



Dementia Services Information and Development Centre

DSIDC Newsletter

Issue: No 15 Autumn 2008

Welcome to the Autumn 2008 edition of our newsletter!

Since our last newsletter in the Spring, we have been busy. We were delighted to welcome members of the **North Sea Group** (dementia practitioners from 11 European countries) to a meeting, which we hosted in April. The **Alzheimer Europe** Conference 'Breaking Barriers' held in Oslo in May was an exciting event where Dr. Susanne Cahill presented a paper on the experience of people with dementia attending a memory clinic. One of the highlights for me was a visit to '**Great Granny's Garden**' in the Botanical Gardens. This initiative preserves Norway's horticultural heritage and provides a wonderful sensory experience for people with dementia.

For the first time this year, we delivered a number of **education** courses over the summer months. These were very well attended and may reflect the fact that non-national staff who now make up a significant number of our course attendees take their annual leave at other times during the year. We were involved in a number of **consultancy** projects ranging from design work with firms of architects to review of dementia specific units. We also worked with public and private nursing homes planning new or refurbished environments for their clients with dementia.



We said good-bye to Orla Fagan, our administrator who left to be at home with her young daughter. She was replaced by **Lorraine Lovely** (photo on left) who with an honours degree in psychology has been working in St. James's Hospital since 1999. Lorraine has wide experience in many departments including the CEOs office and The Emergency Department where she was the Deputy Business Manager. Many of you will know her voice on our busy phone line! Maeve Clark started a career break to return to Canada in July and our new education staff includes **Dearbhla O'Cahey** and **Niamh Martin**. Dearbhla (on

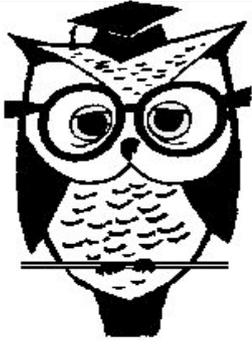
the left in the photo below) has an honours degree in Psychology and English from NUI Galway as well as a Higher Diploma in Health Promotion. She has worked in the HSE in services for individuals with physical and sensory disabilities and in Sligo General Hospital. Niamh (on the right) has a Ph.D. (Exercise and Health Science) from Dublin City University. She is a Registered General Nurse (Beaumont) and completed her B.Sc. in the University of Limerick. She has worked as nurse and/or researcher in Dublin, Sydney and Cape Town. Most recently, she worked as Health Promotion Officer with the HSE where she developed a resource and training pack for carers of older adults at risk of falling.



I'm sure you can see why, with our full complement of staff and with the high calibre of those we have been able to recruit, we are very hopeful about the development of our service in 2009. We plan to have our 2008 Report, a Review of DSIDCs first 10 years and our 2009-2011 Strategy ready to launch on 5 March. More details about these in our next newsletter.

Below you will find information on our psycho social research, Living with Dementia Programme and articles by our staff on a Homely Environment for people with Dementia (Cecilia Craig), on Younger People with Dementia (Matthew Gibb) and on Autumn Activities (Dearbhla O'Cahey), which I hope you will find of interest.

Patricia Hallahan, Director



Psycho Social Research

The programme of psycho-social research in dementia care entitled "Living with Dementia" is going from strength to strength in Trinity under the direction of Dr. Suzanne Cahill. Two Ph.D. students, Andrea Bobersky and Treena Parsons are now in place. Andrea is working in the area of environmental design and dementia and Treena is working on a project evaluating reminiscence therapy in different dementia care settings. Two additional Ph.D students will start in April 2009. A pilot study looking at the prevalence rates of cognitive impairment in nursing homes is being undertaken at present.

YOUNGER PEOPLE WITH DEMENTIA IN IRELAND

Matthew Gibb, Social Worker / Researcher

Nobody is quite sure how many younger people with dementia (i.e. those under the age of 65) there are in Ireland. The best figures available are statistical extrapolations or 'guesstimates' if you are feeling ungenerous. The Alzheimer Society of Ireland launched a report in 2005 titled 'Early Onset Dementia: A needs analysis of younger people with dementia in Ireland'. This document put the number of younger people with dementia in Ireland at about 3,500 or approximately 10% of the total number of people diagnosed with a dementia. Here, in the Mercer's Memory Clinic in St James's Hospital, our statistics show that we have seen and diagnosed just over 50 younger people in the last two years – about one a fortnight. Not startling numbers I know, but devastating for those involved and a significant challenge for the professionals involved in providing suitable supports.



Younger people with dementia and their families often face a different set of difficulties than their older counterparts. Many are still in employment, paying mortgages and have children still in formal education. These factors, in addition to the needs arising from their dementia means, that they often need a high level of support. Information and advice on welfare benefits, finances and legal issues can be sought from social workers or agencies such as the Free Legal Advice Centre or Citizens Information Centres. Practical support is a different issue and many young people with dementia and their families struggle to get appropriate services from statutory providers such as the HSE.

Unfortunately, there does not appear to be a clear or consistent pathway to these services with different Local Health Offices choosing to respond to the challenges posed by younger people with dementia in different ways. Ideally, as dementia can be classified as a disability, people under the age of 65 should access assessment procedures and services via the local Disability Services Manager. This works in some areas but in many others, young people with dementia and their families struggle to find anyone in the health and social care system to take responsibility for service support. This is a less than ideal scenario and it is time that the statutory bodies adopted a single point of access to assessments and services for younger people with dementia.

