

Community links: dementia on the high street

Mary Keating, Becky Hayward, Lucy Hennessey and Angela Willis describe a range of efforts in Gloucestershire to develop dementia-friendly communities – including taking over a shop for a day to offer information about dementia

The needs of people who live with dementia stretch far beyond what can be met by the NHS or local authority social services departments. Here we describe work being done by the Gloucestershire Dementia Training Partnership, to take a leading role in local partnership working to develop dementia-friendly communities. We will report on two key areas of work: developing a growing network of local people who will nurture dementia-friendly communities within their work and neighbourhoods, and the hosting of a pop-up dementia shop on high streets across Gloucestershire.

The Gloucestershire Dementia Training Partnership is a multi-agency partnership, including representatives from the NHS, the local authority, voluntary organisations (including the Alzheimer's Society) and members who are Experts by Experience. The partnership oversees the work of the local Dementia Education Team, which develops and delivers a leadership programme and a variety of training workshops and resources.

Our work to develop dementia-friendly communities has been guided by using a strengths-based or asset approach. The asset approach promotes identifying local solutions to wider challenges in society (see Foot *et al* 2010). It encourages building on the assets or strengths of a particular community and engaging people in taking action. It can be cost-effective, since it provides a conduit for the resources of a range of organisations to complement the work of service providers. It can help communities to develop their own resources, which in turn can promote sustainability and also reduce discrimination.

In the table on p22 we set out our learning from using an asset approach to develop dementia-friendly communities within Gloucestershire. Some small practical examples of how we have put this into action are: a crèche club at a local care home, where people with dementia care for and play with the toddlers while their parents have a break; at Fair Shares, a time banking scheme, one gentleman with dementia who is skilled at making wood kindle bundles does this for his neighbour in return for a weekly grocery shop, as he is no longer able to drive.

Community dementia links

One of the key ways we have put the strengths-based approach into practice is by developing a network of local people who will work at a grassroots level to promote dementia-friendly communities.

In 2013, 12 local people from different

backgrounds, all with one common interest in the role of civil society for people with dementia and their families in Tetbury, came together to train as community dementia links (CDLs). The group consisted of a person who worked at the local supermarket, a business manager, a building society manager, hairdresser, receptionists, a day centre worker, a teacher and a representative from the local chamber of commerce. Each person had come forward at the end of a community awareness raising workshop, facilitated by the Dementia Education Team, saying they wanted to be involved more and were interested in training as CDLs.

Overall, the CDLs work with others in the community to facilitate opportunities for strength, sustainability and growth where people with dementia can live, feel welcomed, involved and valued. More detailed aims of the role of the CDL are:

- to encourage people to be more supportive, accepting and considerate of those with dementia in their communities
- to consider and disseminate the benefits of being known as 'dementia friendly'
- to identify strengths in the person with dementia, and support the individual or group to find new or alternative ways to contribute to their community's growth and development
- to support people with dementia to feel welcome in their community
- to identify individuals within your community who may benefit from appropriate information or guidance or from other forms of support available in your community, such as a memory cafe
- to contribute to stopping or delaying inappropriate or premature admission to hospital or a care home, by engaging support to sustain the person in their community
- to share your knowledge and understanding with other community groups or individuals.

The group attended seven workshops, designed around the strengths-based approach in developing a dementia-friendly community. The workshops were developed and delivered by the Dementia Education Team on behalf of the Gloucestershire Dementia Training Partnership. They learned how to map the assets in their community of Tetbury – this process helped the group to identify the community's strengths as well as its deficits.

