Certificate of Attendance

This is to certify that:
CHRIS WELSFORD

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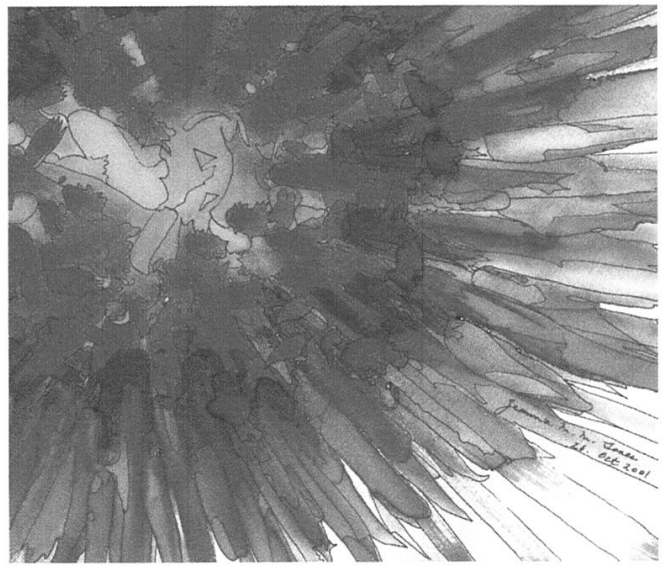
has attended the one-day course

"Lighting DARC – Dementia Awareness Reaching Communities"

Held on: 3rd JULY 2015
Held at: Riverside Centre, Newport, Isle of Wight



Course developed / taught by: Gemma MM Jones
Dr. Gemma MM Jones

Course Organiser:
Maggie Bennett, Chair

Course Commissioned by:
ALZHEIMER CAFÉ IW supported by funding from Wessex Innovation Fund

Certificate of Attendance

This is to certify that

CHRIS WELSFORD

has attended the four day course:

"Communication and Care-giving in Dementia: A Positive Vision"

Held on: 5th, 6th OCT & 23rd, 24th NOV 2015

Held at: RIVERSIDE CENTRE, NEWPORT, IW

Course Tutor: Gemma M. M. Jones

Dr. Gemma M. M. Jones HBSC, BSN, CVT, PhD

Course Organiser: _____

M A BENNETT (Executive, AZ café (IW))

Organising body :

ALZHEIMER CAFÉ IW supported by funding from Wessex Innovation Fund

Handout sheets, along with Vol. 1 TAD newsletters (thoughts about dementia) book, [1], for the one-day Course:

Lighting DARC – dementia awareness reaching communities

Developed by: Dr. Gemma MM Jones, Oct. 2012

At the end of this course participants will receive a **certificate of attendance** and a **window poster (A3 size)** to hang up in the window of their establishment to show that people there are aware and interested in being of assistance to people with dementia and their carers.

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 misunderstandings and fear about dementia, so that people with dementia will be actively supported to participate in the life of the community as fully and long as possible, with their families 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.

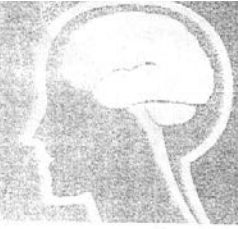
Motto behind DARC:
The motto, coined by Maggie Bennett, and being used to encourage the creation of dementia-friendly communities is ***"educate, engage and enable"*** - with an emphasis on the word educate.

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
2) who are motivated to notice and assist people with dementia and their family carers
3) more user-friendly public environments. Various articles contain references to shops, banks, pubs, hotels, cafes, restaurants, churches, theatres and public transport. These are obvious starting points.

Note: there is no guarantee that education alone can increase people's motivation to help others or feel a sense of solidarity with them.

Have you ever given any thought to the following questions?
- 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 – where some/enough citizens feel a sense of solidarity with people with dementia and their family/carers, to ?
- Do you think that *dementia awareness education* alone will be enough to change public attitudes to dementia, promote the acceptance and inclusion of people with dementia, and motivate citizens to interact helpfully with them?
- What content would you include on a one-day 'dementia awareness course' for members of the public?
- How much /what type of public education, role-modeling and goodwill will be required to create them?
- 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?



Still struggling

In no time, everyone was ready to order their meal, except for the grandfather. He was still searching for his glasses to read the menu. When he found them, he studied the menu, at length, while the others waited. He then ordered - very slowly. Within minutes, he called Diane back because he had changed his mind again. He seemed to be struggling with his hearing a little. Thereafter, he changed his mind twice again, and was still undecided about one of his choices. Several family members seemed very embarrassed. One of them apologized to Diane, out loud, in front of the grandfather - thus making their frustrations about him known to everyone around. Another family member mentioned that they had 'things to do' and said they would have leave before dinner was served if he didn't 'get on with things'. The atmosphere was unpleasant.

