

Yearly programme evaluation of 68 Dutch Alzheimer Cafés against the new European Quality Control Criteria

Translated by: Gemma MM Jones, 22 May, 2007

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Abbreviations:

AC/s = Alzheimer Café/s

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

QCC = Quality control criteria

SEP = Self Evaluation Procedure

Some background information by the translator

In the Netherlands; the 103 Alzheimer Cafés (ACs) are very much becoming a ‘national phenomenon’. They operate under the umbrella of Alzheimer National (AN). AN has members on AC steering committees. It helps to advertise ACs in its newsletters and refers enquirers to their nearest AC. Two day ‘AC Training Session’s are conducted by the Dutch Alzheimer Society to train Interviewers and Discussion Leaders how host new ACs, or, to serve as refresher days. AN also provides new groups with ‘start-up’ advice and seed-funding.

In the UK, the Alzheimer Cafes have developed largely ‘piecemeal’, by people who have not had much opportunity to access special training. Some ACs have started through efforts independent of local or regional Alzheimer Society personnel.

The [UK] Alzheimer Society hosted a single Teaching Day in 2002, to introduce the AC concept to a small number of persons interested in it. It did not, at that time, take on leadership and development of ACs, as part of its own ‘service-product’ remit or vision. In 2006, the UK Alzheimer Society decided to promote and support the development of ACs, as first reflected in its advertising for new Regional Managers.

Currently, a further mini-conference about ‘How to run an Alzheimer Cafe’ is being planned, so that the AC vision can be shared, developed and supported in a consistent way.

The current number of ACs in the UK is unknown to me, but, from various contacts it seems there are about 20 operating throughout the country; and, an encouraging number are in the planning stages.

Although the AC is a patented concept, any group can set one up providing they adhere to the original philosophy of the ACs, which are reflected in the 33 QCC. Start-up information can be obtained from Kandy Redwood. The logo and other materials are for use by those groups who are trying to fulfill these criteria and have annual programmes which adhere to the majority of the ‘AC themes’ further described hereafter.

Some groups are using the name “Alzheimer Café although they are not using the ‘themed topics’ for interactive discussion, and thus not really adhering to the original philosophy and purpose of the AC concept. They are operating primarily as supportive, pleasant social gatherings.

It is the utilization of these ‘themes, (which, unlike other medical information about dementia, are not easy to obtain information about, and are challenging to discuss), which allows ACs to function

as a type of 'low-threshold group therapy'. There is no doubt that there is a great need for 'safe, supportive, social gatherings', but the remit of ACs goes beyond that.

Where groups are not able to operate to fulfill the criteria for an AC, they are asked not to call their group an 'Alzheimer Café' but something else, so that the different purposes are not confused.

In reading this report, it is important to know that persons with dementia are diagnosed in the Netherlands, on average, 2 years earlier than those in the UK. In terms of the 'average figures' presented below, persons with dementia at Dutch ACs have better verbal abilities and participate in both interviews and discussions more than their counterparts in the UK.

The 33 European AC 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 concept' visible whilst still allowing given groups to make the adaptations necessary in their areas.

These QCC were derived from 10 years of experience with the rapid growth of ACs nationally, and with the help of 250 volunteers who carefully considered the essential content.

Evaluating the Dutch Alzheimer Cafés

By July 2006 there were 103 AC's in the Netherlands.

AN decided it was time to evaluate, for the first time ever, Dutch ACs against these 33 QCC.

This was done via a 'Self Evaluation Procedure' (SEP), for the time period of 2005-2006. The cut-off date for returning replies was Oct. 2006, so that analysis could get underway.

Sixty-eight ACs (66% of existing ACs), returned SEPs by this date. Other replies continued to be returned, but too late to be part of this analysis. Some ACs were not yet finished holding their yearly AC programme, and so felt unable to respond to an evaluation of their annual efforts. Other ACs were just starting up and did not have enough information to report on.

The goal of the SEPs was to find out 'What existing cafes do well?' and 'What could be improved?' This evaluation was not initiated because of signals that the ACs were not doing well. To the contrary, AN wanted to use the evaluation of the new QCC to further stimulate good and best practice.

Presentation of the findings of this QCC study

On Nov. 2nd, 2006, the findings of this study were formally presented to the organizers and volunteers of the ACs at a special meeting arranged by AN.

