

# Living with dementia magazine September 2010

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A drive for best practice and a person-centred approach have resulted in excellent care for people with dementia at a hospital ward in north west England by Caroline Grady

Improving quality of care for [people with dementia](#) is at the heart of the [Society's Putting Care Right campaign](#). [Our Counting the cost report](#), published last year, revealed unacceptable variations in the quality of care people with dementia receive in hospital.

For Joan O'Hanlon and her dedicated team at Peasley Cross Hospital in St Helens, there is no excuse for poor dementia care. Joan is the manager of the Stewart Assessment Ward, part of the 5 Boroughs Partnership NHS Foundation Trust. Joan and her team are the driving force behind a range of initiatives at a ward for people with dementia.

By putting the well-being of patients at the heart of their work, they have created a culture of person-centred care, improved the ward environment and introduced a range of dementia-friendly activities.



## Taking the lead

Joan was part of the commissioning team when the ward was built about 20 years ago. She took the lead in recognising the challenges in dementia care, and, with her team, has been introducing good practice initiatives ever since.

Each year, the ward is assessed using the government's Essence of Care standards, which identify how to achieve best practice. The assessment team includes [carers](#) and service users, as well as [professionals](#) who don't work on the ward, to ensure an unbiased and objective assessment. As part of the process, action plans are drawn up to overcome obstacles to best practice.

One result of these plans was the creation of a dementia-friendly garden. Joan says,

'We couldn't meet best practice criteria because we didn't have any safe outside space. Patients felt trapped and found the environment challenging.'

The team put a proposal forward and received funding for a specially designed garden.

Another assessment exercise looked at staffing. Joan says,

'We saw that we needed a nurse specifically for activities. Nurses were feeling guilty about doing activities as it meant leaving more routine tasks to their colleagues.'

The recruitment of an activity nurse is one of the many developments that contribute to an engaging, dementia-friendly environment. The ward also has a Reminiscence room and a multi-sensory Snoezelen room. The activity nurse and staff run daily sessions of Sonas (Gaelic for well-being, joy and contentment) - a therapy that stimulates the senses and encourages communication.

## Essential training

The ward has also developed its own training facility. Staff across the trust who care for patients with dementia are trained in person centred care using [Alzheimer's Society's introductory dementia training resource](#).

Joan says,

'Attitudes, approaches and getting to know the patient are the key to providing person-centred dementia care. That's why it's essential that the whole team receives training.'

## Understanding the person

In order for staff to understand the needs of patients on the ward, nurses complete a questionnaire with each new patient, involving relatives where possible. Joan says,

'If a person is having problems sleeping at night, it could be because they worked night shifts all their life. Once you understand that, you can work around it.'

Some extra background knowledge made all the difference for an Indian patient on the ward who wouldn't eat any of the Indian meals nurses were ordering for her. They discovered from a family member that the patient had never liked Indian food and preferred English cooking. Joan says,

'You've got to get to know as much as possible about the person, and avoid making assumptions about them on the basis of their culture or background.'



This tailored approach leads to improved well-being for [people with dementia](#) on the ward. Joan says,

'Patients who are admitted are often agitated. We are able to discharge them, having identified ways of understanding and managing their behaviour.'

## **Safe hands**

Former carer Carol Wilcock was impressed with the care her late husband Terry received on the ward. She says,

'If Terry was distressed or shouting, a member of staff would spend time with him one-to-one. It was awful to leave him when he was distressed, but it was comforting to know that he was in safe hands.'

Carol and another volunteer now hold weekly carers' surgeries - the latest ward initiative - to support and advise other carers with loved ones on the ward.

## Staying on top

Keeping fit, having time to yourself and sharing a joke are Harold Williams' secrets to being a good carer, but the former Royal Marine commando still finds himself reduced to tears at times

Former Royal Marine Harold Williams has been [caring](#) for his wife, Audrey, who has [Alzheimer's disease](#), for the last five years. Although he has cared for others all his life (he spent 17 years working as carer for people with physical and learning disabilities), he says that caring for someone with dementia brings challenges that have at times beaten him.

Aged 78, Harold leads an active life, and says he has always been a doer. He is one of the oldest lifeguards in the UK, regularly teaches swimming and lifesaving skills, and is currently building a gym in his back yard.

Earlier this year, he completed a biathlon which involved swimming 25 miles in the Red Sea in Egypt, followed by a 25 mile cycle ride around Rutland Water, which has so far raised £1,200 for Alzheimer's Society. This is in spite of two strokes that have resulted in damage to his legs.

Over the last 30 years, Harold has raised £30,000 for different charities. This year, he decided to [donate](#) the funds from his biathlon to Alzheimer's Society. He says,



'It means a lot to me, especially now, knowing what people go through.'

## Out and about

Although [caring](#) for Audrey is his first priority, Harold makes sure he has time for himself every day. He pays for nurses to come to their home in Leicester to care for Audrey for three hours a day.

On Mondays, Audrey attends a day centre. During the week, friends and family will drop in and may take Audrey out. Harold says,

'I include Audrey in most of the things that I do and I like taking her out to places where there are other people. You have to carry on treating people with dementia like human beings and lead as normal a life as possible. I think it does Audrey good to get out as she enjoys herself.'

