

Sussex Dementia Partnership Bulletin

Issue 2

July 2010

- *A Collaboration between the 11 NHS and Council agencies in Sussex*
- *Working closely with people with dementia, their carers, and the 3rd sector*

Did you know?

- One third of people with dementia live in care homes
- At least two thirds of people living in care homes have a form of dementia
- A 2008 report found that the typical person in a care home spent just two minutes interacting with staff or other residents over a six-hour period of observation (excluding time spent on care tasks)

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Introducing HOPE!

The HOPE of People with Experience Group (HOPE) has been formed in Sussex. It consists of a group of people living with dementia.

Working with West Sussex County Council, Brighton and Sussex Universities and Sussex Skills for Care, HOPE has been helping to deliver training to professional staff and students.

HOPE has already been involved in the Service Users and Carers Network and the Skills for Care Conference on Dementia,

and is going to be used in training social workers, occupational therapists and other professionals in West Sussex.

This is a particularly **Real People Real Lives Telling How It Is for Them**

exciting and innovative Project, enabling staff to hear directly about the impact of the disease.

“We believe that by sharing our experiences of dementia, staff and

students can gain important insights that would be difficult to acquire any other way.”

Members are also involved in an advisory panel for a research programme on the efficacy of physical exercise in slowing down cognitive impairment.

HOPE can work with a variety of staff, including those in Care Homes.

For more information, contact: david.moore@westsussex.gov.uk.

The Dementia Information Portal

Did you know that there is a whole website dedicated to improving dementia services?

The Dementia Portal is a Department of Health site offering information and resources to people involved in implementing the National Dementia Strategy (NDS).

Under each of the 17 objectives of the NDS, the Portal gives ideas for how it can be achieved, providing examples of best practice and innovation from around the country.

It also provides national and regional news stories, personal testimonies and discussion forums.

Access to the Portal is very simple. After a brief registration process, the site enables quick log-in at **www.dementia.dh.gov.uk/**

If you have an example of best practice that you feel could usefully be added to the Portal, contact Charlotte Clow (contact details on page 3)

Visit from Professor Alistair Burns



Professor Alistair Burns, National Clinical Director for Dementia

Professor Alistair Burns, the new National Clinical Director for Dementia, visited the South East last month.

Professor Burns spoke passionately about his commitment to improving dementia services.

He affirmed, that despite the economic recession, dementia continues to be seen as a key priority within central government.

Professor Burns was interested to hear about the work of the Sussex Dementia Partnership in taking a pan-Sussex approach to improving services.

He revealed that, whilst all the 17 objectives of the NDS are important, his four priorities for immediate action are:-

- 1. Early diagnosis**
- 2. Improved care in general hospitals**
- 3. Improved care in care homes**
- 4. Reduction in the use of anti-psychotic medication**

“This film gives a voice to older people and carers so that they can tell us in their own words about the problems they face”

“Knowing You Matter”

An innovative new film giving a voice to older people called “Knowing you Matter” was launched in East Sussex on 28th June.

The film has a particular focus on dementia and features older people in East Sussex talking openly about what matters to them and how they feel.

It also includes family members giving moving accounts about the heart-breaking decisions they have to make when someone close is moved into care, with all the guilt and emotional pain that involves.

The film will be distributed by DVD to care homes and hospitals in East Sussex, so social care workers

and medical teams can use it to raise awareness and to train their staff.

A DVD of the whole 37 minute film can be obtained from Carol Wilkinson in Adult Social Care, East Sussex County Council.

Please email: carol.wilkinson@eastsussex.gov.uk



Dementia in Care Homes

75% of registered care homes for people with dementia are rated good or excellent in Sussex.

Unfortunately, these figures from the Care Quality Commission in

2009 also reveal that **21% of homes are rated as poor or adequate**—bad news for the people who live there.

There is now a strong drive to support care homes in enhancing their ability to provide

excellent dementia care.

One such initiative is being led by Sussex Skills for Care which is currently developing a resource pack to sign-post care home and domiciliary staff to learning materials and resources.

Dementia Care Mapping

Seeing the PERSON with dementia

Dementia Care Mapping (DCM) is an observational method that looks at the experience of being in a care setting from the viewpoint of the person with dementia.

Developed by the University of Bradford, it has shown to be very successful, particularly within care homes.

DCM enables staff to enhance the wellbeing of people with dementia

through developing an understanding of the uniqueness of the person and identifying the activities a person can enjoy.

Sussex Partnership NHS Foundation Trust has trained staff in the use of DCM, piloting it in some of the inpatient wards in West Sussex, with very beneficial results.

“Just by knowing that a patient had been a builder really helped my understanding of his reality...We talked for some while about a workshop I was building. He really seemed to come

alive”

The changes have led to a more “homely” feel on the ward, higher levels of social interaction and increased engagement with activities.

DCM has also been used in Sussex in a number of care homes and in day services.

To find out more about DCM, see the University of Bradford’s website www.brad.ac.uk/health/dementia/

Or contact sally.stapleton@sussexpartnership.nhs.uk

Having dementia does not prevent you from feeling joy and well-being

“During her stay in the care home, she lost many of her skills in the activities of daily living”

Sussex Carers Story

In early 2009, it was discovered that I had a large tumour and during my period of recovery and convalescence, my wife had to go into a care home.

She was well looked after, but unfortunately during her stay she lost many of

her skills in the activities of daily living, and so my job of looking after her has become much more difficult.

It seems a pity that when you are paying £100 per day, the patient cannot be involved in meaningful

activities and be encouraged to do as much for themselves as possible.

As any Occupational Therapist will tell you, meaningful occupation is the key to wellbeing in dementia. It should be the model for everyone.

Contact us

Please get in touch if you would like to:

- Know more about the work of the Partnership
- Let us know a piece of local best practice
- Submit a personal account

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