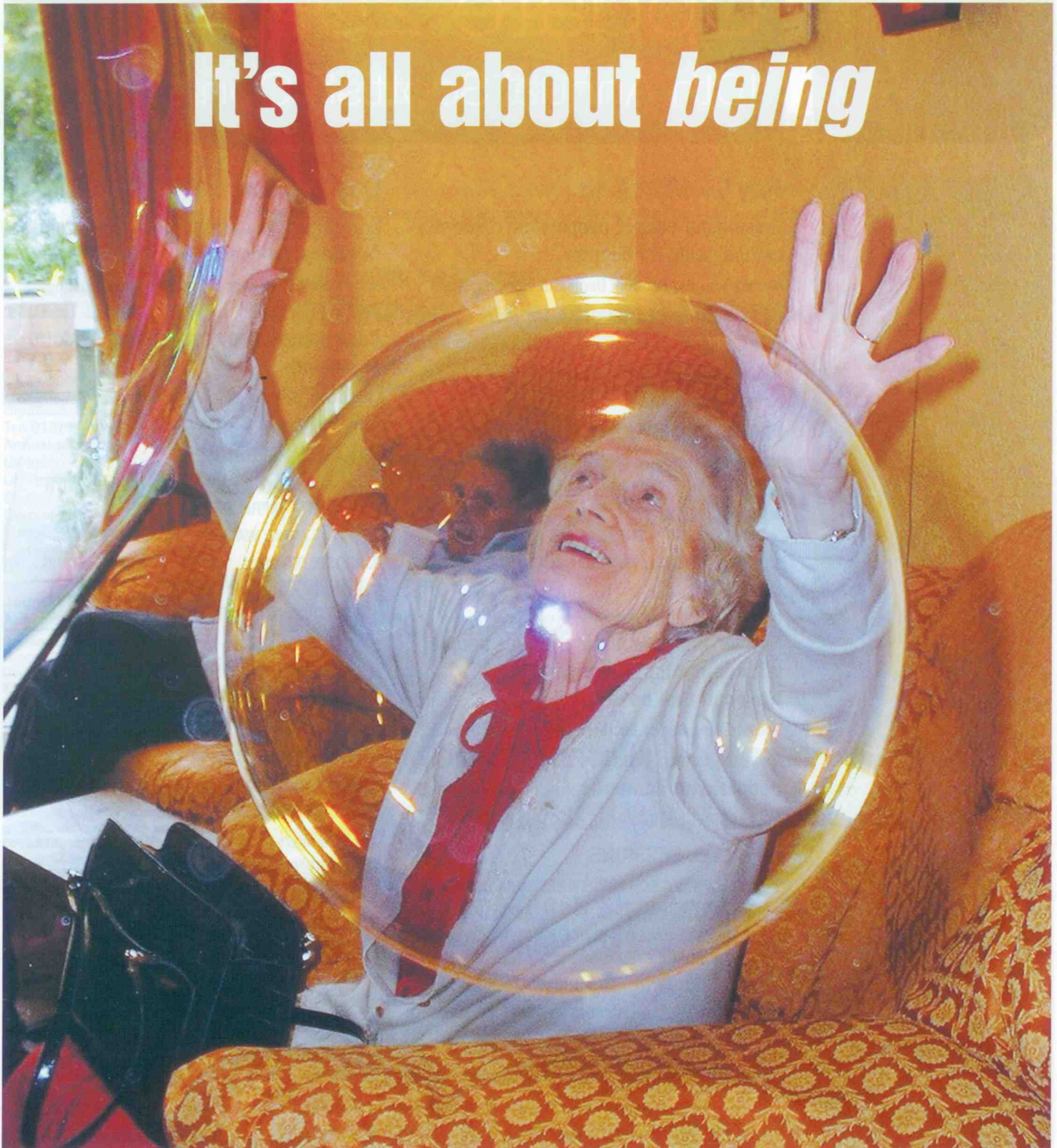


# The Journal of **DementiaCare**

For all who work with people with dementia

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**It's all about *being***



- **Tom Kitwood and culture change in dementia care**
- **Alzheimer Cafés compared and evaluated**

individuals had found helpful, such as keeping their brains active through a range of mental activities such as puzzles.

Support was fundamental and, in addition to their families, many had found this through Alzheimer's Society networks. Bill Wilson said that his local branch had become his extended family. "If I don't 'phone every day they ring me to find out if something is wrong," he said.

