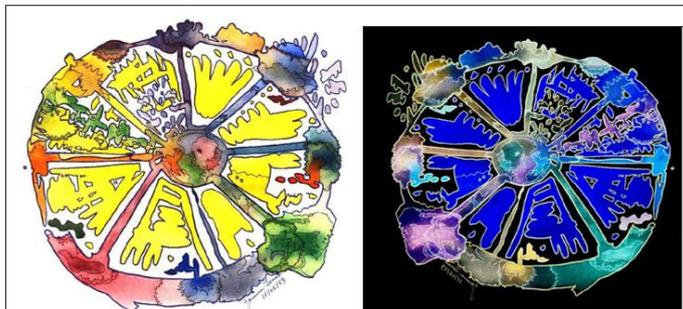


from 'the wide spectrum' website

TAD (Thoughts About Dementia) Newsletter



TAD 60 14 July, 2014

Sustainability of Alzheimer Cafés: using 'the NESSIE mnemonic' for planning

Related ideas for observations and research:

- . Do you belong to any formal or informal network that supports you in your dementia-related work?
- . **If so**, in what ways does your network help you to do your work/role?
- . Is there anything else that it could do to assist you?
- . **If not**, can you think of anything else that could be helpful in terms of providing up-to-date information, clinical examples, or peer support?
- . How often do you consider a *networking group* has to meet to be *sustainable* and motivating?
- . Have you thought about 'accountability' as being directly related to 'sustainability', and the ways in which your own accountability shows?

Dear Reader,

'Sustainability' is a term that is usually used to refer to the ability of processes and systems to persist or endure – in regard to production processes and environmental resources. There are many definitions of sustainability. **Box 1** gives a simple one that does tie in with efforts to support people with dementia and their families.

Box 1 A simple definition and some thoughts on sustainability

One definition of sustainability is – [optimizing and] "improving the quality of human life while living within the carrying capacity of supporting eco-systems." ¹
[Contents of the square brackets are my addition.]

The simplest description of sustainability I've seen, though I can't recall the source,

is: “Accountability is sustainability.”

I also read somewhere - “embedded sustainability is good fertilizer for creativity”.

This TAD newsletter considers sustainability in terms of **what is required to sustain existing Alzheimer Cafes (AC *) and their quality** – regardless of whether new ACs are started. We (the AC UK Trustees) are envisaging ACs persisting into the next decade, at least. To do this we need to help AC organisers to simultaneously create opportunities for AC guests to feel welcome, participate, learn, meet and interact with others who are ‘in the same boat’, and to feel supported there - over time.

(The ideas for ACs mentioned here, are also likely to apply to other similar support service endeavours.)

[DEFINITION: ACs are post-diagnostic support interventions for people with dementia, family, and anyone else interested in dementia. ACs take the form of monthly gatherings to provide psycho-social dementia education, support, and opportunities for socialization - in a safe environment. ACs are professional and volunteer-led. With much gratis input from professionals and volunteers, ACs are economical interventions to provide, but the venue, refreshments and equipment do require financing. It is assumed in this TAD that financial input to maintain them is stable. In that way, sustaining ACs is different from sustaining most businesses. ²⁻¹²]*

As Dr. Bère Miesen explained, in an interview on 11 June 2014, - it is not trivial to host an AC. It requires a lot of expertise, information about dementia, and other types of ‘know-how’. (See the transcript of this interview on the website alzheimercafe.co.uk).

Numerous factors and influences make ACs sustainable; the most obvious include:

- . remaining relevant to the needs of people with dementia and their family carers through maintaining the founding AC vision and intention (the essentials)
- . providing education for AC coordinators, and for those attending ACs
 - Formal education* – courses on how to host an AC; providing dementia-related interviews and talks for the AC guests
 - Informal education* – the role-modelling of *inclusion and communication* by AC coordinators, leaders and volunteers at ACs
- . stimulating people’s motivation to continue hosting ACs (with positive feedback from attendees/guests)
- . maintaining AC attendance -through links with other dementia services and support groups who refer and sign-post people to the AC, local publicity, and AC info on a website
- . trying to host ACs in new settings, and making any needed adaptations
- . inspiring and including the ‘next generation’ in AC involvement, creativity and leadership

For discussion and planning purposes, I came up with “the NESSIE mnemonic” to guide the planning efforts of the AC UK Trustees. To start with, we want to make ACs sustainable, for the coming decade (**Box 2**).

