



Dementia Services Information and Development Centre

DSIDC Newsletter Issue: No 16 Spring 2009

Spring is here and time for another edition of our newsletter through which we aim to keep you up to date with developments in DSIDC and in relation to dementia in general both in Ireland and internationally.

In the final quarter of 2008, members of our education staff were busy running many education-based workshops and training sessions. All of us were involved in a strategic planning process, which culminated in a facilitated workshop in November, which has helped us, after 10 years

of operation, to review our current situation and set our goals for the next few years. We will be launching our new strategic plan along with our 2008 Annual Report at a seminar here in St. James's Hospital on 5 March.



UK NATIONAL DEMENTIA STRATEGY

One of the key themes of this seminar will be to look at the UK National Dementia Strategy which was launched on 3 February and see what lessons can be learned for Ireland. The UK strategy involves a five-year plan backed by funds of £150 m. It includes key reforms for care homes, the setting up of memory clinics, long-term training programmes, a national awareness campaign and a new inspection scheme to monitor implementation. You can download more information from the UK's Department of Health website www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/Olderpeople/NationalDementiaStrategy/index.htm

NEW DSIDC WEBSITE

We have been busy working on our own website, www.dementia.ie, and we are almost ready to launch. On it you will be able to:

- Keep up to date with the latest news
- Find out about workshops and seminars
- Have your questions answered by using our new e-query system.
- Find information on our products and services.

NEW DSIDC BROCHURE

We have just launched our 2009 Education Brochure which details the different scheduled courses we will be running here in St. James's in 2009. A copy will be included with this newsletter but you can also find it on our website.

DEMENTIA AND DISABILITY SEMINAR

The DSIDC Living with Dementia Programme hosted a very successful seminar with the National Institute for Intellectual Disability (NID) in Trinity College Dublin, on 16 January. This one-day seminar entitled Dementia and Disability was very well attended.

Speakers on the day included Prof. Bob Woods, Professor of Clinical Psychology at the University of Wales and Director of the Welsh Dementia Services Centre, Professor Mary Mc Carron, Head of the School of Nursing and Midwifery at Trinity College and Margaret Gordon consultant trainer in the area of Reminiscence and Intellectual Disability in Northern Ireland. Zoë Hughes and Jessica Breen, PhD students in Trinity also shared their research.

Topics discussed included reminiscence work in dementia and disability care, and the positive impact this can have on quality of life. Issues of dementia and disability, with particular attention to Down Syndrome, were discussed. This is an area where there is a growing need for more specialised care provision. The use of technology in creating life stories was explored and we had a preview of the Archive of Life stories, a project which is being developed by NID. We were also treated to a session on how a life story approach can be used in conducting qualitative research.

RESEARCH PARTICIPANTS NEEDED



Andrea Bobersky, one of our PhD students on the Living with Dementia Research Programme is conducting research and would value your assistance.

Her work involves an exploratory study into the experience of relocating to a specialist dementia care unit from the perspective of residents and caregivers. She is particularly interested in talking to you if your Specialist Dementia Care Unit is likely to be admitting two or three new residents within the next 12 months or if you are about to open a new specialist Dementia Care Unit.

The research is concerned with how people with dementia and their caregivers experience a transfer from the community, an acute hospital, or a long-stay nursing home into a Dementia Specialist Care Unit. It will explore the experiences and views of people with

dementia, their caregivers, and care staff involved in the relocation process.

Your participation will contribute to a better understanding of the needs of people with dementia and of care staff and family caregivers involved in the process. If you wish to find out more about this study, or if you are interested in participating in the research, please contact **Andrea** at **01 896 2913 / 087 2455 981** or **bobersah@tcd.ie** or check out **www.dementia.ie**.

HOME INSTEAD SENIOR CARE

In January, Home Instead Senior Care published a new information guide for carers of people with dementia. The free guide - *Helping Families Cope*, covers issues such as communication and activities and can be found on **www.homeinstead.ie**

DSDC N. IRELAND CONFERENCE

Our colleagues in Northern Ireland are organising an interesting 1- day event entitled 'Consent, capacity and human rights in dementia care'. It will explore the issues central to the care and provision of services to people with dementia and people with a learning disability who have dementia in the context of national and European law. It will be held in Belfast on 18 February. Further information from **www.dementiacentreni.org**.

EUROPEAN ACTION PLAN ON ALZHEIMER'S



At European level, on 6 February, 465 MEP's from all 27 EU countries called on the European Commission and the member states to recognise Alzheimer's Disease as a European public health priority and to

develop a European Action Plan. They urged the promotion of pan- European research and collaboration in order to improve early diagnosis and the quality of life of people with dementia and their carers. For more information see **www.alzheimer-europe.org**.

COMBATING STIGMA IN DEMENTIA CARE

All of us who are working in this area will have come across the stigma associated with dementia in one form or another. According to Louise Nolan et al (2006), the series of myths and stereotypes that surround dementia facilitate a public perception that people with dementia have no quality of life or capacity for pleasure. This creates a stigma that is attached to dementia and is a key problem in the provision of care. A stigma emerges when attributes are present that deviate negatively from

a perceived societal norm. The loss or lack of cognitive skills that is associated with dementia can lead to prejudice against those who are perceived not to function properly. The stigma of dementia often leads to exclusion from full and equal participation in daily life because society "labels" people with dementia as being incapable of decision-making or of having their own preferences or opinions.

Negative perceptions of dementia can be addressed by looking beyond the stigma, to the person. Being seen as an individual means that the person is seen before the disability. The provision of care should therefore focus on remaining capacities, thus facilitating a positive experience of dementia care for the person and their carer.

Educational programmes should discuss personal beliefs and images of stigma in dementia. A comprehensive and realistic depiction of the person with dementia can balance both the deficits and capacities of the disability. The involvement of people with dementia and their carers in this process, provides them with a



voice and an opportunity to input into their future, eliminate the misconception that people with dementia can not make decisions and also improve the quality of life of persons with dementia and their carers.

The participation of persons with dementia in programmes and decision-making contribute to positively changing public perception about dementia. Stigma in dementia care can also be addressed through public awareness-raising campaigns, focussed on what persons with dementia can do and their experience of pleasure, rather than what they cannot do. Please write to us to let us know how stigma has manifested in your work and if so what strategies you have developed to deal with it.

Nolan, L., Mc Carron, M., et al, *Perceptions of Stigma in Dementia: An Exploratory Study*, School of Nursing and Midwifery, Trinity College and The Alzheimer Society of Ireland, Dublin, 2006

DSIDC CONTACTS

Telephone: **01 416 2035**

Fax: **01 410 3482**

Website: **www.dementia.ie**

Email: **dsidc@stjames.ie**

**Top Floor, Hospital 4, St. James's Hospital,
James's Street Dublin 8**