



DSIDC NEWSLETTER

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**Dementia Services
Information and
Development Centre**

Warm greetings from all of us here in DSIDC.

Since our Spring newsletter, we have had a very busy but highly productive period in which we started to deliver our **improved 2010 education programme**. This included new courses on '*Management and Leadership in Dementia Care*' and '*Caring for the Person with Dementia in an Acute Care Setting*'. These courses were well attended and the feedback we received will ensure we will continue to improve and deliver them again later in the year.

During this period, our design consultancy and education services were provided here in DSIDC and in many locations around the country. These included Cork, Tipperary, Laois, Meath, Cavan, Dublin, Wicklow, Kilkenny, Sligo, Galway, Waterford, Kerry and Mayo. It is a great privilege to work with so many of you who are making a real difference to the lives of people with dementia in your care.

Our **Spring Synapse Research Seminar** was a great success. It started with the official launch by **Minister Aine Brady** of the Living with Dementia Programme. I'm sure that like me, you will be delighted to hear that in her address, Minister Brady announced that the government is committed to the development of a **national strategy on dementia**. This is very good news for all of us working in this area and the people for whom our services exist. Let's hope that the strategy development process does not take too long and that it learns from the experience of our UK and European neighbours who have already made progress in this regard.

The seminar was well attended and all of us were inspired by the talk given by **Bishop Brian Hannon** who has been 'living well' with Alzheimer's Disease since his diagnosis a few years ago. Bishop Hannon also featured on the

Prime Time investigation on Alzheimer's Disease which I'm sure many of you saw.

You will find details of the prize winning pieces of research that were presented at the Seminar below and all of the excellent presentations can be found on our website.

Our Education department is currently developing a tool for managers to identify the dementia care **training needs** of their staff. It is a questionnaire / quiz and we will be sending it out during the summer to nursing homes in the Dublin area, later expanding to the rest of the country.

We are planning our **Autumn Conference** at the moment. This will be held on 23 November and will focus on design in dementia care. Our team is getting an excellent line-up of speakers for you. If you would like to share an experience of design you have had, please do get in touch.

During the summer months, we usually review our courses and plan for the year ahead. This year, due to demand, we are for the first time, collaborating with the palliative care team in St. James's Hospital to deliver a course entitled '**An introduction to End of Life Care for the person with dementia**'. This is open to staff both from within and from outside of St. James's Hospital.

Our 'Fundamentals in Dementia Care' is a two day course which delivers the same content as our Extra Mural Course which is given in 2 hour slots over 6 weeks. Our findings indicate that participants are better able to absorb the learning when it is spread over a longer time as it allows for reflection and opportunity to discuss issues with course facilitators. Our next **Extra Mural Course** is starting in September so do get in contact if you would like to benefit from this approach.

Below you will find articles on Making Contact with the person with dementia by **Cecilia Craig** and on Mild Cognitive Impairment by **Dearbhla O'Caheny** which I hope you will find of interest. Cecilia will be running a new course on '**Communicating with the Person with Dementia**' later in the year.



Slán go fóill
Patricia Hallahan
Director

LAUNCH OF LiD

The Living with Dementia (LiD) programme which was officially launched in April seeks to impact on policy development and to contribute to the design of best practice models for those affected by dementia. It is hoped that by creating closer linkages between research, practice and education more timely responsive and accessible interventions will be developed to support the unique and complex needs of this very vulnerable population.



Pictured at the launch of the Living with Dementia Programme, Patricia Hallahan, Director DSIDC, Prof Robbie Gilligan, Head of School of Social Work & Social Policy and DSIDC Steering Committee member, Minister Áine Brady TD and Dr Suzanne Cahill, DSIDC Research Director.

The LiD programme has made available findings with significant implications for policy. A research study estimating the prevalence of cognitive impairment and dementia in Dublin nursing homes has been published recently. The implications of having large numbers of residents with cognitive and memory loss problems in residential care are far-reaching and present serious concerns regarding safety, staff-patient ratios, staff training and recruitment and the physical layout of buildings.