The group has gone on to work independently and to do some amazing work. The supermarket employee organised for a leaflet about dementia to

Mary Keating leads the Dementia Education Team with Gloucestershire Dementia Training Partnership; Becky Hayward is the Dementia Lead and Neighbourhood Services Manager with Gloucester City Homes; Lucy Hennessey is the Dementia Lead and Manager at Hawthorns and Broadleas Care Homes; Angela Willis is Organisational Development Business Partner for Human Resources with Gloucestershire County Council. To follow up on this article, email Mary on Mary.Keating@glos.nhs.uk

Where we started from	Where the asset approach took us	Gloucestershire's approach now
Identify deficiencies and needs within the community	Start with the assets in the community	We have interested people and organisations
Respond to problems	Identify opportunities and strengths	Start a buzz to generate enthusiasm
Develop & provide services	Invest in people	Dementia Leads and Community Dementia Links
Emphasis roles of agencies	Emphasis the role of civil society	Emphasis the role of civil society
Focus on individual	Focus on communities, neighbourhoods and the common good	Focus on experiencing and understanding well-being with dementia
View people as needing a service	View people as equal members/co-producers with something to offer	Include people with dementia to offer their strengths
Treat people as passive & done to	Facilitate opportunities for people to take control of their lives	People with dementia have control in their lives
People with dementia have control in their lives	Support people to develop their potential	Support people to develop their potential
Implement programmes as the answer	See people as the answer	New community links and networks developed



Above: Outside the pop-up shop and (right) inside

be put into the pay packets of 400 members of staff. The hairdresser asked all her regular clients if she could take a head and shoulders photograph of them after they had their hair done, to make a personal portfolio for them. Her aim was to support people who have difficulty with word-finding or making decisions to look through their portfolio and point to the hairstyle they want that day. And the teacher worked with local school children and developed a model of a nerve cell to show how tau tangles and amyloid plaques develop in the brain in Alzheimer's disease.

The Tetbury group of 12 trained to become CDLs in summer 2013. The success of their work has rippled throughout the county. The second group (a group of 13) was drawn from across

Gloucestershire and finished in December 2013, and a third group of 10 in the Cotswolds has just completed a course in April 2014.

A mobile pop-up dementia shop

A second key area of our dementia-friendly communities work has been to open a pop-up dementia shop. The idea came from Lucy Hennessey and Becky Haywood (both authors here and care home managers). Both women had previously completed the Dementia Education Team's Dementia Leadership award which involves producing and implementing an action plan that can improve existing care or develop a new and innovative concept to enhance dementia care and support within the community. Both wanted to build on the work begun in Tetbury.

The Prime Minister's Challenge (DH 2012) identified 14 key commitments to improving health and care. Three of these commitments are directed specifically at supporting communities to offer more dementia-friendly care and support. For example, the Prime Minister committed the government to an awareness-raising campaign, to gaining support from businesses and a major networking event. We wanted to take a similar approach in our efforts to open a pop-up shop.

Raising awareness

Despite the projected rising numbers of people living with dementia, public understanding and awareness can be limited. We know that poor understanding of dementia has a fundamental impact on the health and well-being of people with dementia. Many people with dementia, their families and carers can struggle to remain independent in a society that does not understand dementia or how to support people and their families to live well with it.

Raising awareness about dementia is central to developing a community's strengths. The more the general public understand, the greater the interest and support will be. Raising awareness can bring the term 'dementia' out into the open, and help people with dementia to be better understood and valued. Raising awareness may mean that a person living dementia can continue to make a substantial contribution to their community – say by participating in skills banking or attending an intergenerational day facility.

In Gloucestershire we began to raise awareness about the pop-up dementia shop by sending out 1,000 leaflets to shops, homes, schools, businesses and as many other individuals or agencies as we could, constantly asking them to spread the word about the shop. We also contacted the local newspapers and radio requesting they advertise the shop. We had group members who spoke at events from the Women's Institute meetings to more formal planned opportunities such as exhibitions.

We wondered how we would entice the public in to the shop on the day itself. So we decided to offer free coffee and we rented brightly coloured tables and chairs which were inviting. The shop windows were covered with a local artist's work – again, giving a bright and appealing look.

Commitment and support

Gaining commitment and support from local businesses and agencies was relatively easy. What was difficult was negotiating the free use of an empty high street shop and this took a lot of planning and communicating. We were offered inappropriate spaces in the centre of arcades, rooms above buildings and shops in neighbourhoods, but not central to the general population. This all substantiated our perception about wider society misunderstanding dementia – it seemed as though there was a need to guide us towards being a bit hidden from busy areas for fear of reprisal and also as a means of protecting us.

