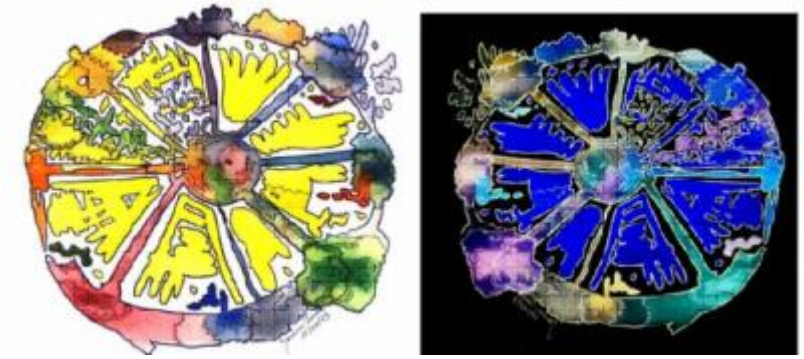
TAD (Thoughts About Dementia) Newsletter



#52: 20th November, 2012

New Course: Lighting DARC – Dementia Awareness Reaching Communities

Related ideas for observations and research:

- Can you imagine what a dementia-friendly community would look like and be like?
- Do you really think it will be possible to have dementia-friendly communities?
- Do you think that *dementia awareness education* alone will be enough to change publ the acceptance and inclusion of people with dementia, and motivate citizens to interact
- What content would you include on a one-day 'dementia awareness course' for memb
- How much and what types of public education, good role-modeling and goodwill will
- What features would you recommend having *as standard* to create dementia-friendly with dementia to make use of public buildings and spaces?

Dear Reader

The first "**Lighting DARC: Dementia Awareness Reaching Communities**" **course** was piloted on Oct. 27th 2012, on the Isle of Wight *. It is the first of these courses that have been planned to reach particular groups and members of the 'general public' who are interested in making the island a more dementia-friendly place.

Interest in creating dementia-friendly communities

Ongoing endeavors to create dementia-friendly communities were in the press in October - with the statement that the government is supporting the training of large numbers of 'dementia friends' by 2015. Apparently, volunteers will be taught to recognize early signs of dementia[1] and how to assist them. This effort will be in addition to the Prime Minister's "National Challenge On Dementia" (March, 2012), which promised a doubling of funding for research into dementia by 2015.

Many people have been working towards making society more dementia-friendly, for years already. Some, have been participating in discussions to consider the issues

involved in balancing the roles and responsibilities of individuals and society to provide support, education and quality care for people with dementia and their carers. Others, have been piloting education and information schemes to try to determine the best ways to stimulate the creation of dementia-friendly communities (counties, localities, neighbourhoods, environments and services [2-7]). A range of practical teaching materials will be needed to educate the various groups of people in society - also hopefully students, young adults and children.

Pro and con views about educating the general public

Some people are critical of the current emphasis to try to educate the public because they are concerned that even many dementia caregivers and professionals still lack formal dementia education. Their point is that since much fear of dementia comes from fear of a lack of good care, the caregivers and professionals should be educated before the general public. The counter-position is that with the ever-increasing numbers of people with dementia, the need for accurate information is imminent and great - especially since the public has already been exposed to many negative portrayals of dementia and dementia care in the media. Proponents of this position assert that we can no longer wait for caregivers and professionals to be educated first, and that everyone stands to benefit if dementia education is offered to all, concurrently.

Regardless of your position, efforts have already started to educate groups of people within the public about dementia. The immediate focus is on starting to develop (small) *pockets of good practice* or *dementia-safe bubbles* within pilot communities, which can serve as beacons for others to get ideas from, emulate and/or expand upon**.**

Required ingredients for achieving dementia-friendly communities?

To my knowledge, there is not yet a *working definition* of a dementia friendly community. I.e., how would it differ from a community currently considered to be 'disability friendly'? Regardless, a dementia-friendly community implies that (whether people have been formally diagnosed or not), some of the difficulties they may have while trying to participate in everyday activities in the community, will be recognized, and that they will be offered help – whether in the form of patience, encouragement, or direct assistance.

