

# The Journal of DementiaCare

For all who work with people with dementia

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## Positive spin The benefits of cycling



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- Immersive learning
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- What is truth? Dilemmas when two realities meet

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### Letter: We still need good dementia design

I thought the important article by Jill Manthorpe and Steve Iliffe in the last issue (What is dementia and how big a problem is it? *JDC* 25(1) 16–18) was immensely useful in the way it pulled together, referenced and explained the disability approach to dementia. Those of us in the dementia design world have been basing our work on this approach for years. If you are designing for people with dementia, you have to consider all the impairments that are common in late life as well as those relating to dementia. It is the complex interrelationship between impairments that makes this field so challenging.

Jill and Steve also gave a very considered view on the “scale of the problem” and the fact that the proportion of people with dementia is going down. They rightly suggest that the implications of this should be considered by a wide range of professionals. They specifically mention architects, designers and others who are dementia specialists. This is perplexing since they are clear that the absolute numbers are increasing as the population ages, although less than expected. It is perplexing since it seems obvious that specialist knowledge will still be required.

We need much greater attention to internal and external environments for several reasons. First, to ensure that they do not cause unnecessary disability to people with dementia. Second, because they are really helpful to people with other conditions such as delirium, learning disability and some brain tumours, as well as for people with some medications that affect perception and cognition. Thirdly, good dementia design is helpful to any older person – and probably to most people. All care homes, hospitals and other buildings where there is likely to be a high proportion of older people, should be designed for them and for the large proportion who also have dementia and are most profoundly affected by design.

Mary Marshall, senior consultant, Dementia Centre, HammondCare

**Jill and Steve reply:** Thanks for this observation and your support. We need to think about the home and outdoor environments and we may also want to do more on refurbishing in general housing with the assistance of specialists in architecture and the environment.

There are good opportunities to think about outcomes not just in terms of choice of place but also whether it is warm, safe and clean. Some recent social care outcomes studies suggest that these three things matter greatly.

Your work on toilets and how confusing they can be is a good example of how responding to dementia needs this type of investment, critical thinking and sheer practical action. We think it should be considered as part of the biopsychosocial response to dementia that seems to have a great deal more promise than other areas.

# Positive spin:

Cycling is fun and taps into procedural memory, which can remain remarkably unaffected in people with cognitive impairments. **Clare Morris** talks about the joy of taking part in “Positive Spin”.

**P**ositive Spin is a cycling project for people with dementia and their carers. Scepticism was a frequent reaction when I first floated the idea and this may have been justified, given the symptoms of impulsivity, poor planning and judgement that can accompany dementia. But cycling relies on procedural memory, an aspect of memory that is often unaffected in people with cognitive impairment despite some of the very disabling movement disorders that often coexist with it.

Cycle Training UK (CTUK) is a not-for-profit cooperative that exists to promote cycling as a form of transport and provide training to people whatever their age of ability. Thanks to CTUK's support, and funding from the London borough of Lambeth to conduct a pilot study, I was able to establish Positive Spin as a project. So far it is offering cycling sessions in two London boroughs, but we plan to extend it to other parts of the UK.

People with dementia can remember whether they have experienced a movement before, in addition to which advances in our understanding of neuroplasticity (Doidge 2015) suggest that people with dementia can learn new procedural skills. The brain can recover function by developing new connections. We have found this in relation to cycling and this year we hope to begin work on an evidence base to demonstrate it. Similarly, I have heard reports of success in learning to swim and there is wonderful work in progress with Dementia Pathfinders

and New Adventures' Dance for Life, Rambert and other dance initiatives.

### Inclusivity and validation

An inclusive approach which enables meaningful success is key to the value of this project. We have several people with various forms of young onset dementia who are very disabled in activities of daily living, yet not only can they still cycle but the regular cycling has brought about a perception in the family of slowing down the progression of symptoms. We find that people with dementia have often been more skilled cyclists than other members of their families.

In some instances, it has been the only service that the person with dementia has agreed to take part in, addressing the isolation of those caregivers whose relative responds to their difficulties with denial. In others, it has been the only time they leave their home and get out and about in their community in the fresh air.

National standard outcomes for teaching cycling break down the skills required into very small steps. This framework is used across the board in teaching cycling skills, for children in schools, for experienced cyclists seeking training on-road, and for people with special needs. Piloting Positive Spin we have used this framework to enable people with dementia to develop cycling skills safely.

■ Clare Morris is a Dementia Pathfinders associate and psychotherapist working with Cycle Training UK.



# the benefits cycling brings



For some, this is the only service the person has agreed to take part in; for others it's the only time they get out in their community in the fresh air

## Risk assessment

Each trainee, carer and person with dementia is assessed on an ongoing basis, as would be done with any cyclist of any standard. We call this dynamic risk assessment and it is key to validating progress with cycling skills while managing risk. In our experience, all trainees with dementia have appreciated and responded very well to this framework, including those for

whom impulsive behaviour has been of concern.

Cycling gives people a sense of freedom to move around independently and under their own control. Osteoporosis, chronic pain, reduced mobility when walking, stroke and wheelchair dependence have not been a barrier to engaging in cycling. Quite the contrary, pain-free mobility has been facilitated. The opportunity for

carers to engage mindfully in cycling without worrying about their relative, and share a joyful experience on equal terms, contributes enormously to the therapeutic value of this project.

Other benefits have been reminiscence about cycling, making new friends and socialising with people you recognise. It has been a chance to share frustrations and problem-solve the trials of living with dementia as well as indulge the pleasures of trying out a variety of bicycles. Reports of improved cognition beyond the cycling sessions support the wealth of research pointing to the benefits of exercise for everyone, including people with dementia.

assured national cycling club for people with dementia and their families that can be accessed wherever they live. It would use the approach that has been refined and shown to facilitate engagement in our initial work.

To date there are two established projects in Lambeth and Hackney and roadshows to help isolated people access them will restart in March. Last year more than 130 people took part, with 17 regular participants attending most weeks come rain or shine.

For more information and updates go to [www.cycletraining.co.uk/our-services/positive-spin.html](http://www.cycletraining.co.uk/our-services/positive-spin.html) Scenes from a day trip from Finsbury Park to Springfield Park for a picnic involving 12 people with dementia and their carers can be viewed on YouTube at <https://www.youtube.com/watch?v=hxRSqBmJWaQ>

## Reference

Doidge N (2015) *The Brain's Way of Healing: Stories of Remarkable Recoveries and Discoveries*. London: Allen Lane.

## Granville's face lit up – he was delighted to be back on wheels

As a dementia advisor, I must admit to having been somewhat sceptical about the idea of Positive Spin – cycles and people with dementia not immediately striking me as being an altogether happy combination. I am, however, now a convert!

A week after having had his first go on a bike through Positive Spin I met with Granville. He was accompanied by his daughter. Granville is a lovely man – quiet and contained – who doesn't often join in conversation and very rarely initiates it. But when his daughter mentioned the bike ride, Granville's face lit up and he interrupted her to tell me about how when he was a boy he had ridden from end to end of the island of Barbados.

Granville was clearly delighted at being able to get back on wheels and it was great to learn of an aspect of his growing up that we had not heard of before. Positive Spin really does tick all the boxes!

*Claire Wheeler, Hackney & City Alzheimer's Society.*

## Our vision

Given the enthusiasm for our initiative, CTUK is looking to expand Positive Spin "hubs" across London, and there are a number of not-for-profit cycling organisations elsewhere interested in taking it on as a franchise. We would like to see the development of a quality-