



A new year, a new decade and time for the DSIDC Spring newsletter! I hope you had a happy Christmas and New Year and are rejuvenated to continue in 2010 to make a real difference to the lives of people with dementia. DSIDC is here to help you do that, so do get in touch if you have any ideas you would like to explore or to share with us or with other readers.

Since our last newsletter, we had the pleasure and privilege of hosting our Autumn Conference, the theme of which was *Dementia and Rehabilitation*. Over 150 of you attended and indicated that it was not just our staff who thought it was a great success! An amazing 98% said the conference was good or excellent. I think the enthusiasm and expertise of the speakers were what impressed me the most and I know a lot of you felt that they demystified the concepts and gave us useful tools to improve our practice .

We are currently completing our 2009 Annual Report due for publication soon. We found that despite the gloomy economic picture last year there was a high demand for dementia education and our information and consultancy services. Our new three day *Life Story and Activity in Dementia Care* course was a great success and because of demand we are repeating that course twice in 2010.

There is a lot going on in relation to dementia in Ireland at the moment and so we have decided that our 'free' Spring Seminar on 29 April will showcase current research activity on quality of life for the person with dementia. See back for details of this and other important up-coming dementia specific events.

Most of you will by now have received our Education Brochure for 2010 which is also available on our website. This year we are running three additional courses which include *'Communicating with the Person with Dementia;*

*Management and Leadership in Dementia Care and Caring for the Person with Dementia in an Acute Care Setting.* These have been developed in response to identified needs and we are delighted to include them. Apart from our nine scheduled courses, we are of course delighted to work with you to design courses to address your particular needs.

Two DSIDC staff will be undertaking additional education in dementia design this Spring so we will have all the latest in this important area to share with you in our Summer Newsletter.

The DSIDC Living with Dementia Programme has now recruited Janet Convery as the fourth PhD student. The PhD students are now regularly adding their expertise to our education courses which means that latest research findings are reaching practitioners very quickly.

In this newsletter, you will find articles by DSIDC staff on '*assistive technology*' and on '*walking about*' and you can also read about Marissa Butler's exciting Palliative Care in Dementia Research project in Co, Clare. Enjoy!



*Best wishes,  
Patricia Hallahan  
Director*

### **Assistive Technology** **Matthew Gibb**

When we think about assistive technologies for people with disabilities it is possible that the first things that spring to mind are expensive items such as electric wheelchairs or technologically advanced items such as integrated telecare systems. However, this would be too narrow a focus and we really should be looking at assistive technology as "any item, whether purchased off the shelf, or customised, which enhances an individual's independence."

The argument persists that technology generally is designed without any thought to people with disabilities. They would like to see a move towards 'universal design', where a little bit of thought has gone into a product or an environment so that the design encompasses the needs of all citizens



where possible. This could be something glaringly obvious such as 'dropped' kerbs at road crossings that facilitate wheelchair users, parents with pushchairs or the tourist with the wheeled suitcase alike or it could also be something slightly less noticeable such as a 'loop system' fitted into theatre and cinema auditoria to assist hearing aid users.

For people with dementia, there are already many products on the market that can assist with day-to-day living and promote independence.

There are easy to use mobile phones such as the Doro Handle Plus that does not have the confusing plethora of buttons that are common on regular mobile phones. There are signs using words and pictures to assist way finding and there are automated pill dispensers (pictured above) to prompt medication compliance.



For more ideas, advice and information on assistive technology you may find the following website a useful starting point:

[www.atdementia.org.uk](http://www.atdementia.org.uk)

*Terry Cooper who trained as a Dementia Care Mapper would like to make contact with others interested in DCM in the north east area. Terry can be contacted at [tmjcooper@hotmail.com](mailto:tmjcooper@hotmail.com)*

### **Integrating Palliative Care in Dementia Care an Action Research Project** **Marissa Butler**

The philosophy of the person-centred model of care advocates for people with dementia and resonates with the broad principles of palliative care<sup>1 2</sup> These include a focus on quality of life with good symptom control; a holistic approach taking account of the person's life experience and current situation; care of both the person with dementia and those who matter to them and emphasis on open and sensitive communication with patients, carers and professional colleagues.