To make matters worse, the grandfather then needed to go to the toilet, and left the table, muttering loudly, still without placing his final ordering. Diane changed pop music that was playing to something more relaxing, and turned the volume down a little.

Some spatial orientation difficulties

On coming out of the toilet, the grandfather seemed somewhat lost. He was heading in the opposite direction to where his table was! The family hadn't noticed him yet, but since Diane had, she went to speak with him, and knew what she wanted to say. "It must be difficult with so many people in the family, and some seem to be in a bit of a rush. I'll bet you were hoping to relax a bit and choose something special for your dinner, weren't you?" He agreed, and wondered how she knew that, when his family hadn't seemed to notice. Diane replied, that sometimes families were hard to figure out. She asked if she could escort him back to the table and suggested something for him to order. He beamed, and returned to his place.

She squatted down in front of him, at eye level, so he knew he had her full attention, and said: "We don't tell just anyone, but there's a secret menu'here. It's a combination dinner. It has small portions of all the things on the menu that you seem to like. Would that interest you, Sir?" It certainly did! He felt special, and, he felt like he'd made a choice, although he'd had such difficulty making one before. She told him there was no need to select a desert yet – he could take time think about it - there were so many things to choose from. His mood seemed to improve immediately.

Diane made sure she served him first. She made a 'bit of a fuss' about him. She also asked him whether there was an occasion for this dinner. He said it was a belated Father's Day dinner. She congratulated him, and asked him who the others present at the table were. After dinner, she asked him if a 'secret desert menu' of small tasters of their most popular four deserts, would interest him. He was evidently pleased and accepted.

Success

He enjoyed his dinner - every bit of it. The other family members seemed relieved. The eldest son stayed behind to speak with Diane. He related that the siblings had argued amongst each other about whether or not to take their Dad out anymore - he had recently been diagnosed with dementia. They were embarrassed that he behaved oddly in public and could be so slow and unreasonable, especially moody. The upshot of it was that his children wanted to keep taking him out, but had thought that it wasn't possible anymore. However, with such understanding and help as Diane had shown, they would be bringing him back again, often.

Conclusion:

Diane reflected that, in the same way that buildings can be made user-friendly for people with disabilities, including dementia, - staff can also to be taught how notice and adapt their service to be dementia-friendly. That may seem like a tall order, given that it can be difficult to obtain for carers and caregiving staff in care home settings to get dementia education. Yet, Diane's story also shows there is a pay-off to providing such service. People make choices about where they want to go eat. If it's good they'll return and tell others!

Best Regards,
Gemma

TAD (Thoughts About Dementia) Newsletters, Vol.1; © GMM Jones, 2012 The Wide Spectrum Pubs., SL5 9HD, UK
Individual pages may be photocopied for education purposes.

DARC Course.
3/7/15
See hand written notes too...
Between 4 & 5% of those over the age of 65 have D either diagnosed or undiagnosed.
The group thought between 20% and 80%!
85 plus it's 15 to 20%.
So at most 20%
66% of those with D are women. But women live long!
There is a lot of scaremongering
How the information is delivered and the effect of that information differs between countries. And therefore the perception varies.
No risk increase for children in late onset but for Alzheimers early onset has a 25% probability for offspring.
Factors:
-Head injury
-Down's syndrome family members
-Stroke and other brain injury or illness
-40% of Parkinson disease go on to get Alzheimers and visa versa.
-Brain cell do regenerate.

Normal forgetting and not...
We can tolerate a certain degree of forgetting but there is a point at which this is not normal.
We do not know what memory is biologically speaking. We can measure it but not what it is. There are many types of memory store. And the distinction between long and short term memory really is not correct.
We need to avoid generalisations like 'confused' 'disoriented' etc.
very little proven and some of the theory's are just that - ie aluminium - not proven just a theory. And much I'd it is based on single studies.
Press hype actually stresses the population and creates crazes - like ditching all our aluminium pans and getting stainless steel ones.

No accepted definition of personality or mind.

We all have thoughts and most of these we would not want them out in the open. We put the brakes on them. But in dementia the brakes are off. These thoughts are out and often these thoughts are what they would not normally want anyone to hear. That is not a change in personality. But that is what people say. Similar to drinking or in a group. The brakes come off. Example of seeing a

fine looking person - you wouldn't usually comment but with dementia or drink or in a group that is what happens.
Manners take time to learn and have different cultural contexts. This learned behaviour often fails for those with dementia. But it is not personality change.