Summary of the Evaluation Survey findings of 68 ACs against the new QCCs and resultant recommendations

For the ease of readers, both ‘findings’ and ‘recommendations’ have been provided in Sections A to F, which list the 33 QCC by category.

A The vision and goals

The 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 local Alzheimer Support group] . It offers support and information and works towards achieving more openness about dementia.

Evaluation Survey Findings for section A

Agreement on this definition of AC purpose. No recommendations.

B The AC guests

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

Evaluation Survey Findings for section B

9% of persons visiting the ACs are persons with dementia
50% are family members
19% are volunteer helpers
22% are involved in another capacity

Attendance at the ACs drops as the season progresses [in the winter months].
ACs start with an average of 43 attendees, and this drops to an average of 31, with 37 being the overall average participating annually.

On the basis of the mean responses to this evaluation, and extrapolating to these values for all 103 Cafes, 3000 persons with dementia and 16,500 family members of persons with dementia participate in ACs in the Netherlands.

12% of all interviews at the ACs were with persons with dementia

24% of all interviews were with a family member
51% of all ACs recorded that persons with dementia participated in the questions or dialogue at the AC

88% of ACs had at least 3 different types of health care professionals present
85% of AC's saw volunteer helpers participating in responses and reactions to questions

Recommendations:

- extra attention for keeping the AC 'low threshold' and easy to join for persons with dementia
- extra attention for the 'surplus value' of interviewing persons with dementia in the AC, and for techniques to help prepare persons to be interviewed
- extra attention for the 'surplus value' of making persons with dementia and their families known to the public and the caregivers in the region
- discussion about the overall impact of the ACs. 2% of the target group is being reached per year. Is that enough? How many persons with dementia and their families is it realistic and possible to reach?
- updating the evaluation forms of ACs to more accurately record the different categories of attendees
- discuss with volunteers the best way to record the various types of attendees
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C The Leadership for the themed-discussions

5. The themed discussions are in the hands of a consistent MC-type person or 'duo'; to ensure familiarity and continuity and familiarity for the guests (attendees).
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.

Evaluation Survey Findings for section C

- 76% of all ACs had a consistent 'duo'
- 93% discussion of the themes demonstrated multi-[health care] disciplinary knowledge and input
- 94% of discussions demonstrated practical experience with interactions and support
- 83% of discussion demonstrated good 'role modelling' of interactions

Recommendations:

- extra attention for the continuity of the discussion leaders.
- what are the reasons why some ACs don't work with 'duos'?
- isn't it necessary to work with a duo, or, is it sometimes not helpful to work with a duo?

- what do other ACs do to reduce the vulnerability of, and increase the work-capacity of a single discussion leader?

D Content of the 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 chosen themes reflect the dementia process.

Original Dutch AC Theme topics, which follow the dementia process	Additional parallel topics piloted by the Farnborough (UK) AC since 2001
What’s the matter? How is dementia diagnosed	Living with dementia, after hitting the brick wall of the diagnosis and breaking through denial
How does memory work and what happens in dementia?	The range and purpose of human emotions; Those elicited by: not knowing, getting a diagnosis, looking for a way forward, <u>grieving for changes along the way</u>
It’s getting a bit much: feelings of powerless and increasing communication difficulties. What kind of help is there?	Anger and Fear: the lion emotions Why can they get out of control? How to understand them better.
Who can I turn to for help? May I say I need help? [Where, When, How to start to get help]	The purpose of communication and the range of communication options. Which are used most/ least?
Day care / residential care How is the decision made? How does it affect everyone involved?	Understanding the grieving process. Understanding different types of guilt. Hold a ‘Guilt competition’. Grieving and guilt as separate processes. How guilt can delay grieving. How to shake
How do I go on now? How do people work through their grief and try to go on with life?	Stress; what is it? How can it sneak up on you unawares? Ways of coping with it
	Other topics: -Why is it so difficult to break through denial sometimes? - Understanding behaviour change in light of visuoperceptual changes in dementia. - Improving the environment to aid vision - How does one tell whether ‘mistakes’ are due to normal aging or something else?

- 11 During the AC meetings, psycho-social aspects 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 divided into five blocks of a half hour.
 - half hour socialization with the AC guests
 - half hour interview
 - 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.