**Seizing the power**

Individuals could help to remain empowered by developing a positive approach to living with dementia. Delegates acknowledged that, as in life generally, there are some things that cannot be changed "but we can come to terms with these, accept them as a fact of life and focus on the positive aspects".

People with dementia are also seizing power collectively and many said that a most empowering experience had been becoming part of an outward-looking, positive group of people who are all facing the same issues. "We have helped each other to get back into society, to be active citizens again, to make ourselves heard, and to get back some of the power we have lost."

A range of practical initiatives have resulted from the work of the Living with Dementia Group, such as the 'help' cards, which people carry with them to explain their condition to members of the general public and communicate the type of support that they may need. These had proved to be a lifeline to many people at the Convention.

**Building the future**

People with dementia from all around the UK are actively involved in building the kind of future they want to see. "We are interested in the things we can do something about", explained the Scottish Dementia Working Group, "like the way we cope with our condition, how other people respond to us and the approach of the organisations with responsibility to provide services".

The groups are working to:

- challenge stigma and raise awareness through all forms of media, attending conferences and giving presentations
- help people with dementia to remain empowered and as independent as possible by helping them to maintain their skills and to learn new skills
- ensure that people with dementia are able to influence by involving them in developing government legislation, in the planning of new services, in new publications and on interview panels
- network with people with dementia through local groups and online to different parts of the world; developing the groups' website so that it is easier to use.

The groups are also actively campaigning for the availability of anti-dementia drugs. Another campaign challenges those GPs and consultants who refuse to offer a brain scan to people suspected with a dementia.

Some group members are going into local schools to talk to the children about dementia. Others are negotiating with local supermarkets so that shops are more dementia-friendly, possibly with specific shopping times reserved for people with disabilities. There is also a new concept of day care being developed which aims to recognise the need for constructive and purposeful activity for people who want to achieve something real and of benefit.

The possibilities seem endless and the enthusiasm to achieve real change is clear. As Ken Clasper, Chairman of the Convention, encouraged: "Be inspired, get involved. Don't be afraid to speak out, let's make our voices count. You live with dementia, you don't die with it. There's nothing to be scared of. It's your future – go for it – what do you have to lose."

Details of the Alzheimer's Society Living with Dementia Programme are at [www.alzheimers.org.uk](http://www.alzheimers.org.uk). For more information about the convention, contact Phillipa Hobson at Alzheimer's Society, c/o Sheffield Branch, Venture House, 105 Arundel Street, Sheffield S1 2NT. Tel: 0114 279 9834. Email: [phobson@alzheimers.org.uk](mailto:phobson@alzheimers.org.uk).

# Highlights from the Harrogate Congress

A roundup of reports and reactions from the 2007 UK Dementia Congress

*Maria Parsons, London Centre for Dementia Care*

"I'm an Alzheimer's commando me", said a member of the **Scottish Dementia Working Group** (SDWG). His powerful message about having nothing to lose by publicly taking on the disease and fighting to the end stayed with me through the whole event. At last, I thought, the personal has become political. I hope he went to some of the presentations that followed this opening session, because it is clear that so much progress is being made on so many fronts in the struggle for better outcomes for individuals and their families and against stigma, injustice and social exclusion.

*Rachael Litherland, Innovations in Dementia CIC*

People with dementia from the **Living with Dementia** (LWD) programme and SDWG (pictured on stage, opposite) laid down the most significant gauntlet to the Congress. It is not enough just to "hear the voices of people with dementia" – we must engage with them and take action. Ensuring this key message is at the heart of the National Dementia Strategy and other policy developments should be a commitment of all who attended Congress.

*Dr Nori Grabam, Vice President of Alzheimer's Disease International*

The most startling fact for participants at the Congress was **Dr Jacob Roy's** (right) statement that most people with dementia live in low and middle income countries (71% by 2040). It was amazing to hear how much the Alzheimer's and Related Disorders Society of India has achieved in his country. Education and training of all those involved with caring for people with dementia has been the key to success, as indeed it should be in our country with its infinitely greater resources.



*Hazel Heath, nurse consultant*  
Representatives of LWD and SDWG described the realities of their everyday lives – the challenges but also the positive aspects. Some concluded that, rather than a death sentence, their diagnosis of dementia had been a new beginning – an opportunity to discover a new purpose, learn new skills and find new friends. The effects on the audience were clearly profound. One said: "I have been a nurse for 28 years and a specialist for 16 – I now realise that we are not the specialists – you are".