Box 2 The ‘NESSIE mnemonic’ for sustaining Alzheimer Cafes in the UK

NESSIE stands for:

- . **Network and conference opportunities**; provide fellow AC hosts opportunities to meet, inform, support and share experiences
- . **Educate** everyone about dementia formally and informally; AC hosts, volunteers, people with dementia, family carers, professionals, and interested others
- . **Stabilize** existing ACs - so they are functioning well and AC leaders feel connected
- . **Support** those hosting ACs; visit ACs; share information with those hosting ACs in the UK and in other countries. Provide AC website for general information, locations and contacts, annual AC evaluation data, articles and photos about conference and networking events.
- . **Include and integrate** ACs with other local dementia resources and services and by providing information about them at ACs, inviting representatives to the AC, and asking them to refer and signpost people to ACs
- . **Evaluate and experiment** - evaluate ACs annually using the 33 quality control criteria (QCC); experiment with new ideas arising from local needs, and mentioned on the QCC forms (i.e. new AC topics, locations, fund-raising, publicity, volunteer recruitment and training)

Reflections on using the NESSIE mnemonic this past year

Some of the events that the AC UK Trustees have been involved with are described below, under the key words that ‘NESSIE’ links together.

Network

The first **AC UK Networking Day**, was held on 11 June 2014 in Windsor, England. AC Coordinators and steering group members were invited to meet the new Trustees of the AC UK, and members of the Advisory Committee. This event included:

- . an interview with Dr. Bere Miesen (Founder of the Alzheimer Café concept)
- . a ‘Tweet’ from AC Advisory Board member, Prof. Viv Bennett - Director, Nursing of Public Health England, Dept. of Health
- . three *show-case presentations* about: developing ACs on the Isle of Wight, in Ireland, and responses to the AC courses and supporting ACs abroad
- . an opportunity to self-evaluate their AC according to the 33 Quality Control criteria
- . discussions and suggestions for next year’s networking event agenda.

Educate

Since 2011, the AC UK Charity has been offering the **course: “How to Host an Alzheimer Café: for coordinators and interviewers”**, for those who are already holding ACs and planning to host ACs. The course covers the AC concept, history, background, ethos, theory, methods, themes, trouble-shooting, and adaptations. It was held thrice in 2014. (Altogether so far, 85 people have attended AC courses provided by the AC UK, free of charge.)

The Trustees are encouraging everyone involved in planning and hosting ACs to attend one - i.e. coordinators and/or MCs, interviewers, steering committees and/or work groups members, and volunteers. AC courses in 2014 were held in:

- . Bristol, England (14-15 April)
- . Saint John, New Brunswick, Canada (28-29 April). This AC started in 2012. *
- . Cowes, Isle of Wight, England (19-20 May)

* This is the first AC course to be held in another country. The next external course planned to be in Ireland.

Stabilize

AC UK Trustees **visit existing ACs** - to meet organizers and guests, see how the cafe is going, planning the annual programme, and what, if any, support or education may be welcome. Visits were made to 9 ACs this past year; hopefully the remainder will be visited in 2015. AC Trustees attended the launch of new ACs in Winchester and Farnham this year.

Support

The AC UK **website (alzheimercafe.co.uk)** has been updated to reflect current AC locations, contact people and information. It provides details up upcoming AC courses and events, articles about ACs, an *information pack* about starting up ACs, the QCCs, and the results of the most recent QCC self-evaluation data. (The website is attracting queries from abroad - most recently from professionals in Japan and Canada.)

Three ACs are in planning stages, and the organizers have had the benefit of advance education by attending the AC course, the Networking Day already. The first to open will be the AC in Camberley, Hampshire, UK, on 22 Sept., 2014.

Include and integrate

Inclusiveness at ACs exists **by definition**, since they are open and free to anyone interested in dementia (although people need to be aware that the AC exists and be sign-posted to it). The ‘integration’ comes from ACs **sharing links** to local people and services (professionals; day care, care-home staff and domiciliary care staff; volunteers; dementia support organisations; care services and establishments).

Unexpectedly, the “Lighting DARC courses – dementia awareness reaching communities” that I developed for volunteers and members of the public, have also helped to bring new people to ACs. Most surprising of all, have been the police officers on the Isle of Wight. They are in attendance at the ACs there – and getting to personally know the guests who live in their work areas ^{2b, 2c}. Fire Safety Officers are also becoming involved.

