



# DSIDC Newsletter

Issue No 18  
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Dementia  
Services  
Information and  
Development  
Centre

Welcome to the Autumn edition of our newsletter. I hope that, like all of us here in DSIDC, you had a good summer despite the rainy weather and the gloomy economy!

The summer months offer DSIDC staff a break from the more hectic education schedule during the rest of the year. During this time, we focus on reviewing feed-back from participants and commissioners of our education services and adapt to changing needs in the environment. This year, this included the long awaited implementation of the HIQA National Quality Standards for Residential Care Settings. Thanks to those who responded to our education survey. We are now working on our programme for next year and our **2010 Education Brochure** will be published soon.

I have just come back from York where the Dementia Services Development Centre of the University of Stirling held a two day **International Dementia Conference**. This was a stimulating and informative event entitled *Facing the Future* and covered many important topics in relation to dementia. There was a great buzz with excellent keynote speakers including Mary Marshall, Alistair Burns, Karen Ritchie and Steven Sabat. Workshops covered topics from 'design' and 'behaviour that challenges' to 'personhood' and 'rehabilitation'. The latter was of particular interest in light of our

up-coming conference on **Dementia and Rehabilitation** which will be held on 26 November and which I hope you can attend.

We have an excellent line-up of speakers who are experts in their fields and it should be an interesting day to which I am already looking forward to welcoming you.

In July, we were delighted to be able to host a very interesting workshop run by **AgeWise**, a programme of Age and Opportunity. AgeWise workshops provide information on older people and ageing in Ireland and challenge the prevalent myths and stereotypes. Free, half day workshops help participants to understand the personal, cultural and structural effects of ageism and devise strategies to counter age discrimination in the workplace and community- a very worthwhile venture.

Congratulations to Maria McManus and her team from the **Dementia Services Development Centre, Northern Ireland** on the extension of their programme and move to excellent new facilities in Belfast in September. The new offices were opened by the Northern Ireland Minister for Health and it was a good opportunity for staff from DSIDC to network with our colleagues across the border and we look forward to more collaboration in future.

Our **library** is undergoing refurbishment at the moment and we look forward to welcoming you to expanded space for our print and audio visual resources soon.

I hope you will find our Autumn Newsletter useful and that the articles by DSIDC education staff on the needs of carers (by Dr. Niamh Martin) and on Snoezelan rooms (by Dearbhla O'Cahey) will be of interest to you.



*Best wishes,  
Patricia Hallahan  
Director*

## POSITIVE AGEING STRATEGY

The consultation period by the Department of Health and Children for the National Positive Ageing Strategy is drawing to a close and the time for submissions is over.

The strategy, being developed with a slowly ageing Irish population in mind, aims to take forward the commitment in the Programme for Government of 2007-2012 to better recognise the position of older people in Irish society.

It is hoped it will improve the cohesion of government departments in the formulation and delivery of policy in all issues relating to older people and ageing in Ireland.



The underpinning principles have been drawn from the *United Nations Principles for Older Persons 1991* and the Madrid International Plan of Action on Ageing 2002.

The Madrid Conference was held to review how far member states had progressed in the last 20 years in improving the lives of older people in their societies, to review challenges and barriers to progress, and to provide an outcome document for the World Assembly - a new Plan of Action on Ageing. The National Positive Ageing Strategy is Ireland's response to the Madrid conference.

Along with many others, we have made our submission to the Department of Health and Children setting out our vision of a future where everyone with a personal encounter with dementia in Ireland has the quality of services to enable them to live the life of their choice. We believe that Ireland could

and should become a leader in the provision of dementia-specific services and that Ireland should aim to become the best place in the world for a person with dementia to live. However, this requires that appropriate resources and facilities are available and that authorities, institutions, and organisations work together to develop policies and strategies to deliver high quality services for all those who encounter dementia in any of its many different manifestations.

Dementia must become a national health priority and a national dementia strategy is vital if we are to plan for the projected increases in the numbers of people with dementia over the coming years.

We need to learn from the experience in the UK of the development of national dementia strategies there. We also need to collaborate to ensure effective implementation.

