

# Living with dementia magazine November 2010

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By bringing [dementia](#) out into the open and making services more accessible, the Society is starting to meet the needs of [people with dementia](#) in South Asian communities in Bradford by Caroline Graty

Dementia Support Worker Rani Shukla and Dementia Adviser Atiq Hassan work for Alzheimer's Society in Bradford. They are making great strides in increasing awareness of dementia and supporting families in the city's South Asian communities.

People from South Asian backgrounds make up over half the population in some parts of Bradford. Until now, the Society has had little contact with the city's Asian people.

Language is one barrier that can prevent people seeking help, as well as the perception that services are not for them. Atiq says,

'Services have traditionally focused on the white community, so people from other communities are less likely to walk through the door.'

In addition, dementia is often not recognised as an illness among South Asian communities. Rani says,

'The main South Asian languages have no word to describe dementia. It can be seen as 'madness' within a family and affect sons' or daughters' marriage chances.'

This stigma means that memory problems are rarely spoken about.

## Reaching out

Rani and Atiq are striving to break down these barriers and bring dementia out into the open so that people can access the help they need. They work closely with Meri Yaadain, a service for South Asian



people with dementia run by Bradford social services.

A large part of their work involves visiting day centres, community groups and religious centres to talk about memory loss and tackle the stigma that surrounds dementia. By speaking to people in their own languages and offering culturally appropriate information in different formats, they are able to build up trust and understanding.

Slowly but surely, their approach is paying off. Rani says,

'When I started in this role two years ago the Society was in contact with around 15 South Asian families in Bradford - now I have over 300 on my books.'

Worried about her memory, Vidya Devi approached Rani after hearing her give a talk at a Meri Yaadain support group. With Rani's help and support Vidya received a [diagnosis](#) of [Alzheimer's disease](#) and is now taking Aricept.

Vidya, who comes from India, explains the importance of being able to speak with Rani in Punjabi, her first language. Vidya says,

'It's about trust - you can hire a translator, but you still think, "Are they saying exactly what I'm saying?" It makes a huge difference to be able to speak in our own language and share stories about home, especially because of my memory problems.'

## Reminiscing through landscape

Devising appropriate activities for South Asian [people with dementia](#) is another element of the work in Bradford. One example is an innovative trip which used the rugged Yorkshire landscape as a tool for reminiscence.

Atiq says,

'Many of the people with dementia we work with grew up in rural parts of Punjab and Kashmir. There are similarities between those landscapes and the Yorkshire Dales countryside.'

Atiq wondered if the scenery would trigger memories for people with dementia, and this led to an organised visit by a group of people with dementia to the Dales.

Atiq says,

'The scenery of the Dales, with its open countryside, mountains and farms, evoked happy memories. People saw the similarities with the landscape of their youth, which stimulated their minds and encouraged conversations about their childhoods.'

Rangers from the national park gave a guided walk and spoke to the group about the park's geology, plants and wildlife. A shared lunch was an opportunity for the group to socialise, share memories and support one another.

Atiq says,

'We wanted the trip to benefit people on a variety of levels, by promoting exercise and healthy eating and including an educational aspect to stimulate and engage people.'

Feedback from participants showed they gained a sense of well-being from being in the countryside together and sharing memories. One member of the group, Mr Khan, commented,

'It was a special and momentous occasion. It will always be treasured and remembered.'

The work in Bradford is just one aspect of the Society's activities with black and minority ethnic communities in Yorkshire and other parts of the country.

If you have a story about working with different communities, please let us know by emailing Rachael Doeg at [rdoeg@alzheimers.org.uk](mailto:rdoeg@alzheimers.org.uk)

## **Translated materials**

The Society's Worried about your memory? booklet has been translated into 12 languages and Braille. The booklets are designed to help people understand more about memory loss so that if they are concerned they can seek advice and, if necessary, get treatment and support. The booklets can be downloaded at [alzheimers.org.uk/memorybooklet](http://alzheimers.org.uk/memorybooklet) or you can call Xcalibre on 01628 529249 to order printed copies.

## The magic pills

[Carers](#) and [people with dementia](#) talk about the difference [dementia drugs](#) have made to their lives and share their reactions to the NICE decision

### Mick and Shirley Ives, Shropshire

Shirley, who cares for Mick, says,

'Like many people who would have been elated when they heard the decision, we were very emotional because the implications of it are so immense.