Achieving a dementia-friendly society will require: 1) (some) knowledgeable citizens, 2) who are motivated to notice and assist people with dementia and their family carers, and 3) more user-friendly public environments. I don't know if a specific working definition of 'public places' or 'community' has been developed yet for this initiative, but various articles contain references to shops, banks, pubs, hotels, cafes, restaurants, churches, theatres and public transport. Those places are obvious starting points.

(Adapting environments is a complex issue that is beyond the scope of this TAD. **Box 1** contains some examples of issues that will eventually need to be considered in

detail.)

Knowledgeable, motivated citizens

It seems obvious that creating genuinely dementia friendly communities will require some changes in attitude to both aging and dementia. (And, there is no guarantee that providing education alone can or will change attitudes, or increase motivation to help.) What course content would be most likely be helpful, i.e. to produce individuals who feel *knowledgeable*, *motivated* and *confident* enough to choose to interact with and help people with dementia and their carers? Do you agree with the following listing of essential topics for such a course?

. an accurate definition of dementia: also, an explanation of the many types of dementing illness and the most common types
. naming some of the major myths about dementia, and providing accurate information to dispel and replace them
. listing the types of difficulties that need to be checked with the doctor, and explaining that they may have physical causes (and be treatable), or be early signs of a dementing illness (which are untreatable, but for which anti-dementia medication can be tried, and immediate information and support given). The advantages of detecting dementia early need to be included.
. showing how much of a positive difference improved *general societal awareness* of and support for people with dementia can make. I.e. provide contrasting examples: 1) the value of early and ongoing support, and keeping a person with dementia as connected and as engaged as possible with a dementia-friendly community, *versus* 2) a person with dementia and their carer who become increasingly disengaged from society with the resultant isolation, stress and poor quality of life
. examples of members of the public who have role-modeled positive interactions with people with dementia (alone or with their family carer) in a variety of public places (i.e., shops, banks, restaurants [8], churches, public transport)
. emphasizing that no one asks to get dementia – it could happen to anyone – and there are no cures for it yet. It isn't contagious. So, whatever awareness and support we develop in our communities now, stands benefit anyone/everyone in future.
. assurance that, despite past shortcomings, in the future, various forms of support, education, interventions (anti-dementia medication and others), care services, and quality dementia care in care homes will be available to all who need them in society, equitably.

Why launch the 'Lighting DARC course' on the Isle of Wight (IOW)?

The IOW is a geographically confined community with a population of about 140,000 - hence, similar to a small county. It is sometimes used like a sort of *experimental test tube* to see how ideas and innovations work here before they are tried elsewhere. Since the IOW is a preferred retirement location, it has a greater-than-average number of retired and elderly people, and therefore also people with dementia. It is also a popular short-holiday destination, which means that it has many tourist attractions, hotels and restaurants, that inevitably are visited by elderly visitors, and therefore also - people

with dementia.

The advantage of starting the Lighting DARC course on the IOW is a combination of: 1) it's size, 2) that important dementia services and resources are already in place, 3) that a significant amount of dementia education has already been provided to professionals and caregivers working in these services (including care homes), and 4) that in addition to other post-diagnostic support services, the IOW now has four Alzheimer Cafés (ACs) [9, 10], one in each major urban area. (ACs provide education about dementia, information about local dementia services, support and social contacts for anyone interested in dementia - but especially for people with dementia and family carers. The timing of the ACs has been arranged so that there is a gathering, somewhere on the island, every week.)

The strategy behind the 'Lighting DARC' course

The motto being used on the IOW to encourage the creation of dementia-friendly communities is ***'educate, engage and enable'*** - with an emphasis on the word educate.

