality of an AC and accepts responsibility for enforcing the QCC.
28. The logo of the Alzheimer's Society or other local dementia support group is clearly visible in all information about the AC, Public Relations events, in the annual AC programme, and in general.
29. The steering committee undertakes at least 2 activities per year to attract regional press publicity to promote the AC.

#### **F Evaluation of the meetings**

30. Guests at an AC are always invited to evaluate the AC in verbal or written form [e.g. in a comments book].
31. An estimate of the numbers of guests are made at each meeting [persons with dementia, family members, friends, caregivers, others]
32. An AC steering committee evaluates the atmosphere, content, discussions and Information Table at the AC, at least once every two or three years.
33. The steering committee of an AC evaluates the AC each year according to the QCC criteria and sends their evaluation in to the appropriate person at the AC.

## Related references

**Alzheimer Café UK - web-site** - [www.alzheimercafe.co.uk](http://www.alzheimercafe.co.uk)

### **Articles /chapters about Alzheimer Cafés:**

Jones G, Redwood K, Harding JW, Bullock P (2008) *Comparing UK and Dutch Alzheimer Cafes against the new Quality Control Criteria*. J of Dementia Care16:1 Jan/Feb

Miesen B, Jones G (2004) *The Alzheimer Café Concept: A response to the trauma, drama and tragedy of dementia* In: Caregiving in Dementia, vol 3, (GMM Jones and BML Miesen: Eds.) Brunner-Routledge, London, ISBN 1-58391-189-8

Thompson A (2006) *Qualitative evaluation of an Alzheimer Café as an ongoing supportive group intervention* In: Caregiving in Dementia, Vol. 4, (BML Miesen and GMM Jones: Eds.) Routledge, London. ISBN 1-58391-191-X

**Translated documents** (these are included in this Introductory Information Pack)  
'How to set up an Alzheimer Café', Bère Miesen and Marco Blom

Evaluating the 'year programmes' of 68 Dutch Alzheimer Cafés against the new Quality Control Criteria. '*Kwaliteits criteria for Alzheimer Cafés*' (developed in 2005) *Published by Alzheimer Nederland*. [Translated by: Gemma MM Jones, 22 May, 2007]

### **Books related to Dementia care and other forms of group support**

Miesen, BML, and GMM Jones (Eds), 2006. Vol. 4 Care-giving in Dementia. Routledge, London (pp 436)

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Jones, GMM, and BML Miesen (Eds), 1992. Vol. 1 Care-giving in Dementia. Routledge -Tavistock, London (pp 481)

Miesen BML (1999) *Dementia in Close Up*, [translated by GMM Jones], Routledge, Tavistock, London. ISBN 0-415-12885-4