

## **Ideas to help start an AC - Some frequently asked questions (FAQ's)**

### **What organisational details relate to hosting an AC ?**

#### **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
  - . form a fixed steering group
  - . prepare project plan and costings; seek funding and community support
  - . select fixed time for AC (e.g., second Thursday of each month)
  - . select/book suitable venue (e.g. known location, parking, disabled facilities, kitchen)
  - . find volunteers - to socialize with guests, and help with specific functions
  - . choose suitable music (CD's, cassettes or 'live')
  - . meet with and prepare the volunteers (arrange a dementia course for them?)
- Arrange necessary security checks, and training such as Kitchen Hygiene Certificates)
- . prepare an annual programme of themed presentations / interviews
  - . choose an AC coordinator and interviewer
  - . make arrangements for storing supplies (e.g., AC signs, tablecloths, candlesticks...)

#### **For each AC gathering:**

- . send out flyer about the current AC topic, to local dementia services and providers
- . prepare for the interview or talk (e.g. select questions, practise with interviewee)
- . arrange the needed supplies (e.g., food, tablecloths, sign), transport
- . set up the venue, welcome/registration desk/ Comments book
- . set out the literature table (well stocked and up-to-date)
- . meet and mingle with the AC guests
- . coordinator or MC introduces the topic, Interviewer, and speaker/s
- . encourage participation in the interactive talk and/or 'question and answer session'
- . speak with the guests, also about their responses to the theme, or about specific queries
- . debrief with the speaker/interviewee afterwards
- . thank the volunteers afterwards and get their feedback
- . briefly evaluate the AC gathering (e.g. topic, number of guests, hiccups, memos)
- . tidy the venue/ store supplies
- . make extra preparations for the twice-yearly social gatherings (e.g., decorations, live bands, musicians, performers, arrangements for a BBQ)

#### **Do guests tire of the themes being repeated annually?**

Perhaps some guests do tire of the themes. Since they are announced beforehand, they can choose whether to attend or not. However, there are many guests, like those at the Farnborough AC, who have attended for over ten years. They say that though the themes are repeated annually, there is always variation in the interviewees and the talks. Also - that they hear different things each time, as their own situation, experience or thoughts change.

#### **What Levels and types of support are built into an AC (adapated from Jones, 2010)**

ACs are set up and run by a steering committee. An AC coordinator and Interviewer, function like a familiar 'duo', and ensure the running of the AC. Besides that there is:

- The role-modelling of positive language, accurate concepts, an accepting attitude, sensitive communication, and warm interactions
- Discussion of dementia grounded in a philosophy and vision of dementia care that values people, albeit people with an illness, and promotes their inclusion and participation in life, including the expression of emotion/s
- The presence of a variety of knowledgeable health and social care professionals (e.g. Carer Support Workers, Day Care and Day Hospital staff, Caregiving staff from the local Care Homes, nurses from acute care hospitals, GPs, pastoral care workers, psychologists, social workers, occupational therapists)
- 'Core families' - experienced in attending the AC, who can talk about dementia openly

- the presence of regular volunteers, and representatives from the local Alzheimer's Support Groups and services, who can identify familiar guests and newcomers, introduce them to other guests and 'core families', and speak openly with them
- information leaflets about local services are on display
- Alzheimer society information literature is available (also at some ACs, a 'lending library')

### **What types of people are AC Coordinators and Interviewers?**

A wide variety of people, experienced in dementia care have become AC Coordinators and Interviewers. To date they include - psychologists, counsellors, nurses (hospital based, community, psychiatric, clinical nurse tutors), Carer Support workers, doctors, social workers, dementia service managers, Alzheimer Society, and other related support-group branch representatives, Managers of care homes and dementia care services. (There is a 'two-day course for AC Coordinators and Interviewers' in the Netherlands, and now also in the UK.)

### **What do the volunteers do?**

There are many types of people who volunteer at ACs. They include young and old, with and without experience of dementia, long-term and temporary volunteers, e.g. people doing the service part of their 'Duke of Edinburgh', or other award. Mostly, they speak with the guests and help serve refreshments, but there are also specific tasks that need doing, such as:

- . helping with the purchase and preparation of refreshments
- . setting up the venue (AC signs, tables, chairs, tablecloths, candles, plates of nibbles)
- . setting out the literature table (well stocked and up-to-date)
- . welcoming guests, registration and making nametags
- . assisting in the kitchen area - making coffee and tea
- . manning the 'information table'
- . operating the sound system and putting on music CDs
- . accompanying and seating guests at tables, asking what they'd like to drink
- . tidying the venue, storing supplies
- . extra preparations for the twice-yearly social gatherings (e.g., decorations, live bands, musicians, performers, arrangements for a BBQ)
- . publicity and advertising, and distributing posters and brochures about the AC
- . helping to arrange transport for guests who cannot drive
- . fundraising

### **The best location for ACs?**

ACs have been held in a wide variety of places - city halls, hotels, church halls, libraries and Day Care Centres. Although some are also held in residential and nursing care home settings and Day Care Centres, these are not ideal locations – because people with dementia who are newly diagnosed, and those still somewhat in denial of the diagnosis, are likely to be wary or fearful

### **Evaluating ACs?**

ACs are evaluated in various ways – keeping signing-in information, asking guests to write in a Comments Book', filling in a summary sheet after each gathering, and by filling in a 'voluntary Annual AC self-evaluation form' comparing the AC to the agreed quality control criteria (Meerveld, 2006; Jones et al, 2007). Of course the other qualitative indicators include getting a sense of the ambience, participation, individual responses, and the continued attendance of guests.

### **What are the advantages of Residential Home staff being involved at ACs?**

The role modeling of good communication and attentive interactions can make guests comfortable and can help to educate them. A positive spin-off from this, is that it can be the best form of advertising for care homes and day centres to have. If their staff members attend ACs often enough to become familiar with guests, (or if they 'lend' their professionals to the AC to be interviewed) - it will likely influence the choice of care setting or service provider when one is needed.

Also, as one care home manager recently said, "Having my staff volunteer at the AC has actually helped change their practice - especially the caregivers - as they learn more about the effect of dementia on families and friends."

### **What concerns do people have most often?**

The most frequent concern is about '*How long can people with dementia attend ACs?*' For as long as they feel safe, engaged and comfortable there. (Some people can follow things better if they are seated close to the speaker versus at the back of a hall.) Family carers usually judge when the AC is no longer suitable for the person with dementia. Can people who have moved to care homes continue attending? Yes, some people have continued to attend with their family members (for an example see Jones, 2010, pg. 81).

Some new AC coordinators have been concerned about what to do if people with dementia become uncomfortable, bored, distracted or disruptive to others at an AC. That shouldn't be a concern because there will be enough expertise present to help out - whether that means accompanying someone to the toilet, offering them refreshments, talking to them to give their family carer a chance to speak to others, taking them out of the room to go for a walk with them, (or dancing with them on a social evening), or, helping them to leave if they or their carer want to.

### **Contact the AC UK Trustees about your plans to set up an AC**

We can help in a variety of ways, which include:

- finding experienced people to speak with the new AC coordinators
- providing places on the course, '*How to host an AC; for coordinators and interviewers*', and for permission to use the logo and artwork
- providing links to other ACs that set up in similar circumstances
- inviting new ACs to AC UK Networking Days
- having 'AC neon signs' made inexpensively
- helping to review and make suggestions for the Annual AC Programme
- **supplying artwork for the AC logo, for stationary, t-shirts, banners and signs**