Finally, Cheltenham Town Council came to our aid and we were offered a shop in a good position on a bus route on the Cheltenham High Street. On Saturday 30 November 2013, Gloucestershire opened its first high street pop-up dementia shop. Because landlords want to rent their shops we had to move quickly and we had a month to plan advertise and open the shop.

On the day

People who came into the shop on that day could get access to free expert advice from local solicitors, a GP, a local community police force officer, the Alzheimer's Society, Age UK, the local NHS memory clinic (known as Managing Memory 2gether), and a representative from the Dementia Education Team. Lucy and Becky were there too, giving out information and leaflets about dementia.

Free hand massages were available for people with dementia and their carers. A personal trainer demonstrated the value of engaging in physical exercise programmes designed for people with dementia. Free coffee and biscuits were on offer (although the shop landlord gave us free electricity for the day we had no running water so had to buy bottled water to make hot drinks). We also took the opportunity to display artwork by local schoolchildren, which depicted positive images of dementia. This was completed as part of the intergenerational raising awareness work that is taking place in the county.

Over 80 people came into the shop that day for advice, signposting or emotional support. A further 100 or so stopped outside the shop to read the information we had displayed in the shop window. This was a 'Did you know?' poster with some factual information about dementia, developed by the Dementia Education Team. We knew we needed to offer this for those who for whatever reason felt unable to come into the shop.



Future plans

We think that the shop did what we all hoped it would: it brought dementia onto our high streets, into people's lives and began the process of breaking down stigma and misunderstanding. The shop reached people that other services to date had not managed to achieve. Because of this we quickly identified that we need to move the shop around the county in order to reach all groups of people and continue ensuring that Gloucestershire is recognised by its population as dementia friendly and open and positive about dementia.

We have already received commitments from communities to open pop-up dementia shops in the north Cotswolds, Stroud and the Forest of Dean during 2014.

References

- Cantril H (1965) *The pattern of human concerns*. New Brunswick, NJ: Rutgers University Press.
- Department of Health (2012) *Prime Minister's challenge on dementia*. London: DH.
- Foot J, Hopkins T (2010) *A glass half full: how an asset approach can improve community health and well-being*. London: Improvement & Development Agency.

Comments from passers-by

Fantastic idea. You should have been here two years ago when my Dad was still alive.

What a good way to encourage us to talk about it... It is very hard to talk you know but this makes it more acceptable.

My Gran's got dementia. I have tried for the last hour to get her out of the car to come in to the shop... She is in denial.

I don't want to come in but do you have something that explains what Alzheimer's disease is?

Some people did not want to come in to the shop, but still felt compelled to talk with us. It was very emotional that people shared such intimate details about their lives, their understanding and their families. It is something most of us (all seasoned working with the general public and talking about dementia) were not expecting and had not really experienced before.

We didn't hear any negative comments or experience any difficult reactions – quite the opposite. People showed us a real sense of support and value in what we were doing, even some from a distance.

We also asked the general public to complete exit evaluations of their experience of the shop and its use. The evaluations were designed very simply (and used the Cantril ladder scale - Cantril 1965).

Most people who came into the shop completed exit evaluations (62) and rated their experience as excellent (26) or good (20). Three rated their experience as OK ('Would have liked more information' – these are being followed up). No one rated their experience as not meeting their needs. Eighteen people either did not complete an evaluation or their evaluation was spoiled.

Feedback from visitors

I am concerned that a family member may have dementia and so came in to obtain information and advice in order to be prepared – very helpful, thank you.

My mother in law has dementia and I came in to look for information about how to support her – this was excellent.

An excellent opportunity, very informative.

I am the main carer for my mother who has dementia and am really worried what will happen as I need to go into hospital soon. I have now got carer support information and advice to help us, thank you.

I am getting increasingly worried about my memory and found this event excellent – should be more of these!

I hope this scheme stays supported.

My father has recently been diagnosed – I now have lots of excellent information.

Excellent idea to bring this to the High Street.