*Paul Whitby, clinical psychologist, Avon and Wiltshire*

In my 25+ years in this field I have been impressed by two revolutions. The first was when we began to take serious notice of the subjective experience of people with dementia. This resulted in ideas of person-centred care which nowadays we take for granted. The second revolution was apparent at Congress: to my amazement and delight we now have people with dementia speaking from the podium as experts.



*John Wattis, consultant old age psychiatrist, Huddersfield.* I particularly enjoyed the contribution from **Elizabeth Anderson** of the Bradford Dementia Group on the neurological underpinning of disturbed behaviour in dementia and person-centred care. "Emotions come first" is now imprinted on my memory! I also enjoyed the whole trans-disciplinary atmosphere including people with dementia and their carers who had a central role. A pity there weren't more psychiatrists and physicians there.



*Niall Moore, consultant old age psychiatrist, Bristol* It is a shame that so few doctors are aware of the variety and value of the additional perspectives

which are portrayed at this event. **Dawn Brooker's** lampooning of the IPA annual meeting talking about 'Pharmacological and Non-Pharmacological Treatments'

left an indelible message for me. Reducing the impact of all therapies and other human interventions to the status of 'non-drug' is an appalling indictment of what doctors apparently think.

*David Jolley, consultant old age psychiatrist, Wolverhampton*

The joy of the conference for me came from the pervasive feeling of 'family' – accommodating people of all generations, hardened (or softened) old campaigners alongside neophytes: professionals of every persuasion and perspective, together with some carers and patients. All were treated and received with respect.

What are care homes if not the hospices of dementia care? We should all be much more proud of the good work we are doing, said **Nadine Schofield**, National Lead, Older People's Mental Health Programme, describing an encounter with a nurse who, when asked where she worked, was visibly proud to say that she worked in a hospice. →

**Daphne Wallace**, keynote speaker, retired old age psychiatrist now diagnosed with vascular dementia, said she was determined to be open and talk about her diagnosis and thus help to reduce the stigma. The dismissive reaction of some medical colleagues to the early signs she noticed had been hurtful and demeaning – they clearly felt threatened at the diagnosis coming so close to home. She said that as a medical practitioner and psychotherapist she had always tried to identify with the individual, and was even more determined now not only to do so but to speak publicly about it.

The other lesson her experience had taught her was that there must be one point of contact with services. "It doesn't matter which profession but one person must take the lead, someone the person with dementia can relate to," she said.

*Buz Loveday, dementia trainer, adds:* Dr Wallace described the denial she encountered when telling colleagues of her word-finding and orientation difficulties ("We all have those problems"). For her, described earlier in life as a 'verbal athlete', the problems were new and significant. While it's essential to focus on the abilities and strengths that people retain, we must never lose sight of the process of change and loss they are going through. We need to practise true empathy: not comparing a person's experience with our own, but listening and seeking to understand what's going on for them.



The Dementia Services  
Development Centre  
Northern Ireland



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STIRLING

## Embracing the Challenge: Citizenship and Dementia

6-8 May 2008  
Stormont Hotel, Belfast

The Dementia Services Development Centre – Northern Ireland is pleased to announce details of its 1st International Conference. This will feature presentations relevant to frontline staff, academics and medical teams, as well as people with dementia.

For more information and to book a place visit [www.dementiacentreni.org](http://www.dementiacentreni.org) or contact Jemma Galbraith on 01786 467 740 or [jemma.galbraith@stir.ac.uk](mailto:jemma.galbraith@stir.ac.uk)



In her Tom Kitwood Memorial Address Dawn Brooker, professor of dementia studies at the University of Bradford, assessed the progress made over ten years since the publication of Kitwood's *Dementia reconsidered*. It was a sober reflection confirming that, despite all the good things presented at congress, we still have plenty of work to do. There was one striking exception to this – in the area of involving and consulting with people with dementia, we have made huge strides over the last ten years.



*Jenny Henderson, Alzheimer Scotland*

**Katy Jenks** from Braemont Nursing Home in Glasgow (BUPA Care Homes) was a breath of fresh air! She described how she brought about real change and took staff with her. Many people talk about it or make excuses for not doing it, but she has implemented evidence-based changes and improved the quality of life for her residents.