'I was thinking about how all those people must feel who haven't been able to access the drugs. To watch your partner go downhill day by day, knowing there's something out there that might help, is heartbreaking.

'When Mick was diagnosed with [Alzheimer's](#) the GP said he wouldn't be able to have Aricept because he was in the early stages. We asked around to find out where we could get it from privately, and ended up buying it from Turkey. This carried on for about a year but as we were under financial pressure, in 2008 we changed our GP and ended up getting it prescribed.

'The difference in Mick was amazing. He said it was like a fog had been lifted. He could remember more, he became less depressed and wasn't so agitated. He wanted to go out more and was willing to chat to people - he actually started enjoying life.

'We call them the magic pills because they've made such a huge difference to our lives. Mick's more like his old self and he helps me in turn now as I have asthma and rheumatoid arthritis.'

### Heather Roberts, Derby

Heather Roberts, from Derby, has Alzheimer's disease and says that taking Aricept has allowed her to retain her independence.

She says,

'[NICE](#) should be ashamed of itself for restricting access to these drugs in the first place because they are the only lifeline that people with dementia have.

'I am delighted it is thinking of reversing the decision. I say power to the people who have fought so hard and made NICE reconsider.

'Aricept has made such a difference to my life and I want it to have the same effect for other people.

'When I first started the drugs I was still having memory tests. In just six months my memory had improved to how it had been two years previously. That is a measure of the difference it has made to me.

'I have still got my driving licence and I am still driving, which enables me to go out on my own. I go shopping on my own and things like that. I would never want to risk coming off Aricept at all.

'Thank heavens NICE is changing its guidelines.'

## Grace and Ken Richardson, Beverley

Grace, who has [Alzheimer's disease](#), says,

'I think I was lucky because I worked in the health service. I went straight to the GP and was put onto treatment. This was at a time when NICE was saying the drugs were too expensive but my GP felt it was the right time to prescribe it at the beginning.

'It's difficult to say how I would have been without Aricept but I don't think I've deteriorated while I've been taking it. The psychiatrist is very pleased that I'm as good as I am.'

Ken, Grace's husband, says,

'The GP seems to think it's holding things in check as much as possible and I think that's right. We live in the country and Grace still able to drive as long as we stick to familiar roads. She still cooks and likes gardening. We go away a lot and lead as normal a life as we possibly can.'



## Changing practice

Sarah Voss is a Research Fellow with the Avon & Wiltshire Mental Health Partnership NHS Trust and the six practices that have tried out the training are all in that area.

People with dementia and carers have contributed to an educational training programme aimed at boosting person-centred care and [earlier diagnosis](#) in GP surgeries.

After three years of hard work, Dr Sarah Voss has developed a [training programme](#) that can help to change the attitudes of GPs, practice nurses and reception staff to dealing with dementia.

Funded by an Alzheimer's Society fellowship grant, Dr Voss has worked with [people with dementia](#), [carers](#) and health professionals to design, develop and test a structured training session focusing on the issues that affect people with dementia when they use primary care services.



### Reluctance to diagnose

'Research shows that GPs can be reluctant to [diagnose dementia](#). This can be due to a lack of appropriate skills or knowledge or a concern that making a diagnosis will bring little real benefit to that person.

'Our aim in delivering the training was to ensure GPs are better equipped to diagnose [the early stages of dementia](#) and that they treat and refer patients more appropriately.'

Dementia can be difficult to identify. Even people who have the condition can easily overlook its early signs and symptoms, and may even ignore or deny the changes they are experiencing.

### Being proactive

The dementia awareness training promotes the idea of person-centred care. It focuses on the experiences of the person with dementia rather than just the biology of the illness.

Dr Voss says,

'This training reduces the barriers to diagnosis that exist in primary care. It helps staff to understand patient behaviour. For example, someone with developing dementia might make repeated appointments at the surgery and miss them, or attend but not say clearly what they are anxious about.'

The training helps staff to understand the need to be proactive in raising the possibility of dementia.

Primary care staff who have received the training say they feel more confident in knowing that dementia is not just limited to memory loss, but can also affect someone's state of mind and consequently, their behaviour.

## **Input from people with dementia**

The hour-long training sessions are delivered using a printed training manual as well as slides and videos that can be shown on a computer.

Dr Voss spent many months collecting the experiences and opinions from people with dementia and those who care for them. She incorporated these into the training sessions so they include first hand accounts of what it is like to develop dementia and how a GP or others can help.