The only previous study undertaken on this topic in Ireland was in 1988, where cognitive impairment prevalence rates of 58% were estimated across nursing homes in the then Eastern Health Board area. New findings from the Living with Dementia study reveal that a large proportion (89%) of nursing home residents had a cognitive impairment of whom, 42% were severely, 27% moderately and 20% mildly impaired. Only 14% of those surveyed were admitted to nursing homes because of dementia and only 32% had a clinical diagnosis of Alzheimer's Disease or a related dementia. Other studies which have been completed recently include a study of perceptions of quality of life of those living in long term care as well as

a study about the professional services delivered at Memory Clinics.

Current study projects being undertaken by LiD include:

- an investigation into anti-dementia drugs and their impact on quality of life for those with mild to moderate dementia;
- a study examining the relocation and adaptation of persons with more advanced dementia into specialist care units;
- a project looking at the participation levels of older people with a cognitive impairment at hospital discharge planning meetings;
- research examining the potential, supported sheltered housing schemes have in responding to the special needs of people with dementia;
- a study investigating end of life/palliative care for people with end stage dementia;
- the experience of Reminiscence Therapy.

The LiD programme aims to train five PhD and five Masters students in the field of dementia care in order to improve practice outcomes and promote the independence and dignity of all those affected by dementia.

SPRING SYNAPSE SEMINAR

Congratulations to the prize winners for best research presentation at our 2010 Spring Synapse Seminar which included Dr Emer Begley, Sarah Donnelly, Patrick Glackin and Anna de Siún.

Dr Emer Begley, a Policy Officer with Age Action, won first prize for her presentation entitled *Learning from People with Dementia*. This provided insight into the lived experience and health and social care needs of a group of people living with early stage dementia. It linked the 'personal' to the 'political' by placing this experience within the context of the Irish health and social care system. The central crux of Dr Begley's enquiry is that a consideration and understanding of the lived experience reveals appropriate and effective ways to respond.

Research of this kind had not been undertaken in Ireland before. Findings provide new and original insights into the experiences of dementia. Respondents often 'normalised' symptoms within the context of ageing. However, in exploring their awareness of the extent of their symptoms and how these affected others, findings show a higher level of insight and awareness than had initially been revealed.



At the Spring Synapse Research Seminar L-R Cecilia Craig, Joanne Flood, Dr Kate Irving, & Dr Emer Begley

Sarah Donnelly is currently completing research on behalf of the 'Care and Connect' Project which is an academic, practice partnership between Tallaght and the School of Social Work and Social Policy, Trinity College Dublin. Sarah's research examined the participation levels of cognitively impaired patients within hospital family meeting processes and focused specifically on the language and behaviour of the multi-disciplinary team within these meetings.



Also at the Spring Synapse Research Seminar L-R Treena Parsons, Andrea Bobersky, Prof Davis Coakley, Sarah Donnelly (2nd Prize) and Dr Suzanne Cahill

Patrick Glackin and Anna de Siún presented initial findings from a three-year research project funded by the National Council for the Professional Development of Nursing & Midwifery.

The aim of this project is to address the knowledge deficit of care staff when caring for older people with dementia and to facilitate them to create a caring and dignified environment, where a person-centred approach to dementia care can be fostered. The project is being managed by Mary Manning, Regional Practice Development Facilitator for Older Person Services, Nursing & Midwifery Planning & Development Unit, Dublin Mid-Leinster.

MAKING CONTACT

by Cecilia Craig

The person with dementia who has lost the ability to speak can appear silent and non-communicative. It may look as if they do not interact with their environment. We confer on them the usual social greetings and instructions when assisting with their activities of living. We may initiate, direct and finish interpersonal interactions with them. However, if we do not make a conscious effort to make contact with that silent person sitting in the chair, there is a risk of their being treated as part of the furniture in our 'caring' process.

The person on the other side of our interaction sees, hears, feels, smells and tastes their environment with varying degrees of accuracy and intensity. Their world may be limited to just a few feet around them - the ward, bedroom, sitting area or wherever they are. They may be in social contact with few people. What happens around them is part of their life experience. They depend on this environment to meet their needs as human beings. Their loss of ability to control and relate to others can seriously hinder their quality of life experiences.

Perhaps both parties equally fail to connect with the other, albeit for different reasons. We can never not communicate. Non-verbal ways are the principle methods used to communicate. The silence of the person with dementia in itself communicates the most;

'I need you who care for me, to make a bigger effort to make contact with me'.

