

Dr. Bère Miesen - opening address for the first, Alzheimer Café UK Conference for 14 May, 2010, Ascot, UK,
[given by Dr. David Wilkinson; Dr. Miesen still in hospital]

Inspiration and the underpinning of the Alzheimer Café (AC) Concept

Greetings to everyone present. It is an honour to be asked to be here yet again, for time for this first national AC UK conference. Today is about meeting and learning from each other - it is also about celebrating the tenth anniversary of ACs in the UK and the work that you are doing in your own respective areas.

1. Personal anecdote

I remember when the first AC was inaugurated in the UK – for more than one reason. I thought I'd get a really early flight from Rotterdam Airport to London Heathrow at half nine in the morning. But the really bad weather at the time turned out to have far-reaching consequences. I didn't leave until two hours later. The plane wasn't given permission to land at Heathrow and had to be diverted to a military airport. My luggage didn't fly with us, but was taken to London City Airport. I took the bus there and waited for my case. By now it was already four in the afternoon. Once reunited with my case, I then took a taxi right across London to Ascot. At seven o'clock precisely – ten or so hours after leaving home – I finally turned up very relieved at St. Peter's Parish Centre in Farnborough.

And I have to say – my respect for London taxi drivers has since grown manifold. The calm, reassuring and cheerful way my driver dealt with my stress soon made me accept the unavoidable fact that I would surely be late. After all, that was what was actually worrying me. Thinking about it afterwards, I realise that the taxi in fact, reflected the atmosphere of a true Alzheimer Café, albeit a very small one on four wheels. A few days later, on Wednesday November 22nd, Joy Francis wrote in The Guardian: 'In the unlikely setting of St. Peter's Parish Centre in Farnborough Hampshire history was made last week when more than 200 people turned out to witness the launch of Britain's first AC.'

On September 15th 1997, the first AC opened its doors in the Netherlands and now thirteen years later, we are well on the way to having 200 cafés. Almost wherever you are in the Netherlands, you'll find an AC within a radius of 9 km! For some years now, the AC has been a major spearhead of the policy adopted by 'Alzheimer Nederland' [the Dutch Alzheimer Society] to support people with dementia and carers.

2. AC in layman's terms: a low threshold and everyday environment

An Alzheimer Café is a place where people with dementia, their families and professional caregivers come to meet once a month. It is held on a set date at a set time, and is based on a set format. It usually follows a programme of themes, which for the most part is repeated each year. You can therefore join the meetings whenever you want. The various topics are expertly handled at Alzheimer Cafés. Information is shared and time is set aside for discussion, questions and emotions.

An Alzheimer Café is intended to be a real café. In other words, you don't have to book a place before going there, you can come and go as you please, there's food and drink available there, you can listen to some music, talk about what you're going through, you can always find a listening ear, and you can remain anonymous (but usually only for a while) if that's what you want to do.

In formal terms, the Alzheimer Café Concept can be described as a low-threshold group intervention for anyone affected by dementia, integrating all the benefits of an ordinary café. And this holds true in terms of psychological-education, information, therapeutic contact with professionals and people in the same situation.

3. AC: underpinning

The AC Concept is based on the following views:

- . Dementing illnesses are chronic diseases of the brain, which means that 'the person with dementia' also becomes 'a patient', requiring professional care and treatment interventions
- . Most people with dementia retain a lot more awareness of the (consequences of the) disease, and for a longer period of time, than people thought in the past. It is therefore possible to refer to people with dementia as having an 'awareness context' of their dementia (as was also described for people with cancer three decades ago).
- . If you add this 'awareness context' to having a dementing illnesses, a 'psycho-trauma' [psychological trauma] scenario can emerge.

The person with dementia is therefore not only a patient but (potentially) also the victim of a disaster that never ends; so each person/patient is fighting not just against a loss of control but also against feelings of fear and insecurity. And this fight is often invisible. (It goes without saying that the ability of the person with dementia to cope is influenced by individual factors: what may be a serious disaster each and every day for one person may not necessarily be the same for another).

Families of people with dementia can also be seen as (potential) victims. They are embarking on a complex and complicated process of caring and grieving that will only end when the person/patient dies. This process can be understood as the reverse of when someone 'goes missing'. What's

more, the family members have to witness their loved one fighting a losing battle. And these various factors often remain invisible to the outside world. **Together, the person with dementia and his/her family are as it were, fighting against an imminent emotional separation or isolation.**

4 Regaining some control and new connections

From this perspective, "an Alzheimer Café is a place where dementing illnesses acquire status, and where those involved are acknowledged, sometimes after a long time. Here, they [at last] they receive a voice and recognition. It can help towards their emancipation in the sense that if you go to a café gathering, you are acknowledging that you have 'something to do with dementia'. And that's already a significant step for nearly everyone. In a certain sense, this step is crucial to be able to live and cope with the disease.

'Acknowledging' (coming out) that 'I've got Alzheimer's' [or whatever dementia], or, 'I've got something to do with dementia' is often the first step on the road to regaining some control, and taking charge of your own life again. By 'coming out of the closet' about dementia, you can stop yourself from becoming 'stuck' in the role of victim. A good quality Alzheimer Café is a sort of safe haven, guaranteeing the security and assurance needed to enable people with dementia and their families to as it were explore the disease and its consequences (both now and in the future), giving them the ability to look their enemy in the eye as quickly as possible.

Then they can stop trying to walk away or deny it.

5 Closing thoughts

I personally find the Alzheimer Café to be a sort of ritual for ridding oneself of fear, emotional separation and maintaining a long-term resistance against what is happening. At the AC, you will meet people, perhaps even from your neighbourhood, who are facing similar problems. Throughout all these years, I've seen some really solid friendships developing at ACs.

And finally, as we all know: 'Tragedy is not deep and sharp if it can be shared with friends.'

I wish us a successful conference, and hope that collectively we can work towards offering and extending this form of support to many others.

Bère Miesen