Family / personal examples definitions:
"horn - no more solos" can still enjoy playing but not out front the band.
Carpet - moths eating away
Noodles all tangled up.

Medical Definition:
It's a syndrome
Large number of causes and changes
Severe enough to cause problems at work and in family and other social interactions
Irreversible v reversible
Diagnosis needs to eliminate all the reversible causes of the same symptoms.
See photo slide

Alzheimers caused by damage to proteins resulting in Plaques and Tangles in the nerve cell in both hippocampus. Disrupts the communication between cells and this explains the intermittency of the illness that is reflective of the disruption in the early stages when sometimes the communication works and sometimes it doesn't
Cannot be diagnosed by scans or other investigations until Post Mortem.

Aside - Two enzymes break down alcohol. Not all humans have the same quantity of these enzymes. Some onto have one and others none. The less they have the longer the alcohol remains and the less they can take before becoming intoxicated and for longer than others. Native Americans have no enzymes and they are poisoned by alcohol. For others the alcohol is dealt with immediately and they can drink more without ill effect.

Medication for Alzheimers is fraught with difficulty. Cause other problems such as strokes. Better to manage the illness, educate those who are caring or interacting with them.

Blackboard metaphor all different sizes for different people. And it changes from time to time for each of us depending on mood and other factors. Mental illness can damage the blackboard space.

This affects communication with a D sufferer. Looking through eyes to know if you are exceeding the blackboard limit! A person with D will become distracted and disinterested.

The bookcase model of memory
Those with D get stuck between shelves and find it hard to move from shelf to shelf
And skip shelves

It's not the memory's that disappear it's the shelves that are damaged.

So they may deny agreement to certain things - not being deliberately difficult they simply don't remember because the bookshelves are wobbling.

Once the bookshelves collapses then they can no longer store any new memories. They can access memories but it is hit and miss. The easiest being the old memories and hardest are the recent ones, nothing to do with time, just the framework and the extent to which it is damaged.

When the main case collapses then the alternative is the emotional bookcase. And this allows substitution. Lookalike memories.
The emotional memories are the used to reconstruct the present into a place they recognise from the past via the emotional memories.
Not crazy - but linked to memories.
They behave normally in an abnormally perceived world.

4/7/15.

DARC COURSE.

INTRO

Maggie Bennet. Mngr.
Alzheimer Cafe (W. - Provide info + support.
Monthly venue. (New one planned = 1 x WK.)
x 6! in the UK.

Dementia friends x 1m the realistic! 2012 policy aspiration by Gov
1:3 scared of people with dementia + would avoid if possible.
The old are normives - they can't be hurt by
what you say cos they're tough + shut out
what they don't like - a shutter comes
down + they become unreceptive.
The only Q = WHY = dangerous for
people with D. ! ! they don't have logical thinking ability
they then have 2 choices = lie or ignore.
> Need to find alternative Q to find out why.
Otherwise the aggression levels ↑. Aggression is what
people fear the most about D. Where then
what but never Why. find the facts + use them
to figure out why.
Fear behavior is what we see in D - not their true
personality.

(1) Thinking they not proper people - "why if people notice I'm not a proper adult?"
Loss of time perception. At this stage if they
(2) feel safe then they feel safer found.

How could the expect it when professionals can't diagnose.

Accentuation of Conference Behaviour - anchoring to familiar faces.

Hypocampus: | Resides either side of the brain.
> Memory | In most D these are damaged
> Attention | There are >200 types of D
> Logic | Alzheimers is the most common.
- A VISUAL COGNITIVE ILLNESS. -

Almonds = Amygdala - the emotional centres of the Brain alongside the Hypocampi
+ This is where we have to go.

People with D are very reliant on emotion + pick up on other peoples emotions. They quickly work out who they like + who they don't.

With Alzheimers: they make visual mistakes + can't do the problem solving. (Descartes)

> AMYGDALA AMELIATED MEMORY. (Tendancy to Glance.)

Kinesthetic - Spacial awareness + ~~to~~ ability: The only ability that gets better after age 25.

Does the desire for fun happy people lead those with D to alcohol + social settings?

Alzh. = Symetric

Vascular D is left. STIA/STROKES etc. ∴ asymetric.

69% of people with D are not known to their CPS.

TAD = Thoughts About Dementia.

Age UK
Care Navigators.

RUN KEEPER.

'Dementia like a Mountain Peak in the mist.'

"Barbara + Malcolm a Love Story."
Film

They use verbs + adj to describe the word as an alternate way to say it. Eg:

Ruler = Measuring thing.

Picturing a word is hard. eg - What does a Susan look like?

Attaching emotion to a word is possible