Evaluation Survey Findings for section D

- 87% of ACs had formalized programmes of year's topics ready starting each new AC season
- 68% of ACs follow that cycle of year themes which match the dementia process (listed above)
- 80% of ACs place more emphasis on psychosocial aspects than medical aspects of discussion
- 69% of interviews are with/done by health care professionals
- 7% of interviews are of a person with dementia
- 21% of interviews are with a family member
- 82% of ACs portion the timings at the Café into 30 minute portions
 - (eg. 30 mins. Socializing with refreshments
 - 30 mins. interview or talk
 - 30 mins. socializing and refreshments
 - 30 mins. questioning about interview and additional discussion
 - 30 mins. socializing and refreshments)
- 76% of ACs use guest speakers from their own region

Recommendations:

- Uniformity between ACs is relatively large. A small number of ACs are departing from the criteria. It would be good to emphasize the 'content arguments' for the choice of the QCC at training days for discussion leaders, and during other times of contact with discussion leaders.
- Extra attention for the importance of following the themes of the dementia process during the annual cycle of the AC. Is this really necessary? What are the reasons for not doing so?
- The visibility and participation of persons with dementia at ACs is important. The surplus value to AC attendees, of an interview with a family member or a person with dementia, is worth discussing during the Training Days for discussion leaders and volunteers

E Organization of the 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 Society and other 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 Society.
- 21 The room chosen to hold the AC in, is in an environment which is as non-threatening (low threshold) as possible for persons in the beginning stages of dementia or memory difficulties. Residential and nursing home settings are not the location of first choice.
- 22 Attending an AC is free-of-charge for guests. No donations are asking for during the AC meeting.
- 23 Volunteers greet and attend to guests on arrival, on leaving, and if they are sad, restless, or are having difficulty with some of the information being discussed.
- 24 A given AC is organized in conjunction with the regional division of the Alzheimer society and volunteers from a minimum of 3 different professional sectors (care assistants, nurses, supportive family carers, pastoral care workers, Carer support workers, social workers, OTs, physiotherapists, speech and language therapists, psychologists, doctors).
- 25 An AC is organized by a steering committee or workgroup, wherein all persons [specified in item 24], actively participate. [This committee comprises a fixed number of persons who organize the meetings.]
- 26 A designated contact person at the Alzheimer Society will be responsible to appoint a fixed contact person, local to the AC, on behalf of the AS, to the steering committee.
- 27 The steering committee of an AC is responsible for the quality of the AC and accepts responsibility for enforcing the QCC.
- 28 In PR and information about the AC, in the programme and in general, the logo of the Alzheimer Society is clearly visible.
- 29 The steering committee undertakes at least 2 activities per year to attract regional press publicity to promote the AC.

Evaluation Survey Findings for section E

- 72% of ACs hold more 10 or more meetings per year
- 86% of AC meetings saw the sound system working satisfactorily
- 66% of ACs meetings had 'live music'
- 29% ACs had music on CDs
- 97% of ACs had an 'Information Table'
- 80% of ACs had special information about the Season's theme topics and programme
- 94% of meetings had a representative of the local Alzheimer Society Branch member

manning the Information Table

- 46% of ACs were held at Residential or Nursing Care Homes
 - ACs held in these Care settings had an average of 7% attendees with dementia
ACs held in other locations had 11% persons with dementia
 - 56% of ACs do not ask for financial contributions for their expenses
 - in 96% of ACs, Volunteers greet persons on arrival, leaving, and care for them if they become sad, restless or don't know what to do with the information
 - 78% of AC workgroups (steering committees) are organized in cooperation with the local Alzheimer Society Branch and representatives of at least 3 other health care professional sectors (caregiving, nursing, SW, psychologists, OT, speech and language or physiotherapists, family support workers, outreach workers, home care workers, pastoral care workers or chaplains)
 - 71% of the organizing partners actively participates in the work group
 - 96% of ACs have an permanent 'contact person' appointed by the local Alzheimer Society Branch group
 - 84% of ACs had folders and the logo of the Dutch Alzheimer Society visible
 - 82% of ACs hold/ are involved in, at least 2 activities per year to get the attention of the local press
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- The 'professional input' listed as being 'most missed' by those organizing ACs, were Pastoral Care Workers, home care workers, local hospital staff, day care centre staff, nursing home staff and the GP.

