Introduction

Welcome to this our Summer 2005 issue of the Dementia Services Information and Development Centre’s newsletter. Most years, we welcome the opportunity the summer provides, to take a break from workshops and study days in order to develop new training materials, since during the holiday period requests for specialist training generally nose-dive. However this year has been an exception and already during the month of June, training has taken place in areas as far a field as Macroom, Churchill, Bray and in Dublin at St James’s and Cherry Orchard Hospitals and interestingly the demand for training continues to pour in this summer.

The recent and I might add very disturbing account of the way in which a sub-group of our elderly are being cared for in one Dublin based residential care setting has tended to dominate media attention and has also received much political attention. Whilst such an expose is welcome, in that it, in no small way, reminds us of the vulnerability of older people with dementia living in long stay environments, the lack of control some family caregivers have over the “powers that be”, and the need for more adequate and rigorous inspection procedures, sadly, it to my mind, provides a rather unbalanced and biased account of care practices, since as those of us working in the field know, we have all around us, examples of excellent practice where our elderly with a cognitive impairment are being cared for by highly committed staff keen to do the right thing and bring out the best in people with dementia.

An interesting project I think might be that of filming a day in the life of residents with dementia in a nurturing day care centre or in a customised nursing home and observing some of the fun and humour, which can be shared between staff and residents whilst detailing the opportunities and gratification that people with dementia can give staff. We must reward good practice and not just penalise those who engage in degrading acts, which further marginalise and humiliate persons with dementia.

We must think about the individual’s journey through dementia and its trajectory and not just hone in on early stage i.e. seeking out a diagnosis or challenging behaviours (more often associated with advancing dementias). We need to think about dying with dementia – and where is the optimal place for the individual to spend his or her last few weeks. In planning services we need to take account not only of where people want to live but also where people with dementia would wish to die.

I had occasion to recently attend a European meeting on this topic - end of life and dementia. An interesting paper given by Isabella Vedel from the Alzheimer’s Foundation noted the fact that across Europe most people with dementia die in hospitals, whilst in the Netherlands where community services are extremely well developed there is a tendency for people with dementia to die at home. I was also struck by the words of Astrid Norberg from Sweden whose research has shown that people with dementia in the last hours of their lives may experience moments of lucidity and may remember events probably best forgotten. It makes sense that we now start planning good collaboration between the world of dementia and that of Palliative Care. We need to be thinking not only about quality of life but also about quality of death, as surely death is a phase of life that needs to be planned for, doesn’t it?

Suzanne Cahill (Director)

Education and Training

Training continues to be requested from various parts of the country. Workshops in Person - Centred care are given to those with no previous experience in this area but increasingly specialist subject days are requested. These include coverage of topics such as communication, philosophy development, challenging behaviours, sexuality, assessment, care plan development, and meaningful activities. To meet the demand for Extra Mural courses for Care Assistants, three six week courses were given since January – two of them concurrently. These were well attended and very successful. Extra Mural classes will re-commence in the Autumn.

At St.James’s Hospital, Dublin, a continuing education programme in dementia care was introduced in January. This hospital programme is organized by the Centre, in conjunction with one of the Clinical Facilitators Mary Curran. It was recognized that there are difficulties in releasing staff from areas due to time constraints and workload. Consequently, short, focused presentations/workshops known as ‘Rolling Sessions’ lasting forty minutes are organized and repeated three to four times to facilitate staff attendance. These are popular and so far 116 staff members have attended these sessions. All professions have been represented at various stages. The Rolling Sessions have ceased for the summer and the programme will be reviewed and commence again in the Autumn.

Much work is being done on devising a new educational strategy, to include e-learning, based on the centre’s philosophy of dementia care. Various teaching and learning strategies and methods are being identified and programme content is being updated and revised. It is hoped that this strategy will carry the Centre over the next three to five years.
though Leinster has the highest number of people with dementia remain somewhat underrecognized. He also referenced and highlighted the fact that the financial implications up such negative images? She saw research as one mechanism by which the stigma of dementia could be reduced. She called for Awareness Campaigns to lobby for peoples needs and posed the question, why when only 5% of people reach the last phase of dementia, does the term dementia conjure up such negative images? She saw research as one mechanism by which the stigma of dementia could be reduced. Eamon O’Shea from Ireland opened the second day of the conference and highlighted the fact that the financial implications of dementia now live in Co Leitrim. Another interesting paper relating to dementia care in Ireland was that given by Trutz Haase who had undertaken research with the family caregivers of people with early onset dementia. He referred to the absence in Ireland of any real service provision for younger people with dementia and made the point that this sub-group often has to share resources such as Day Care Centres with people who are much older. Other somewhat novel concepts discussed at this four day conference included rehabilitation and dementia (Scotland), community based dementia link service providers (Australia), and an EU funded project EUROFAMCARE which will be looking at differences between spouses versus adult child caregivers.

DSIDC Conference December 2005

The DSIDC are delighted to announce it’s second national conference in Dublin on 2nd December 2005. The theme of this year’s conference is that of promoting a culture of education in dementia care. Plenary papers will address this important topic across each of the relevant care sectors. Invited speakers will include Dr. Steve Iliffe (London), Professor Bob Woods (Wales) and Professor Astrid Norberg (Sweden). The venue for this conference will be The Gresham Hotel, Dublin and registration forms can be downloaded from the DSIDC website www.dementia.ie in early Autumn.

Library

WE ARE ENDEAVOURING TO UPDATE OUR LIBRARY TO MAKE IT MORE USEFUL TO YOUR EDUCATIONAL NEEDS. BY WAY OF ASSISTING US, WE WONDERED COULD YOU SPARE A FEW MOMENTS TO COMPLETE THE ENCLOSED SHORT QUESTIONNAIRE AND RETURN TO:

THE DSIDC,
HOSPITAL 4, TOP FLOOR
ST. JAMES’S HOSPITAL
DUBLIN 8.