While it is acknowledged internationally and within Ireland that palliative care has a role in the care of people with dementia, there are very few

evidence-based service models which demonstrate how this can be achieved.

Introducing palliative care in the dementia pathway is particularly challenging due to the duration of the disease, the progressive inability of the individual to communicate and participate in decision-making about their care and the sensitivity surrounding the subject.



The Irish Hospice Foundation / HSE Report of 2008 "Palliative Care for All: Integrating Palliative Care into Disease Management

Frameworks" which looked (*inter alia*) at the palliative care needs of people with dementia recommended that a palliative care approach should be introduced early in the disease trajectory, and found that more clarity is required on the role of all levels of palliative care for people with dementia<sup>3</sup>

In response to this key recommendation, a two-year action research project began in November 2009 to devise, implement and evaluate appropriate palliative care responses for people with dementia within an Irish health care context. The project is jointly funded by the IHF and the Alzheimer Society of Ireland.

The project is based at St. Joseph's Residential Facility, Ennis, under the auspices of Clare Mental Health Services for Older People. As part-time Research Project Officer I will be supported directly by the Consultant Psychiatrist and the Assistant Director of Nursing.



Our key research partners are the local primary care network and the specialist palliative care (SPC) services from Milford Hospice, Limerick. There will also be links with two other action research projects which will be developing frameworks for palliative care for people with heart failure and advanced respiratory disease respectively.

The anticipated outcomes of the project are:

<sup>1</sup> Hughes JC, Robinson L, and Volicer L, *Specialist palliative care in dementia*. British Medical Journal, 2005. **305**(7482): p. 57-58.

<sup>2</sup> Fahey-McCarthy, E., et al., *Supporting persons with intellectual disability and advanced dementia: Fusing the horizons of care*. An Introductory Education and Training Programme: Trainer Manual. 2008, Dublin Trinity College Dublin (TCD).

<sup>3</sup> Irish Hospice Foundation and Health Service Executive, *Palliative Care for All: Integrating Palliative Care into Disease Management Frameworks*. 2008, IHF/HSE. p. 151.

- Clarity on nature, potential and timing of palliative interventions for people with dementia, their families and staff.
- A model of support and intervention for implementation in other services.
- Education material for key personnel in delivering palliative responses.
- Guidelines for the introduction of palliative interventions and referral to SPC.
- Information materials for service users, family members and staff outlining symptoms, treatment options and advance planning for people with dementia.

More information on this project from Marissa Butler, Clare Mental Health Services for Older People, St. Joseph's, Ennis, Co. Clare Tel: 087 2251218; Email: marissa.butler@hse.ie www.hospice-foundation.ie

### Walking about: walking with a purpose Cecilia Craig

Some people with dementia tend to walk about in an apparently 'aimless fashion'. There are of course many valid and varied reasons as to why someone walks about and the apparent aimlessness is only our subjective view. Walking about often concerns carers, be they health professionals or relatives as the person's safety may be thought to be at risk or they may be experiencing distress. How should 'walking about' be viewed?

There are a number of positive aspects for the person that may not always be acknowledged. It can be regarded as a form of exercise thereby preventing stiffness; a common complaint in the elderly; It can be a way in which the person can exert their freedom to do what they wish, an important right that is sometimes denied to people in care; a way of providing a change in surroundings, thereby facilitating mental stimulation; a way to socialise and interact with others; an enjoyable occupation in itself and many other individual and unique advantages.



However, there are risks involved. Of these, the most significant is the risk of falling. As well as the pain involved, a fractured hip even after repair, can decrease significantly physical and cognitive abilities to deal with life. Another risk is that of getting lost in

the community, which is a real possibility and one that frightens relatives into locking doors and experiencing stress. Other disadvantages include interrupting other residents, becoming distressed at not knowing what is happening.

It is the possibility of a negative consequence occurring that tends to usurp our viewpoint resulting in an over emphasis on safety. While safety is important in the care of the person with dementia, there is a danger that we may become risk averse as a result. A balanced perspective needs to be taken on the risks and benefits of walking about. The fear of, not just litigation, but the wrath of relatives, managers etc. can tip this balance towards viewing walking about as high risk only and little thought is then given to its benefits. How do we respond?

