

## DEMENTIA HARROGATE - ALZHEIMERS CONFERENCE

Harrogate Conference Centre – April 24<sup>th</sup> 2013

I believe that those who are connected in any way in the caring (health & Social) services including the voluntary sector are aware of the benefits of early diagnosis than was the case a few years ago. I hope to hear from the speakers that early diagnosis is happening across the UK as a whole and that the problems some people experienced of waiting up to ten years for a diagnosis are things of the past. We may joke with one another about episodic dementia when one of our friends cannot recall the name of a person or place within 2 seconds, but do the public have sufficient awareness to judge the difference of mind overload or the beginnings of a more serious loss of short term memory.

The first speaker was Professor **Murna Downs**, professor in dementia studies and head of the Bradford Dementia Group at the University of Bradford. Her interests focus on improving the quality of life and quality of care for people with dementia and their families. She highlighted the early needs of someone diagnosed with a form of dementia. People like to be sociable so there is a need to think of the 3 'Cs'.

Commonality - Curiosity - Courtship

Communications are at the heart of dementia care and the need to step into that person's world. Start with common ground, reminiscing, nostalgia groups, memory classes. It is very important to talk about something the person with dementia knows about. Those with memory loss can feel lonely if they have no one to talk to about what they know (a survey in 2012 showed that those with dementia are more lonely than ever)

A practical way of communicating with people with dementia was demonstrated by the use of old photographs (**Chatterbox cards**) arranged in decades to stimulate conversation at the level of a person's memory level. Memory Bank has the same aims by using old films from York Archives. The still photographs are £19.00 a set whereas the old films with work cards to help stimulate discussion are £29,95p

**Trevor Jarvis** was diagnosed with vascular dementia in 2001. He is an ambassador for The Alzheimers society and speaks regularly at Conferences particularly on younger people with dementia. He firmly believes that with the right level of support you can be more independent. His line is: '**Adventure before dementia**'  
He is an active committee member on a self help group for younger people with dementia in Doncaster, and is an active member of the Royal College of Psychiatrists Consumer Group. He talked about the things which matter to a person with dementia and how he copes with the challenges of his condition and how he overcomes them. He spoke mostly without reading his script. A very engaging speaker.

Jean Tottie who is chair of Uniting Carers, I have known for some years, we first met when both of us were involved in The National Service Framework for older people. Jean now works voluntarily to improve services for older people with dementia and their carers. She is also chair of Life Story Network and an active member of the Dementia Action Alliance. Her father was diagnosed with dementia which advanced rapidly. She retired and cared for him with the help of an Admiral Nurse. She is focussed on the need to ensure that the perspective of the carer is essential in any dialogue around dementia.

A word or two about **YECCO**.

Introducing YECCO – innovative technology to assist the day to day lives of care givers. YECCO is a unique software solution enabling families, friends and professionals to create a social network to support others in the community by the using a 3 ways system, web browser, mobile app and tablet. If a person with dementia goes missing, the technology enables that person to ‘be easily located’. They have a tracker system with 10 tel. nos. social media and would have the incentive to use it to the full. Yecco *is* working to get places/events to cater for those in wheelchairs e.g. Chelsea Flower Show.

(I attended the launch of the results of the Membership Survey of Sheffield 50+ in early May. One of the key statistics which is haunting me was the results showed that of the 2123 members only 255 have email addresses )

The concept is excellent but unfortunately the presentation said so much whilst describing the technology and how it works for people that many of us at lunch said we couldn’t take it all in it was too much, so it wasn’t just me!!

**Carolyn Denne** (SCIE)

NICE’s new Collaborating Centre for Social Care hosted by the SCIE was established in April 2013. Carolyn is responsible for strategic level planning and liaison with NICE. SCIE and partners are helping to ensure that key stakeholders who commission, provide and use Adults’ and children’s services know about and contribute to NICE guidance and quality standards for social care and can make best use of them hosted by SCIE (Social Institute for Excellence) Carolyn suggested that only half of those in the community with dementia, have been diagnosed. She reiterated the importance of Awareness, early diagnosis and quality of care were principles to which we should all adhere.

There is still stigma attached to dementia, inadequate health and social care and lack of research. The target must be to increase the numbers of those diagnosed.

**Conclusions**

***Once more speakers gave me the confidence that everyone, from sufferers, carers, the care services and the use of appropriate technology, are clear about identifying what is needed to face the challenge of a society where thousands have dementia. What has been highlighted again at this conference is the need for early diagnosis, training in awareness, development of dementia friendly neighbourhoods, support for carers, opportunities for sufferers to lead as normal a life as possible following diagnosis but **Is it all happening and happening fast enough to match the growth in numbers of those with dementia?*****

There has been considerable commitment to developing friendly neighbourhoods during the last two years and the Prime Minister's support and mass campaign for 1m Dementia Friends has helped enormously but what about the care services where are the improved developments for the rest? The Conference producer says that one statement has especially resonated with her:

*"all that is wrong about health and social care is magnified, highlighted and dramatised by dementia services."*

I emailed Dr. Oliver Corrado (member of Future Years and Dementia Champion at Leeds Teaching Hospitals:

*"I attended the Alzheimers' conference in Harrogate yesterday. There were some interesting speakers, but I do wonder how much progress is being made and how many hospitals have embraced a change of attitudes to those in hospital with dementia, especially getting to know the whole person. One speaker spoke about a 5 day stay in a hospital of her mother who deteriorated so much she never returned to her own home again.*

I was pleased when Dr. Corrado emailed me with these comments which does show some implementation of the actions needed to improve the quality of life for those with dementia.

*I fear you may have hit the nail on the head ! All too often these new initiatives are seen as mandatory 'tick box' targets and don't translate into improved care. Having said that I Chair the Y and H 'Acute Hospital' dementia Champions and over the past year I have been really impressed with the differences in care for people with dementia Trust's have initiated.*

*Including Bradford's Dementia Friendly Wards, Doncaster's 'Delirium' ward, many have introduced 'This Is Me' type documentation (including Leeds !!), Forget Me Not/Butterfly Schemes, Dementia Care pathways, anti-psychotic policies etc*

*So a lot has happened but we still have a long way to go! Dr. Oliver Corrado (Dementia Champion at the Leeds Teaching Hospitals and member of Future Years)*

Report and thoughts about the Alzheimers Conference

Shelagh Marshall Chair, Future Years, Yorkshire and Humber