

# People who are losing their past still deserve a future

## Care homes, arts projects and other innovations in dementia treatment could save people from a life of bland reassurance



By Anne Karpf  
The Guardian, Wednesday December 3 2008

To most people the very mention of Alzheimer's induces a state of hopelessness. We make nervous jokes about "senior moments", or express don't-know-how-you-manage sympathy to carers. Those with Alzheimer's themselves, meanwhile, are often talked of as if they've already slipped the bonds of humanity: they're ex-persons.

So if I told you that I'd spent an evening at the Wellcome Collection in London a few weeks ago discussing dementia and emerged feeling excited, you might wonder about the soundness of my mind. Yet the pioneering work described there is profoundly improving the experiences of both people with dementia and their carers. Later this month the government launches a national dementia strategy. If these new methods are given enthusiastic backing and money, there could be a revolution in the lives of the 417,000 people with Alzheimer's in the UK.

At its forefront is John Zeisel, visiting professor at Salford University, who runs seven innovative care homes in the US, and whose book, *I'm Still Here*, will be published in the US next month. Zeisel argues that attention so far has been focused on pharmacological treatments - no wonder we feel hopeless since no cure is in sight. Incurable, though, doesn't mean untreatable, and if we shift our focus to the non-pharmacological then dementia becomes treatable in many different ways, including the design of the very buildings where people with dementia live.

The environment, he argues, "is like a prosthesis for those who have difficulty carrying a cognitive map". Designed skilfully, it can give the person knowledge about how to use it properly, rather than relying on what they themselves remember. It's as if the walls themselves have brains and ears. Among the design characteristics that can improve the lives of people with Alzheimer's are camouflaging exits leading to dangerous places; providing destinations at the end of pathways that encourage walking rather than aimless wandering; gardens designed therapeutically - contact with nature, natural light and seasonal change can help people orient themselves; and a sensual environment,

promoting seeing, hearing, touching and smelling. A common design myth in dementia care, maintains Zeisel, is that if everything is sedate and bland, residents will be soothed. But soothing taken to an extreme itself can be anxiety-producing, while the changes to the physical environment advanced by Zeisel can, according to a National Institute on Ageing study, reduce symptoms.

Other myths about Alzheimer's - that it obliterates all memory, and that people with the condition can't learn anything new - erase people with dementia's pasts, but also their futures. In fact, though cognitive and complex memories are compromised, body, emotional, skill and artistic memories are often still intact and acute. Together with Sean Caulfield, Zeisel established Artists for Alzheimer's, through which artists share their work with people with dementia. Those with Alzheimer's also tour museums like the Museum of Modern Art in New York and the Louvre in Paris, where they show not only a remarkable sensitivity to the work but also do powerful creative work themselves.

Zeisel is part of a growing movement for person-centred care, one encouraged in the UK by the Journal of Dementia Care and expressed in numerous interesting projects, as well as by individuals such as writer and researcher John Killick. Killick set up the website Dementia Positive, two words not often found as neighbours, and has worked with people with Alzheimer's to produce three books of startling poems. These people have a lot to say but are often not listened to, Killick contends. They often speak in metaphors, a poetic language of elation, wit and despair. One woman told him: "The arts is all that's left. Give them us!" Another wryly commented, "The brilliance of my mind has slipped away while I wasn't looking."

Yet for all these exciting approaches, there are scores of older homes with poorly paid, demoralised staff and residents sitting in rows gazing blankly at TV sets. No wonder relatives dread visiting, their hopelessness compounded when they arrive and say: "Hi Mum, remember me?" only to be met by a vacant stare. Don't test them, implores Zeisel, it only increases anxiety (we've all felt it when someone says accusingly "you don't remember me"). Far better to say "Hi Mum, this is your grandson Adam who you always enjoy singing with."

Now Zeisel's work is to be piloted in an ambitious new project in Barnet, one of the biggest providers of care in the country for people with dementia. In a pioneering programme blending non-pharmacological with pharmacological approaches Barnet primary care trust and mental health trust, jointly with Barnet local authority, will retrain its staff, including social workers and community psychiatric nurses, and is trying to establish collaborative ventures with the Arts Council and even football clubs.

Killick and Zeisel talk of "the gift of Alzheimer's". They don't pretend that anyone welcomes the condition. What they mean is that spending time with someone with dementia forces you to slow down and stay in touch with what's essential in a human being when the trappings have gone. And that's a gift not just for them, but for all of us.

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