'I'm no cook, so I tend to buy our meals in and twice a week we go out for a meal. On Saturdays we have fish and chips. Sometimes Audrey will comment on someone's fat belly, but I try to make a joke out of it and say to her that someone will be commenting on her grey hair.'

'On the whole, life has been good to me. I came from a very close family and it was one big laugh, so I like to bring fun into things. But it's not always easy.'

## The tough times

Harold says,

Caring for someone you love who doesn't recognise you does hurt, and you have a job to come to terms with that. It's also very hard when Audrey is aggressive. For no apparent reason I will be kicked or kneed between the legs, and Audrey doesn't know she's done it.

'If I mention later on that we had cross words and a bit of a squabble, she doesn't know anything about it. That makes me feel very sorry for her. Although I'd like to know why she did it, I can't question her so you just have to forget it. But it may well happen again.

'At times she's broken me and I've gone into the yard and sobbed my eyes out, but I come back in and just act normal again.

'One of the hardest things we've dealt with is cleanliness. [Washing](#) was not a happy event for the two of us so we arranged for nurses to come in and that makes life easier.'

## The happier times

'There are some wonderful bits to caring. Sometimes I'll spend ages hunting for the salt, as Audrey will put things away in the wrong places. I might find it in the microwave. There have been times when I've laid the breakfast out, popped out of the room and I've come back and both plates are empty! It's good to laugh about these things.

'I still make sure she gets away every year. I'm lucky enough to drive still and we always go down to Dawlish in May and again at the end of September. There are no set answers to caring for someone with dementia, but my secret is to try to get fun out of everything, get help in where you can, and get out and about.'

## GPs prescribed earlier diagnosis

Diagnosing dementia at an early stage gives people more time to access the right services and plan ahead, and also reduces care costs. A London-based research team is testing a new way of improving GPs' abilities to spot dementia and offer ongoing support by Caroline Bradley.

Good quality early [diagnosis](#) and intervention for all is a key goal of the [National Dementia Strategy for England](#). Everyone agrees that primary care services have a vital role to play in making this happen. However, few of the suggested solutions have been tested in experimental studies.

Steve Iliffe is Professor of Primary Care for Older People at University College London, and Principal Investigator of a research project known as EVIDEM-ED\*. His research team is looking at developing new ways of improving GPs' abilities to identify [dementia](#) at an early stage, and offer appropriate follow-up support.

Past research has shown that it is possible to improve the rate of diagnosis, but not the care and services offered afterwards. Professor Iliffe says,

'By tailoring this research intervention we hope to focus on the response as well as the diagnosis. This is not just about recognising dementia, it's about doing something about that recognition.'

### On prescription

Researchers are working with 23 GP practices, all of which have more than 200 patients. Just over half the practices receive the team's intervention, with the others acting as controls. The team is half way through the three-year trial.

The first stages of the intervention involve a GP educator spending an hour with the practice staff to find out how they currently diagnose and handle cases of dementia.

Following the discussion, the educator produces an 'educational prescription' for the practice. This typically has between four and six items on it, all aimed at improving how the professionals interact with people affected by dementia. The items include ideas for improving practice, such as:

- considering new ways of assessing changes in people's behaviour
- ensuring the patient gets the most out of a medication review
- finding out about the availability of practical and emotional support for people with dementia in the local area



Practice staff are also offered a training programme designed to boost their skills and understanding.

## **The bigger picture**

Dementia has proved difficult for GPs to identify as it is a complex condition that usually only becomes apparent through gradual changes in an individual's personality or behaviour.

Professor Iliffe says,

'We want to encourage the idea of a global assessment. Diagnosis is about recognising a pattern of change that adds up to dementia. It's about considering how the person's behaviour has changed. We need to ask whether their memory has changed, of course, but there's too much emphasis on that, so we also want people to think about hobbies, personal care and daily activities.

'Are they struggling with things that they once found easy, for example? It's about stepping back and assessing the bigger picture.'

## **Better support**

The EVIDEM-ED programme aims to move practices to a point of being able to offer a rounded package of support to people with dementia and their carers. Its aims are to improve diagnosis, but also to ensure that staff then make the necessary next steps. These may include ensuring that a medication review is meaningful to the person and their carer, managing any psychological or behavioural symptoms that arise, and attending to carers' needs.

As well as improving communication and empathy, a key element of the intervention involves raising awareness among the practice staff of voluntary sector services in the local area. This may involve finding out about Alzheimer's Society's services, or about the information the local authority can provide.

Professor Iliffe says,

'Practices don't have this information in a single place, so we collect it, laminate it and put it on the wall, or produce an electronic version for the desktop computer. Simply letting people know that services are available to them can have a significant impact on their ability to cope.'

## **Results?**

The team will be ready to present its findings in about a year, and hopes that their interventions will have increased the number and quality of dementia reviews carried out by the practices. If this is the case, the NHS will have a proven method of making improvements available to them immediately.

\*EVIDEM is the short title for a programme of research funded by the National Institute for Health Research. The programme includes five projects, of which EVIDEM-ED (early diagnosis) is one. All projects are investigating the impact of interventions for people with dementia. To find out more about the programme, visit [www.evidem.org.uk/projects/evidem-ed](http://www.evidem.org.uk/projects/evidem-ed)

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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