Therefore, the plan is to hold the Lighting DARC course for people in a range of specific groups and sectors of society, as well as for general members of the public who are interested in dementia. This will make it possible to emphasize particular types of situations and interactions with people with dementia that certain groups may have in common. The courses are planned to be held for:

1 volunteers who work for charities involved in supporting the elderly, and thus inevitably also working with some people with dementia (both undiagnosed, and in early stages), and volunteers at care homes and ACs
2 local government counselors and interested politicians
3 staff working in shops, stores, supermarkets, banks
4 staff working in hotels, pubs, restaurants, and at tourist attraction sites
5 churches and religious communities
6 police and emergency service workers
7 people working in public transport (i.e. bus and taxi drivers, vehicle breakdown and rescue services, staff working on the ferry services)
8 organizations that have links to hospitals, and GP practice managers
9 schools and colleges, especially those offering social care courses
10 people working as privately employed personal assistants and befrienders to people with dementia in the community
11 members of the public who are interested in dementia

How did the first pilot of the Lighting DARC course go?

Eighteen people attended – all were volunteers for age-related charities and care homes on the IOW (Age UK, Action on Hearing Loss, LINK health and care projects, and the Alzheimer Café). See **Boxes 2** and **3** for a photo of the participants and a summary of the course content. Besides attending the course to assist with their volunteer work, more than half of the participants had some experience of dementia in their extended

family, or were currently concerned about someone who was becoming increasingly forgetful. They were very motivated to learn. Some related their *burning questions,* alreadyduring the introductions; some asked them privately, during the break times (see below). In my experience these questions are typical of those asked on any dementia course. They illustrate: 1) some common misunderstandings and myths about dementi a, 2) the enormous fear of dementia, and, 3) the tremendous goodwill and desire that people have to be of help - providing that they feel competent and confident to do so. These questions also illustrate that a one-day course is not too long for a meaningful dementia awareness course. Besides the *planned teaching content*, people's specific questions need to be answered if they are to be as comfortable as possible interacting with people with dementia.

The first question asked was: 'Is dementia Alzheimer's, or is Alzheimer's dementia?' Other questions included:

. How long can dementia last?
. I read in the newspaper that there is a new a cure for dementia. Is that so?
. I know someone whose husband had dementia and he became violent. How often does this happen?
. Does everyone with dementia lose their modesty and act inappropriately?
. I know someone who is in their 50's and forgetting things; surely it can't be dementia at this age?
. How come the GP couldn't diagnose my father's vascular dementia, and said there was 'no problem', even though we explained that there was?
. My biggest fear is to get dementia; what can I do to prevent it?
. My concerns in helping people with dementia would be *not knowing what to say*, and *not wanting to embarrass them* about whatever it is they are struggling with. Is everyone with dementia aware of, and embarrassed by their mistakes?
. My mother died of dementia. Is it inherited?
. I've seen some family carers who were more distressed than the person with dementia. What is the best way to help them?

Evaluation and outcome:

Course participants were positive in their evaluation of the day. They reported: being less frightened about dementia; thinking they would be more able to identify people having early-stage difficulties and engage them in conversation; and, that the course was well worth attending. All said that it had been valuable for them personally, as well as for their work.

Participants received **Certificates of Attendance**, and a bright, laminated, A3 size, **Window Poster** to hang in their workplace, so that passers-by could see that some members of staff there were dementia-aware and dementia-friendly (see **Box 4**). Participants liked the window poster idea. They thought the posters could work in a similar way to the 'Neighbourhood Watch' signs that are hung in conspicuous places in neighbourhoods that participate in this national programme. *(It might be very helpful for those involved in funding dementia-friendly communities, to speak to the*

originators and organizers of this national scheme, to find out how they first started and developed. After all, Neighbourhood Watch areas are like pockets within society where residents are committed to being aware and vigilant about potential and real thre ats to safety.)

Several participants asked if they could already sign up their family and friends to attend future courses. This was the response hoped for by the course coordinators. Some participants were so interested that they hope to attend the four day course, "Communication and care-giving in dementia: a positive vision". A number of people stayed afterwards to ask additional questions. This pilot of the Lighting DARC course was judged as being successful. It is also the hope that some of these volunteers will be curious enough to come to see what an Alzheimer Café is like, so that, should they meet people with dementia, they can tell them about this resource too.