Recommendations:

- extra attention could be given to inviting and working with Pastoral Care Workers and other professionals who have been less present at the ACS. This could be done at the National Annual Meeting.
- extra attention could be given to 'press publicity for ACs' at the National Annual Meeting.
- the use of music at the ACs is intended to make such evenings pleasant, not just informative. It helps to generate amusement and frame the different sections of the evening.
Is it too difficult for some ACs to organize music, or do they not find it important?

F Evaluation of the meetings

30 Guests at the AC are always invited to freely evaluate the AC in verbal or written Form [comments book].

31 An estimate of the numbers of guests are made at each meeting [persons with dementia, family members, friends, caregivers, others]

32 The 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 the AC evaluates the AC each year according to the QCC criteria and sends their evaluation in to the appropriate person at the AS.

Evaluation Survey Findings for section F

- 75% of ACs evaluate each AC evening. This is done either through asking for individual or collective feedback, or through providing a comment book or evaluation forms
- 66% of ACs have already evaluated the functioning of their AC in a previous year
- 10% of ACs have only started evaluating their ACS as a result of this Evaluation Survey, which now constitutes their first evaluation of their AC, and which they can build upon
- 2 ACs said that they did not wish to evaluate their AC, but did fill out the Evaluation Survey questions.
- It is possible that among the ACs who did not participate in this first Evaluation Study of ACs, there are others who see 'evaluating' as a tiresome chore

Recommendations:

At the next National Meeting, discuss ways to make evaluating ACs easier and more informative for those of the Dutch Alzheimer Society and their partners in the AC steering committees.

Summary conclusions about the first Evaluation Survey of ACs

The carrying capacity to achieve the vision and goals of the Alzheimer Café concept is large: the ACs are virtually unanimous in supporting the vision and goals in so far this evaluation has shown. These study results bid us to anchor the vision and goals of the AC concept in the existing Quality Control Criteria, unchanged.

Although 35% of ACs are well above the suggested minimum of ensuring that at least 5% of persons with dementia are present, a few ACS have never had a person with dementia present.

In 51% of AC evenings persons with dementia are visible, participate in questions and discussions and even are sometimes interviewed. It would be interesting to see if it is possible to interview persons with dementia more often at Cafés.

Attendance at ACs dwindles somewhat throughout the year.

The help of the volunteers is enormous: they are present and active at 90% of meetings and also respond to questions from other attendees at the Café.

The steering committees are positive about the discussion leadership at ACs. The discussion leaders are knowledgeable, experienced and role model good interactive behaviour to others at the Cafés. 25% of ACs do not have a fixed 'duo' who lead the discussions. It will be important to see whether and by how much, this affects the continuity of the ACs.

80% of ACs fulfill the quality control criteria with regard to the content of the year programme. The uniformity and methods of the ACs is large, with one notable exception. 32% of ACs do not have yearly programme themes that follows the development of the dementia process.

Most ACs hold more than the recommended 10 meetings annually; a few hold less than 10.

Most ACs are organized in accordance with the QCC for steering groups. Apparently, the QCC are well supported and readily achievable.

Half of all ACs are located in 'care homes'. The preferred choice would be for more 'low threshold' locations, especially for persons in the early stages of dementia or memory difficulties. Changing locations is mostly a costly, time consuming and expensive enterprise. It will be interesting to see if, in a few years, less ACs are located in care home settings.

It is very positive that about 80% of regional Alzheimer Society branch groups work together with at least 3 other organizations. The Alzheimer Society functions as a 'continuity factor' in almost all AC steering committees. The 'partner' listed as most missed at ACs, are pastoral care workers. Their increased involvement is looked forward to.

Information Tables are present at ACs, however, at times some of the information, or numbers of items are not sufficient for the purpose of, or the number of attendees.

Music is thought to be an important aspect of the vast majority of ACs. Why a minority of ACs do not use it needs investigating.

82% of ACs hold successful events which are reported in the regional press. However, in the 'Client Panels' held by the National Dementia Programme, it appears that a large number of persons are still unaware of their Local Alzheimer Café. This is reason to see if ongoing, local AC contacts with the press, can be improved.

66% of ACs have held their own evaluations, even before this Evaluation Survey. The question remains, how often should yearly AC evaluations such as this current survey be done, to encourage those that do not yet evaluate, to do so?