## LIVING WITH DEMENTIA

Our *Living with Dementia* programme at Trinity College has a number of important research projects underway. These include a study looking at reminiscence therapy and dementia, another examining the relocation experiences of people with dementia moving into specialist care units and a new study exploring anti-dementia drugs and quality of life.

A further project exploring the cost effectiveness of assisted living dwellings for people with dementia is about to commence.

A North South CARDI funded project looking at end of life care and dementia is underway. It is hoped that the findings from this work will be used to develop an all-Ireland end of life standard for dementia care.

Other completed research work includes a recent study investigating dementia and cognitive impairment in long stay care facilities. This study found that in a random

sample of 100 residents surveyed across 4 nursing homes, 89% had a cognitive impairment, of whom 42% had a severe, 27% moderate and 20% mild impairment. Only one third of these residents had a prior clinical diagnosis of dementia.

Dementia was not a major reason for nursing home admission. Findings from this study would suggest that there is much under-detected dementia/cognitive impairment in Dublin based nursing homes.

Research focusing on quality of life for people with dementia in long stay care and another study investigating the location, staffing and type of services offered by memory clinics in Ireland have also been undertaken. Results from these works will be used to produce information-kits/pamphlets providing a useful resource to members of the public and health care professionals. The Memory Clinic pamphlet will provide details on where across Ireland, Memory Clinic services are available, their referral pathways and waiting times. The Quality of Life pamphlet will offer insights and suggestion to staff and carers with a relative in long term care. We hope to have these new resources ready for release by the end of November.

## **SNOEZELN ROOMS**

*by Dearbhla O’Caheny*

In recent years Snoezelen rooms and Snoezelen therapy have become popular in nursing homes and similar residential settings especially for people with a dementia.

The term 'Snoezelen' is a combination of two Dutch words, *snuffelen* which means *to seek out* and *doezelen*, which means *to relax*.

The concept of a multi-sensory room was developed in the late 1970's by the Dutch psychologist, Ad Verheul and his colleague, Jan Hulsegge. Initially it was designed to help people with learning difficulties but it is now used with success in

other areas such as for children with autism and increasingly for people with dementia. The theory behind Snoezelen therapy is that stimulating the senses can help people to connect to their environment, which due to their cognitive impairment they find it hard to do.

Snoezelen rooms contain many multi sensory devices such as glowing fibre optics lights, lava lamps, bubble tubes, music, and relaxing lights. Some of these are small and portable so they can be brought to the person's own bedroom if they are unable to go to the Snoezelen room.

Snoezelen therapy has been used with some effect during 'sun downing' and a visit to the Snoezelen room can help to decrease agitation, restless and the desire to 'go home' among residents.



*Example of a Snoezelen Room, showing a bubble tube, catherine wheel, fibre optics, etc.*

Although there is limited scientific evidence thus far as to the benefits of Snoezelen, some research has found that residents who availed of Snoezelen were much happier than those who did not (Van Weert et al, 2004).

A Snoezelan room is a useful facility to have in a dementia care setting both for the person with dementia and the staff who care for them.

Van Weert et al. Behavioural and Mood Effects of Snoezelen Integrated into 24-Hour Dementia Care, *Journal of the American Geriatrics Society* 2004; 53: 24-33.

## ADDRESSING THE NEEDS OF CARERS

by Niamh Martin

The challenge of caring for people with dementia is increasing, not only because of a growing ageing population and longer life expectancies, but also because of the limited availability of resources and support to family carers.

It is estimated that the provision of care by family members to children, adults with disabilities and older adults in Ireland saves the state over €2 billion every year (Carers Association, 2008). A recent study by the Irish College of Psychiatrists (O'Brien, 2008) reveals that family carers in Ireland feel over-burdened, unsupported and exhausted and that the impact of caring for their relative is negatively affecting their own health status. This survey of over 2,000 family carers found that:

- 20% were diagnosed with depression.
- 25% were diagnosed with anxiety.
- 27% were diagnosed with back injury.
  
- 38% have provided care for 1-5 years.
- 25% have provided care for 6-10 years.