The first question to ask is: does the walking about behaviour present a safety risk or cause distress to the person? It may be that it is more problematic for the carer than the person. Assessing the walking about behaviour gives the carer information about its frequency, usual time of day, duration, onset, location and triggers. Examining the probability and potential degree of injury that might occur will provide guidance to the type of changes to be made to the environment and selection of helping interventions.



Whatever these interventions are, they need to be individual and unique to the person. The person's life story is an invaluable resource when developing beneficial interventions. Changing the environment to suit the needs of the person can make a dramatic influence and often simple changes can make a big difference. Consideration needs to be given to any sudden or uncharacteristic presentations of walking about as these may be triggered by physical needs such as pain, discomfort, impending medical emergency etc. Consider and explore any unmet psychological needs the person may have such as security, occupation, belongingness etc.

Walking about is frequently a positive characteristic and helpful to the person. The risk to safety needs to be determined while taking an unbiased attitude. Modifying the environment and developing helpful interventions based on the person's individuality and life story leads to a more person-centred way of caring. Finally, if we can respect and facilitate the person's right to walk about in safety, let's do so.

*Dates for  
your diary*



## DSIDC DEMENTIA RESEARCH SEMINAR

Thursday 29 April 2010

Sharing current research activity on  
quality of life for the person with dementia

IMM Durkan Lecture Theatre  
Trinity Centre for Health Sciences,  
St. James's Hospital, Dublin 8.

The DSIDC 2010 Spring Seminar will focus on recent research findings that have the potential to make a difference in the practice of providers of dementia care. We have received papers from many parts of the country and from Wales and we are confident that we will have an exciting programme for you.

This free seminar promises to be a stimulating and thought provoking event so please note the date for your diary and let us know as soon as possible if you would like to book a place.

For further information and booking form please visit [www.dementia.ie](http://www.dementia.ie) or call **Lorraine Lovely** on 01- 4162035.

## DSIDC Living with Dementia Seminars

**March 10 Family Perceptions of Mild Cognitive Impairment: Individual Changes and Relationship Challenges** Board Room, 3 College Green TCD. Time: 16.15

**March 26 Dementia : Person Centred Care and Relationships** Board Room, 3 College Green TCD. Time: 14.00 – 15.30

**April 16 Memory Clinics – for whom, for what?** Maxwell Theatre, Hamilton Building, TCD. Time: 12.30 –14.30

For more information on LiD seminars contact Colette Garry tel: 896 2914 email: [ageing.research@tcd.ie](mailto:ageing.research@tcd.ie) or visit website: [www.socialwork-socialpolicy.tcd.ie](http://www.socialwork-socialpolicy.tcd.ie) / living with dementia

## Other Events

**February 17** Conference: **Your memories matter – Showcasing reminiscence research**  
The Mount Conference Centre, Woodstock Link, Belfast For more info see [www.rnni.org/](http://www.rnni.org/)

**March 3** Conference **The Business of Ageing, investigating business opportunities in the ageing world** For more info see [www.businessofageing.com](http://www.businessofageing.com)

**March 3-5** Education **Design School** DSDC NI For more info see [dementiacentreni@stir.ac.uk](mailto:dementiacentreni@stir.ac.uk)

**March 9** Conference **The future of Neurological conditions Ireland**  
For more info see [www.nai.ie](http://www.nai.ie)

**May 11** Conference **Behaviours as an expression of communication in dementia**  
This is the Sonas aPc second annual dementia conference which will take place in the Royal Hospital Kilmainham, Dublin.

Topics will include Understanding behaviours, feelings and emotions; Intervention strategies for challenging behaviours in care homes and Evidence of care that meets HIQA National Quality Standards.

Speakers will include

- Professor Brian Lawlor, Consultant Old Age Psychiatrist
- Ian James, Director, the Newcastle Challenging Behaviour Service
- David Sheard, Director, Dementia Care Matters
- Penny Garner, Founder, SPECIAL



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