Health and social care students have long visited ACs, and continue to visit and to volunteer at them (nursing, occupational therapy, social work, physiotherapy, and speech and language therapy). A pastoral care worker, about to start seminary studies attended a recent AC event, with a view to learning more about dementia, and being able to hold spiritual services in care homes with more insight and less anxiety.

See the notes on Bère Miesen’s interview at the June 11th Networking Day, on the AC website about other spin-offs that have occurred from people like politicians, and lobbyists attending ACs.

Evaluate

Evaluation is part of accountability, and remembering accurately for planning and teaching purposes. There are at least four ways to evaluate an AC:

- . by verbal and non-verbal feedback to organisers and others at ACs
- . by written response in the ‘AC Comments Book’
- . by AC summaries; notes on the ‘AC summary Evaluation Form’ recorded by AC organisers of each AC session. This includes records of attendance, topics, speakers, glitches, and surprises. [These summary notes are the basis for being able to fill in the QCC form.]
- . by word-of-mouth accounts from newcomers, accounts by AC guests in articles, interviews on the radio
- . annual evaluation: AC Steering Committees are invited to fill out a voluntary self-evaluation of their AC to the standard 33 AC Quality Control Criteria ^{5, 10, 11}.

This year, the AC UK Trustees piloted another way get responses to the voluntary ‘**Annual AC QCC evaluations**’. They created a slot during the AC Networking Day for participants to evaluate their own ACs, collectively, with a verbal commentary about each item to be scored. Since this was successful this method will be continued in the future. The results of 2014 will be posted on the website soon.

Experiment

As the Trustees have seen in the past year, the word experiment can also have a creative component to it.

The first AC held in a hospital was on 25 June, 2014, at St. Mary’s Hospital, Newport, Isle of Wight. The idea to *pilot an AC at the hospital* started two years ago and the hope is to hold it quarterly. The pilot was timely in that:

- . a full network of ACs has been established on the island, and (the sixth AC opened in Cowes on 8 July 2014)
- . the Community Memory Service Liaison Nurse, who is the link to the hospital wards to support people with dementia, had attended ACs in the community and was instrumental to piloting them in the hospital.

Backdrop: at any time there can be about 50 people/patients with dementia in hospital. Some receive their diagnosis of dementia while in hospital; some are in hospital for a long time. It is hoped that introducing them (and their families) to an AC while in hospital could be helpful in:

- . offering dementia-related education and support as near the time of diagnosis as possible
- . sign-posting people to the AC nearest to where they live, at time of discharge
- . increasing the likelihood that people will attend an AC as soon as possible, since they are already familiar with it, and have seen it as part of the overall care planning given.

The outcome of the AC hospital pilot? Those who attended included Ambulance staff, an doctor from the Accident and Emergency Department, staff from the Rehabilitation Unit, nurses, a health care assistant, visitors to the hospital, and an occupational therapy student. In the discussions with attendees after the AC, there was agreement that the AC was potentially very useful in this setting. They liked what they had seen and would attend other ACs on that basis. They also concurred that, given the hospital's visiting hours, the ACs stood most chance of being well-attended by patients and family carer/visitors if schedule for late afternoon sessions.

Future plans

The plans to date include maintaining the items described above, in particular – holding AC courses, Trustee visits to ACs and AC launches, and hosting annual Networking events. Trustees are considering offering one-day courses for new volunteers at ACs.

AC UK Trustees are still working towards piloting the first **AC in a prison** - for prisoners with life sentences who have developed dementia. Special security arrangements will be required for this. It will also require some dementia education for those who will accompany the prisoners to the AC (volunteers and prison guards? in lieu of family carers).

Conclusion:

The interest and participation of the next generations at ACs is a very encouraging and healthy sign, but is not a guarantee that ACs will continue. [i.e. If there are no guests attending, there is no AC!] To be sustainable, ACs need to remain relevant; they also need to feel safe to visit while providing dementia-related education, support, opportunities for social interaction for people with dementia and their families. AC organisers need remain connected to the 'good will' of organisers, professionals and volunteers.

The NESSIE mnemonic is helping the AC UK Trustees think about the various components of the planning that is and will be needed to sustain ACs.