Dr Voss says,

'The video clips include people's feelings about why early diagnosis is important. They help the staff to think about dementia from an individual's point of view.'

This includes the needs of carers, who are represented as patients in their own right. Case examples also form part of the training to help the team consider the type of decisions they might make.

Dr Voss says,

'This always gets people talking and sharing ideas about people they've seen.'

The final section includes information on making referrals to memory services and what happens for patients and carers at that stage.

## **Tackling dementia together**

Angela Brunning is the practice manager at a medical centre in Swindon, where a team of 30 staff including GPs, practice nurses, reception and administrative staff, received the dementia awareness training.

Angela says,

'It's unusual for the whole practice to attend training together. Sometimes the reception staff and doctors can feel very separate and it's good for the whole team to play a role in patient care. It's not just the doctor's job. Often we see things that they won't.'

The researchers asked the team questions before and after the training to assess its impact on their attitudes to dementia.

Since receiving the training, Angela says that reception staff have voiced concerns about particular patients to GPs. The training has also helped to raise awareness about the Society's [Worried about your memory?](#) campaign and clarified the differences between [dementia](#) and [Alzheimer's disease](#).

## **Impact of training**



So far, training sessions have been run in six primary care practices. Analysis shows that team members who received training have a more positive attitude to the benefits of early diagnosis and greater confidence in understanding [the symptoms of dementia](#).

They also said they feel better equipped in identifying and managing dementia. Analysis also highlighted that staff are more likely to raise the subject of dementia with patients who are reluctant to seek [a diagnosis](#).

Dr Voss's grant focused on developing the style and content of this training. The next stage will be to test whether it can lead to better care and earlier diagnosis by systematically measuring the difference [the training](#) makes in a randomised controlled trial.

She is now waiting to hear from the Department of Health about possible funding for the trial.



## Spreading the word

Carer Carol Smith hopes her idea of raising money through book sales will take off elsewhere, and explains how [fundraising](#) is her way of fighting feelings of helplessness.

One of my favourite holiday occupations used to be browsing in second-hand bookshops. Several years ago while on holiday in Beer, Devon, we followed handmade signs to second-hand books. They led us to a garage where the walls were completely lined with books and a cash box was fixed to the wall.

Newspaper articles on the doors told how the owners had, over several years, raised £30,000 for their local church restoration. I was impressed.

I wanted to find a way to raise money on a regular basis for the Society. They were a great support to me when my mum was diagnosed with [Alzheimer's disease](#) 12 years ago.



## Fighting back

Over the years, I have had to make some very difficult decisions about mum's care. Being an only child I found this particularly painful, especially when I had to make decisions against mum's wishes for her own safety. I have often felt helpless as [a carer](#) because you can't make things right for your loved one.

I first started to raise money for the Society by opening my garden as a way of fighting back. After visiting the garage sale in Devon, I then decided to hold a book sale of my own. I started out with a trestle table and about 200 books. I have now accumulated about 2000 books and hold a sale most months.

## Drawing in the crowds

Along the way I have learned a lot about how to collect books and, more importantly, attract customers. Many customers are now regulars and tell their friends about the sales. I find that the more people understand about dementia, the more likely they are to come along and donate in a friendly atmosphere where people can share their favourite books or recommend authors.

I would like to encourage others to give it a try. Sheffield is big enough to have a second sale in another part of the city, and I would love the idea to spread to cities, towns and villages throughout the country. Since starting the sales, we have raised more than £6,000 (£1,000 was raised through opening my garden).

If anyone is interested in holding a book sale, I would be happy to share advice. Please get in touch through the [Society's Sheffield office](#) on 0114 276 8414.

Aly England, the Society's National Community Fundraising Manager, says,

'As the numbers of people with dementia increase we need more volunteers like Carol to join our dynamic volunteer fundraising team. If you would like to get involved with a local fundraising group or find out how we can support your fundraising idea, please email us at [community@alzheimers.org.uk](mailto:community@alzheimers.org.uk) or [contact your local Society office](#).'

To find out the location of your nearest office, call our national switchboard on 020 7423 3500.

Alzheimer's Society National Dementia Helpline

England, Wales and Northern Ireland: 0300 222 11 22

9.00am-5.00pm Monday-Friday

10.00am-4.00pm Saturday-Sunday

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