The specific impact of dementia on carers lives has been anecdotally documented in publications such as *Telling Tales About Dementia – experiences of caring* (Whitman, 2009) and *Chicken Soup for the Caregivers Soul* (Canfield et al., 2004).

These books tell of the carer's journey through stories and vignettes that deal with issues associated with caring for a relative with dementia. These include:

- Sense of isolation, lack of information and support.
- Physical, psychological and emotional toll.
- Declining career opportunities.
- Strained relationships with spouse and or family members.
- Using holidays from work to care for their relative.
- Maintaining their relative's home.

The Carer's Association of Ireland indicates that little formal needs assessment has been undertaken to examine what service provision is required to adequately support family carers in Ireland (including carers of people with dementia). According to their policy recommendation report *Towards a Family Carer's Strategy* (2006), Ireland falls well below international best practice in terms of service provision for family carers.



Irish carers receive only ¼ of the support services of other European countries. Similarly, availability of technologies to assist home care is much lower in Ireland than in the rest of Europe. Respite services are inadequate, meaning that many Irish carers are not appropriately supported in caring for their relatives. These issues need urgent attention in order to protect the health and welfare of people with dementia and their relatives, who care for them at home. Further information for carers of people with dementia, including details of support groups can be accessed from the Alzheimer's Society of Ireland ([www.alzheimer.ie](http://www.alzheimer.ie)).

Canfield, J., et al., (2004). *Chicken Soup for the Caregiver's Soul*. Health Communications Ltd., Florida.

O'Brien, F. (2008). [www.irishpsychiatry.com](http://www.irishpsychiatry.com)

Whitman, L. (2009). *Telling Tales About Dementia – experiences of caring*. Jessica Kingsley, UK.

The Carers Association of Ireland (2008) *Towards a Family Carer's Strategy* [www.carersireland.com](http://www.carersireland.com).

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**Dementia Services Information & Development Centre**  
promoting best practice in dementia care

## **DSIDC AUTUMN CONFERENCE**

### **DEMENTIA AND REHABILITATION**

*Challenges And Opportunities For Health Care Professionals*

**Thursday 26 November 2009**

**Trinity Sciences Centre, St. James's Hospital, Dublin 8**

The DSIDC Autumn Conference will explore a broad range of issues in relation to Dementia and Rehabilitation. With many expert national and international speakers and facilitated workshops, it will be of interest to those who support people with dementia in any context, including health care professionals from the public, private and voluntary sectors. People with dementia and their carers are also welcome



Standard Fee	€75.00
Early Bird (by 26 Oct)	€65.00
Person with dementia and / or their carer	€50.00

Conference fees include pack, teas & coffees and light lunch.

Formal educational approval received from the Irish Psychological Society, An Bord Altranais and the Irish Association of Social Workers. We are expecting approval shortly from other professions that have a Continuing Professional Development Programme.

#### **Key Speakers and Facilitators**

**Professor Mary Marshall**

Emeritus Professor, University of Stirling, Scotland.

**Professor Linda Clare**

School of Psychology, Bangor University, Wales.

**Professor Ian Robertson**

Trinity College Institute of Neuroscience, Dublin.

**Ms. Jackie Pool**

Jackie Pool and Associates Ltd., Southampton, England.

**Ms. Bronagh Flynn**

Dept. of Occupational Therapy, St. James's Hospital, Dublin.

**Ms. Valerie Twomey**

National Rehabilitation Hospital, Dun Laoghaire, Co. Dublin.

**Ms. Cecilia Craig**

Dementia Services Information & Development Centre, Dublin.

**Professor Greg Swanwick**

Trinity College and Adelaide & Meath Hospital, Dublin.

#### **Parallel Workshops**

- **Social Workers and Psychologists**
- **Service Managers, Nurses and Care Assistants**
- **Occupational Therapists and Physiotherapists**
- **General Practitioners and Hospital Doctors**

Participant numbers are limited to 150, so book early to avoid disappointment and to avail of *early bird* registration.

For information and Booking Form visit  
**[www.dementia.ie](http://www.dementia.ie)**  
or call 01 4162035