'I am in need of company and stimulation so that I can experience life now as it is'.

Body language, facial expression and responsiveness all illustrate what is happening within the person. Are we a silent party also? If so, what does this communicate? Perhaps it may indicate a negative attitude towards the person and the work we do. Our language, body posture, gestures and movements can let others know our mood, intentions and caring ability.

'What's the point – there's never a response. She doesn't know what's happening anyhow'.

Showing that we value the person is important. Sitting at their level tells them that we do not believe that we are better than they are and that we perceive them as being equal in value. Saying their name and referring to personal

information acknowledges their individuality and promotes their identity. Appropriate touching such as a handshake or gently placing our hand on their forearm while talking indicates our caring attitude, gentle, concerned and positive. The intonation of a voice that is not harsh or sounding patronising or condescending reveals that we support them in living their lives to their full potential. Smiling and laughing with the person is a shared experience that brings us both closer.

It is easy to think that there is no point in communicating when feedback is limited and difficult to discern. Making the effort to 'contact' the silent person is vital even though there may be little or no response. We need to be aware of our silence too; what is it saying? At all times we can endeavour to communicate with the person with dementia. We must remember as health care professionals that

'the essence of communication is human contact [so we can] continue to reach out to people and give them a chance to reach out in response'.

Crisp, J. (2003). *Communication. Dementia Nursing: A guide to practice.* R. Hudson. Melbourne, Ausmed Publications.

MILD COGNITIVE IMPAIRMENT

by Dearbhla O'Caheny

Do you find it difficult to remember the name of a person you were introduced to recently? Do you sometimes find yourself at the top of the stairs at home wondering why you went upstairs to begin with? These moments of forgetfulness are very familiar to many of us. However in the majority of cases there is no need for alarm, as most people at some point experience some degree of age-related memory loss.

Forgetfulness is part of the normal process of ageing. Even in young adulthood we are losing brain cells, although this occurs at a very slow pace. So as we get older we may require more time to process, encode and recall information. Some regard these memory lapses as 'senior moments' while others get anxious that it may indicate a more serious problem.

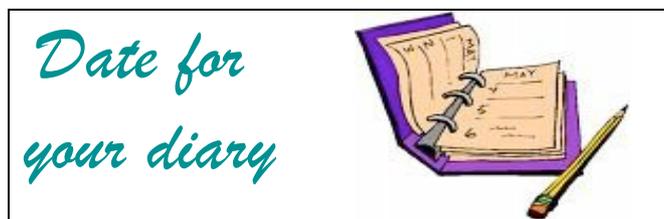
In a small number of cases, these memory difficulties may be the start of a mild cognitive impairment (MCI). MCI is defined as cognitive decline greater than that expected for an individual's age and education level but that does not interfere with the activities of daily life. It is different to dementia, where the cognitive impairments are more intense and the person

often has impairments in reasoning and judgement, often accompanied by high levels of stress (Gauthier et al, 2006).

While not everybody who has a mild cognitive impairment will progress to Alzheimer's disease, they do have a higher risk of progression. It has been observed that 12-15% of people with an MCI will progress to Alzheimer's disease annually, while a third of people will improve over a five-year period (Martin, 2009).

If someone has concerns about memory related problems we encourage them to visit their G.P. who can advise and if required organise referral to a memory clinic or other related specialist.

Gauthier, S. Prof. et al. (2006) '*Mild Cognitive Impairment*'. *The Lancet*; 367(9518):1262-1270.
Martin, M. & Collins, O. (2009) *What is mild cognitive impairment and will it get worse?* Irish Independent, August 24, 2009.



AUTUMN CONFERENCE DESIGN AND DEMENTIA TUESDAY 23 NOVEMBER 2010

We will host our 2010 Autumn Conference on Tuesday 23 November. The conference will explore a broad range of issues in relation to Dementia and Design. With many expert national and international speakers and facilitated workshops, it will be of interest to all those who are involved in designing dementia units and supporting people with dementia including health care professionals from the public, private and voluntary sectors. People with dementia and their carers are also welcome. Please note this exciting event in your diary.

For further information and booking form please visit www.dementia.ie or call Lorraine Lovely on 01- 4162035.

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