*Tom Owen, My Home Life*

It was great to see so many practitioners from care homes and other settings getting up from their seats, communicating their ideas, sharing their expertise and adding to the wealth of knowledge on improving quality of life and quality of care for people with dementia.

*Celia Price, Just Checking Ltd*

The lively debate about the ethics of using technology in

the homes of people with dementia was put in perspective when a delegate, who has dementia, came and ordered one of our movement sensing monitoring systems for herself. She explained she was happy for her friends to be able to 'see' when she needs more help, and when she doesn't.

**Professor James Lindesay**,

professor of psychiatry of the elderly, University of Leicester (left) gave an overview of the state of research into



prevention and treatment of dementia, and concluded that while there will be cures for dementia in the future they will be slow in coming, and expensive. Meanwhile, he said, we need to focus much more than we are at present on disability reduction.

*Amanda Thompsell, consultant old age psychiatrist, London*

I learned some great new ideas for practice: Talking Mats, a simple picture-based system to aid communication; the realities of pet therapy; and the simple but so helpful idea of always having items with you to help stimulate conversation with people with dementia.

All presentations for which we have permission, plus further feedback from delegates, are available on the congress website, [www.ukdementiacongress.co.uk](http://www.ukdementiacongress.co.uk). If you would like to add a comment please email [sue@hawkerpublications.com](mailto:sue@hawkerpublications.com)

# Lies, damned lies and dementia

**The outcome of the debate on the first evening of Congress surprised many: the motion, 'Lies can play an important part in delivering person-centred care', was carried by a narrow margin. The terms of reference were so wide – to include, for example, painting murals over doors and the kind of 'white' lies most of us have used to avoid hurting people – that this outcome was perhaps inevitable. Most controversial, however, was proposer Ian James' description of a rehearsed lie used as part of a care plan (to be used only after all other interventions had failed). Brenda Walker, who sparked the debate in *JDC* with her response to the Newcastle team's first article about lying (Wood-Mitchell *et al* 2006), describes her reactions below:**

The example Ian James gave was of a woman refusing to sit down for breakfast because she had to "pick up the children". He suggested that it was appropriate to say – as a last resort – "Your sister's gone

to get them" (she had indeed done this in the past, and this lie had allayed the woman's anxiety).

To me this is clear treachery – the kind of lie that, I feel, can never be justified. It simply misses the point.

The Newcastle model of assessment is excellent and thorough and I have absolutely no doubt that many perfectly acceptable solutions are found without resorting to treachery. What I struggle with is that a model clearly seeking to find a person-centred response can end in treachery.

Ian James does not seem to be promoting lying so much as saying it is a perfectly acceptable response where no better solution can be found. But if the team's thorough assessment process fails to find an acceptable response then they have simply failed to find an acceptable response; it does not mean there isn't one.

And does this failure justify deception? Whatever we decide, let's not pretend that this response is person-centred.

At the core of this debate lies communication. Given the ravages of dementia and the

devastating effect on language and memory, surely those of us who are lucid need to bridge that gap and try to communicate in an honest way which attempts to make sense to the person with dementia. If we are too literal in our interpretation of their words we are holding them to our rules. We need to move to their rules. There is lots of evidence that their feelings are still intact, so that's a good starting point for honest communication.

Telling this woman that her sister has gone to collect her

*Paul Edwards, Bradford Dementia Group*

The debate about the use of lies on the first evening really challenged my thinking. I was struck by the persuasive arguments and the questions that were generated. Even though the voting did not go the way I'd expected it gave me a real insight into what our collective wisdom is around this issue and our openness to debate such controversial issues in dementia care. A great and challenging start to a really thought-provoking conference.

children may ease the situation temporarily but it doesn't solve anything longer term and the chances are that the resident will return to the same behaviour.

We need to consider how she is feeling, and what might have prompted her behaviour. It could be a multitude of things. Has she heard something on the television or the radio that she's misunderstood? Has she always been busy and feeling that she should be doing something but not sure what it is? Is it her way of saying "I'm not comfortable here"?

If we encourage staff to keep considering these sort of questions then we provide care environments which are truly responsive to people with dementia rather than environments which feel justified in deceiving and manipulating; our clients deserve so much more than that. In my experience, this way of working is well within the grasp of many care staff, though they do need ongoing training and support.

**Reference:** Wood-Mitchell A *et al* (2006) Lying to people with dementia: sparking the debate. *Journal of Dementia Care* 14(6) 30-31.