Conclusion:

If those who attend the subsequent 'Lighting DARC' courses respond similarly to these course participants, then there is good reason to be hopeful that niche places can be developed within our society – places where people with dementia and their family carers can feel welcome, safe, understood and included – as long as possible.

Best Regards,
Gemma

P.S. a related quote
"The only answer in this life, to the loneliness we are all bound to feel, is community."
Dorothy Day

References

* Funding for this course is from an NHS Clinical Commissioning Group grant to the Alzheimer Café, IOW Branch.

1 News article. Gallagher J (Nov. 8., 2012) Million 'dementia friends' wanted for training. *[The government hopes to train a million people in England to become "dementia friends"; able to recognize early signs and to help people with dementia, by 2015]*.
http://www.bbc.co.uk/go/em/fr/-/news/health-20236034
2 Nuffield Council on Bioethics. Report. "Dementia: ethical issues". Oct. 2009
http://www.nuffieldboethics.org/dementia
3 Keady J, Campbell S, Barnes H, Ward R, Li Xia, Swarbrick C, Burrow S, Elvish R (2012) Neighbourhoods and dementia in the health and social care context: a realist review of the literature and implications for UK policy development. Reviews in Clinical Gerontology 22:2;150-163
4 Developing dementia-friendly communities; Learning and guidance for local authorities
http://www.repod.org.uk/downloads/dfc.pdf
5 innovations in Dementia CIC http://www.innovationsindementia.org.uk/projects_communities.htm
6 Dementia friendly communities – "York Dementia Without Walls" project report:
Go to: www.jrf.org.uk/publications/creating-dementia-friendly-york
7 Making Hampshire a demewntia-friendly county; Dementia-Friendly Hampshire Toolkit
http://www.innovationsindementia.org.uk/DementiaFriendlyCommunities/DementiaFriendlyCommunities_ToolkitIntroduction.pdf
8 Jones GMM (2010) TAD newsletter 20, Dementia friendly staff. 27 Sept. The Wide Spectrum Pub., Sunninghill, Berks., UK.
9 Jones GMM, Miesen BML (2011) Dementia care: involving people in Alzheimer Cafés. Nursing and Residential Care 13:9; 442-445 (Sept.)
10 Miesen BML, Jones GMM (2004) The Alzheimer Café concept: a response to the trauma, drama and tragedy of

dementia. In: Vol 3 Care-giving in Dementia (GMM Jones & BML Miesen/ Eds). Brunner-Routledge, Hove. Pp 307-333.

Box 1 Questions being considered for developing dementia-friendly public environments

Some buildings, like nice restaurants, pubs and theatres have been specifically designed to create a particular style and ambiance (e.g. dim lighting, obscured toilets, particular kinds of music and sign-postings). Should they have to change it to make it more dementia-friendly if it goes against their efforts to appeal to a particular kind of clientele?

The needs of each disability group are specific and may be different to those of other groups. Some, are even at odds with those of other disability groups.
E.g. mirrors in elevators can help independent wheelchair users, to reverse out safely. I have seen that mirrors in elevators be misinterpreted by people with dementia, who misperceived their own reflection for the presence of others, thought it was full, and refused to enter.
E.g. the paving tiles with elevated circles and contrasting colours, installed to assist people with visual impairments in public places, can be experienced as obstacles by elderly people who have difficulty walking, and have visual difficulties which can include struggling to interpret different colours in flooring, since different colours can be experiences as different heights of surfaces.

Where there is a conflict between the needs of different groups – how should it be decided whose needs should predominate, if they cannot all co-exist? (The group with the largest numbers of disabled members? The group who makes most use of being out in public spaces?) Who is best placed to decide this?

Box 2 Content for the Lighting DARC (dementia awareness reaching communities) course

***Content**:*
. What is normal forgetfulness? Degrees of forgetfulness
. What is and isn't dementia?
. What can happen to other 'thinking' abilities, besides memory?
. What are the early signs of possible dementia to be aware of and see a doctor about?
. What factors can cause behaviour change in people with dementia?
. How can your awareness, communication, encouragement, help and

inclusion of them, help
someone with dementia, and their family carer?
. What user-friendly environmental adaptations can help compensate for some of the difficulties
that people with dementia experience?
. If you are concerned about someone, what could you do?

