

Description of the one-day Course:

“Lighting DARC – Dementia Awareness Reaching Communities”

By: Dr. Gemma MM Jones, Dementia Care consultant

9:30	registration
10am	start
12:30 – 13:30	lunch
16:15	finish

At the end of this course participants will receive a **certificate of attendance**

The course book is provided: Vol. 1 The TAD Newsletters (Thoughts About Dementia), by GMM Jones ¹

Purpose to help create genuinely *dementia friendly communities*, by providing accurate, essential information to individuals from a wide cross section of community environments and services, who are interested in knowing more about dementia, and willing to be vigilant to help people as needed.

Aim

To help reduce stigma, misunderstandings, and fear about dementia, so that people with dementia will be more actively supported to participate in the life of the community as fully and long as possible, with their families, friends, and social networks.

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.

Motto behind DARC

The motto, coined by Maggie Bennett, and being used to encourage the creation of dementia-friendly communities is, **“educate, engage and enable”** - with an emphasis on the word *educate*.

Assumptions behind this course ²

“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.” (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 we all may benefit from.” (No-one asks to get dementia; it isn't contagious; it could happen to anyone.)

Achieving a ‘dementia-friendly society’ will require changes in attitudes to both aging and dementia.

This endeavour will also require:

- 1 (some) knowledgeable citizens and professionals
- 2 the motivation to notice and assist people with dementia and their family carers
- 3 user-friendly public environments. (A variety of articles contain suggestions for shops, banks, pubs, hotels, cafes, restaurants, churches, theatres, and public transport; obvious starting points.)

Note: there is no evidence that *dementia education alone* can increase people's motivation to help others or feel a sense of solidarity with them. We avoid what we don't understand and are afraid of.

Have you ever thought about questions like....

- 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’? That some/enough citizens will feel a sense of solidarity with people with dementia and family/carers, to create them?
- What content would you include on a one-day ‘dementia awareness course’ for members of the public?
- What features would you recommend having *as standard* to create dementia-friendly environments and assist people with dementia to make use of public buildings and spaces?

Course content:

- . **Numbers:** how many people have dementia: how many are diagnosed, how many are being missed?
- . What language to use to talk about dementia? (...to reduce stigma and make it easier to talk about.)
- . What's the difference between **normal forgetfulness and dementia?** (*The 'RU forgetful' self-test*)
- . **Possible early-stage signs** that need checking with the doctor (*they may have physical causes and be treatable, or be early signs of a dementing illness, which is untreatable, but for which anti-dementia medication can be tried, and immediate information and support given*).
- . Comparing **definitions** of dementia (*Preferred metaphor: dementia is like a mist, which can both thicken and lift around a person. Lucid moments are reported in all stages of the dementia*)
- . **Many types of dementing illness** – the most common types
- . **Advantages of early (timely) diagnosis**, include minimizing emotional distancing which can occur when others think that a person is being deliberately rude or uncooperative.
- . dispel major myths about dementia and provide accurate information to replace them. I.e.
 - ~ dementia is more than memory problems (*attention, logical thinking ability, language, perception*)
 - ~ it's impossible to 'lose all your memory' or, 'to have no memory' (*there are many types of memory*)
 - ~ take what's in news about dementia cures, with a pinch of salt (*single studies aren't positive proof*)
- . **What's happening in early stages?**
(**Models:** 'Shrinking attention blackboards'; 'Wobbling factual memory bookcase')
- . Other factors can cause behaviour change in people with dementia (illness, medications, strong emotions (anger, fear, sadness), being disoriented (lost), and sensory difficulties, i.e. visual difficulties which cause misperceptions, E.g. the lady who misperceives an illusion and sees 'a mouse in the bin')
- . How can your awareness, friendliness, communication, encouragement and inclusion help someone with dementia, and/or their family carer?
- . What 'user-friendly environmental adaptations' can help compensate for some of the difficulties that people with dementia experience?

Case Studies from Vol. 1 The TAD (Thoughts About Dementia) Newsletters book:

TAD 20 Dementia friendly staff (in a restaurant). 27 Sept 2010

TAD 42 Early stage dementia-awareness in public places: a fragile old lady in the bank. 27 Nov. 2011

TAD 49 Recognizing visuo-cognitive difficulties and fear behaviour in dementia care. 13 July 2012
(includes mouse in the bin example)

TAD 46, Accepting a diagnosis of dementia: letting denial be replaced by something better. 10 April 2012

What can help? (If you are concerned about someone, what could you do?)

- . **Awareness and alertness** - that many people in early stages are undiagnosed (old and young)
- . **Notice** details that indicate a person may be struggling – (MAL mnemonic), especially people having difficulty with their:
 - memory for factual details (factual memory)
 - ability to pay attention well enough to absorb new information or instructions
 - ability to think logically and solve problems (i.e. to following steps in a persuasive argument)
 - visual/spatial ability (i.e. finding way around buildings, neighbourhoods without getting lost)
- . **Acknowledge** people and show friendliness with a smile or a greeting to make it easy for them to ask for help if they need it.
- . Engage people in conversation if you notice something that makes you concerned about them;
"Are you okay?" "Can I help you?"
- . **Offer assistance** to them if appropriate, or offer to get assistance for them.

Recommended post-course reading in the Vol. 1 TAD book:

TAD 38 Fluctuating abilities facades and fear. 10 Aug. 2011 (intermittent early behaviours often missed)

TAD 33 Half empty or half full? Bill Drake shares his view. 17 May 2011. (help to maintain quality of life)

References

- 1 Jones GMM (2012) Vol. 1 TAD newsletters (thoughts about dementia) – the first fifty. The Wide Spectrum Pubs., Berks., UK, SL5 7BH. (263 pages)
- 2 Jones GMM, (2012) TAD newsletter 52, New Course: Lighting DARC – Dementia Awareness Reaching Communities. Nov. 12. The Wide Spectrum Pubs., Berks. UK., SL5 7BH