Next year the DSIDC will undertake research in this area that will contribute to the development of a strategy to influence agencies and government to prioritise service provision for younger adults with early-onset dementia so that they can be supported to live at home.

Haase, T. (2005) *Early Onset Dementia: A Needs Analysis of Younger People with Dementia in Ireland*. The Alzheimer Society of Ireland, Dublin.

ACTIVITIES FOR PEOPLE WITH DEMENTIA

Dearbhla O’Caheny, Assistant Education Officer

Activities provide so much fun and enjoyment for people with dementia and are therapeutic, pleasurable and meaningful. Below are a few activities that you may find useful during these autumn months. All the activities take about an hour and are suitable for different levels of ability. The activities are described in more detail in *Activities Directors’ Quarterly*, Summer 2008, Vol. 9, No. 3 and Summer 2007, Vol.8, No.3., which are available in our Resource Centre.



Studies have shown that **music** therapy is of immense benefit to persons with dementia and Alicia Clair (1997) suggests that music therapy can have a positive effect on the relationships between staff and residents. ‘Drumming Circles’, is a music based activity based on research that found that the use of percussion instruments may alter brain wave patterns and reduce stress particularly in persons with Alzheimer’s Disease. Drumming is a great indoor activity when the weather gets colder during the autumn months. Hand drums can be purchased from a toy shop or you can make your own. People improvise, playing whatever rhythm they like and they can either sit or stand. The most important aspect of this activity is that everyone is part of the musical performance, there’s no audience. Family members are also encouraged to participate if possible.

In autumn the scenery around us is changing as the leaves fall from the trees and turn into their autumnal colours. It’s a great time for people with dementia to **explore the great outdoors**. This helps to alleviate stress, boredom and agitation and the fresh air may help some people to sleep better, and cope better during ‘sun down’ ! Take a walk outside and get residents to gather some leaves which can be used later in scrapbooks, art class or for decoration around the unit. Photos of the outing could be taken by a staff member and displayed in the unit or be used in conjunction with scrapbook and life-story activity.



Another activity for residents is the ‘**Weather Club**’. The aim of this activity is to improve cognition and verbal skills and facilitate interaction with other residents; it also gives the residents a break from indoor activities. The participants name the club themselves and decide what time and how often they will meet. This can be either daily or weekly. Participants sit in a circle, outside if possible. They should be provided with a notebook, which will be their weather log, and some coloured pens. The logbook is to record what they see and feel, temperatures, sunny or wet, windy or calm. Make a weather poster and update it every week with their new weather reports.

Have fun and good luck!

Clair, A. A., (1997), ‘The effects of music therapy on interactions between family caregivers and their care receivers with late stage dementia’ in *Journal of Music Therapy*, 34, 148-64

WHAT IS A HOMELY ENVIRONMENT?
Cecilia Craig, Education Officer



**Home
Sweet
Home !**

Increasingly, environmental design for people with dementia is being recognised as an essential element in their care. Mary Marshall (1998), described a number of key design features that are important to the environment of the person with dementia one of which is 'homeliness'. But what is meant by homeliness or a homely environment? The Farlex online dictionary indicates meanings including 'comfortable, welcoming, friendly, domestic, informal and cosy'.

Elements that make a room homely are determined by its function. For example, a lounge which is for relaxing usually includes a central focus, seating, storage, personal items, decoration and lighting. Contemporary fashion may include a leather couch with plenty of scatter cushions, a DVD rack, plasma TV and funky pictures on a wall paper with large designs. This, however, is not age appropriate to the current population of people with dementia who be likely to be more at home with embossed wall paper, floral patterns on the couch, a fire place, sideboard, religious statue and a wireless radio. Each generation has its own fashion and design but elements remain the same.

What makes a room homely for someone will depend on their age, background, culture and personal taste. To make a place homely therefore, the age profile of residents in a care setting should be ascertained. This often, but not always, ranges from 70 to 90 years. Personal background affects our idea of homeliness. For example, someone from a farming background may be used to having a range cooker in their kitchen whereas someone from an urban area may be more at home with an electric or gas cooker. The current generation of people with dementia are quite similar to each other but that will change and in future, the care environment will have to adapt to this. Personal taste influences a person's experience of their environment. One person may hate 'Lino' floors as it reminds them of being cold and unhappy as a child while another may associate it with playing and happy times!

It is not possible to cater for everyone's taste, experiences and ideas of what homeliness is. In practical terms, a care environment can only adhere to a general representation of what is most likely to be appropriate for the majority of its clients. It cannot serve every resident's personal taste while also being aware of issues of safety. For some, a cluttered environment with stools, magazine racks, shoes, and boxes lying around, feels like home. To replicate this would obviously be a hazard to a person at risk of falling. The environment must also be user friendly for staff while providing a safe, homely and appropriate place for all clients.

There is a balance to be struck concerning personal taste, safety, background, experiences, culture and cost, but the idea of 'homeliness' and the principles of best practice in dementia care can really enhance the quality of life for a person with dementia. Do let us know what ideas you have come up with to make the environment more homely for your clients. We will share your good ideas in a future newsletter.

Marshall, M. (1997) Therapeutic Design for People with Dementia in *Dementia Challenges and New Directions* (ed) Hunter, S. London: Jessica Kingsley Publishers.

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