Best Regards,
Gemma

Box 12– Photos from the AC UK Networking Day, 11 June, 2014, Windsor



Seated, ready to start the opening interview: Dr. Bere Miesen and Dr. Gemma Jones



Guests are busy filling in the 'annual self-evaluation form' of their own Alzheimer Cafe for the 33 AC Quality Control Criteria



Left - 43 ACs are marked for England, Ireland and the Channel Islands on this 'button map'; Right – (lower left) Rev. Louise Brown, who generously provided the venue for event at All Saints Parish Centre in Windsor, converses with the participants.

References

See the website for the Alzheimer Café UK at: alzheimercafe.co.uk

- 1 IUCN/UNEP/WWF (1991). "Caring for the Earth: A Strategy for Sustainable Living." Gland, Switzerland. Retrieved on: 2009-03-29.
- 2 TAD Newsletters - about ACs and presentations at ACs, by Gemma MM Jones
 - a. TAD 37; 27 July 2012, *Alzheimer Cafes and other café models* *
 - b. TAD 58; 9 Nov. 2013, *Surprising things can happen when the police attend dementia courses and Alzheimer Cafes* **
 - c. TAD 52; 20 Nov. 2012, *New Course: Lighting DARC – Dementia Awareness Reaching Communities* **
 - d. TAD 5; 28 Feb. 2010, *Alzheimer Cafés: 10 years in the UK* *
 - e. TAD 12; 26 April 2010, *The tyranny of the MMSE test* *
 - f. TAD 27; 10 Feb. 2011, *Doctors, dementia assessment, support and concerns about driving* *
 - g. TAD 28; 20 Feb. 2011, *Professor Andrew Knights: the language and power of music* *
 - h. TAD 29; 18 March 2011, *Nursing and student links to Alzheimer Cafés* *

* Jones, GMM (2012) *The TAD newsletters (thoughts about dementia), Vol. 1, the first fifty*. The Wide Spectrum Pubs, Sunninghill, Berks., UK, SL5 7BH. Pp 269.
 ** These TAD newsletters were sent out as an 'email newsletter's from The Wide Spectrum Publications [website of thewidespectrum.co.uk]. They will be in Vol. 2 of the TAD newsletters.
- 3 Jones GMM, Miesen BML (2011) Dementia care: involving people in Alzheimer Cafés. *Nursing and Residential Care* 13:9; 442-445. (Sept.)
- 4 Thompson A (2006) Qualitative evaluation of an Alzheimer Café as an ongoing supportive group intervention. In: Vol 4. *Care-giving in Dementia* (BML Miesen and GMM Jones, eds.) Routledge Publ., London. Pp 291-312.
- 5 Jones GMM, Redwood K, Harding JW, Bullock P (2007) Comparing UK and Dutch Alzheimer Cafés against new quality control criteria. *J of Dementia Care*. 16:1 (Jan/Feb) pp34-38.

- 6 Miesen BML, Jones GMM (2004) The Alzheimer Café : a response to the trauma, drama and tragedy of dementia. In: Vol. 3 Care-giving in Dementia. (GMM Jones and BML Miesen, Eds.), Brunner Routledge , Hove, pp 307-332.
- 7 Miesen BML, (2002) Het Alzheimer Café. Lifetime, Kosmos-Z&K Uitgevers, Utrecht, pp 208.
- 8 Jones GMM (2010) The Alzheimer Café: why it works, The Wide Spectrum Pub., Sunninghill, UK, SL5 7BH. Pp 212.
- 9 Miesen BML, Blom M (2000) Handleiding Alzheimer Café. Translated and abridged from the document published by 'Alzheimer Nederland' by GMM Jones, April, 2001. (Available on the Alzheimercafe.co.uk website)
- 10 The 33 Quality Control Criteria for ACs, on: the website Alzheimercafe.co.uk
These are available in summary form and also in the extended form based on Meerveld J, in collaboration with B Miesen (2005/2006; version- March 2006) Seizoensevaluatie met kwaliteits criteria Alzheimer Cafés. Bunnik: Stichting Alzheimer Nederland, pp28. [translation of the Quality Control Criteria and the a summary of the Dutch Evaluation report findings, by GMM Jones].
- 11 Jones GMM (2010) AC-UK voluntary, annual, AC self assessment survey for 2009-2010. [Available on the website of thewidespectrum.co.uk under 'AC info']
- 12 Alzheimer Café UK charity (2010) Introductory Information Pack: to help set up and host an Alzheimer Café. Prepared for May 14, 2010 National Alzheimer Café UK conference. For a copy please contact the AC UK charity.