***Style**: interactive – with stories, PowerPoint presentations, examples, and discussion*

***Certificate of Attendance**: given at the end of the day of full attendance*
An A3 Window poster to hang in your workplace is provided; to show your awareness of and commitment to assist people with dementia

***Aim**:*
To provide accurate information about dementing illnesses to members of communities, and to help reduce misunderstandings and fear about dementia, so that people with dementia will be actively supported to participate in the life of the community as fully as possible, with their families and social networks, with increasingly less stigma.

***Vision**:*
To have citizens within communities who are aware of, and able to helpfully respond to the needs of each other – including those of people with dementia – and who will engage with and include them in whatever ways are possible.

***Assumptions**:*
"All behaviour has meaning." (people with dementia can be fearful/lost in various ways)
"Home is a feeling - not just a place." (also within the community)
"People with dementia are more aware of their illness and its consequences than was
previously assumed." (and, it isn't as difficult to talk with them about it as you might think)
"Whatever understanding, inclusion and support we develop in communities now, is part of a legacy
that we all may benefit from." (no-one asks to get dementia; it isn't contagious)

Follow-up: attendees interested in more information will be invited to attend one of the four Alzheimer Cafés on the Isle of Wight (in Newport, Sandown, Ryde, and Freshwater)

Course examples, hand-outs, and additional reading :
Jones GMM (2012) TAD newsletters (thoughts about dementia). Vol. 1, the first 50. The Wide Spectrum Pubs. , Sunninghill, Berks., SL5 7BH

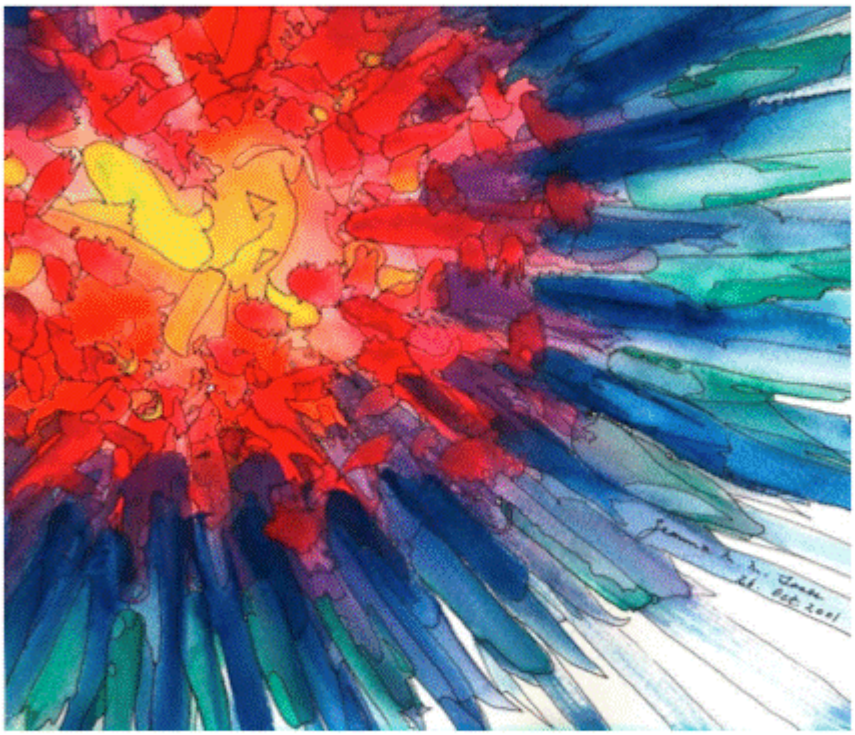
Box 3 Participants of the first 'Lighting DARC' course

Box 4 Window poster for 'Lighting DARC' course

Statement of Commitment

Staff from our establishment have attended the one-day course

"Lighting DARC – Dementia Awareness Reaching Communities"



This poster attests to our commitment to be increasingly aware of and helpful to people with dementia and their family and friend carers – in our service, communication and environment.

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