



DEMENTIA SERVICES INFORMATION AND DEVELOPMENT CENTRE
promoting excellence in dementia care

Newsletter

Issue: No. 6 Autumn 2002

Introduction:

Welcome to this our Autumn newsletter. Life continues apace at DSIDC as our services become better known to all of you. In this issue, we are very pleased to tell you about what we have been doing over the last six months and to keep you abreast of other interesting developments in dementia services. The period has been very busy for all of us with on-going consultancy ventures, the delivery and planning of future customised training and the winding down of some research projects with the commencement of others. We have also been in much demand on the conference circuit, in places as diverse as Amsterdam, Belfast, Donegal and Bradford.

A report from Stockholm

In July, I attended the 8th International Conference on Alzheimer's Disease and related disorders held in Stockholm. The meeting brought together 140 invited speakers and about 2000 oral and poster presentations. Topics covered included the etiology, epidemiology, biology, psychology, genetics and treatments of dementia along with social and behavioural issues. Detailed below are some interesting snippets of information reported on at the conference:

- Having an unhealthy lifestyle in early adulthood sharply increases the risk of developing AD in later life.
- Obesity and lack of exercise are associated with a higher incidence of age-related decline in mental performance.
- Counselling family caregivers may reduce the need for placement in long term care by as much as 12 months
- Keeping fit reduces the risk of dementia.
- A gap exists between dementia guidelines and professional practice. A Danish study has shown that providing GPs with guidelines about early detection of dementia failed to significantly change practice.
- A one year trial of Donepezil in Nordic countries has resulted in MMSE scores remaining stable.
- Challenging behaviours are a more important predictor of caregiver burden than patient's lack of awareness of memory loss deficits.
- A Swedish large scale study has shown that the association between education and increased risk of AD cannot be explained by occupation-based socio-economic status.

Of course any sojourn in Sweden would not be complete without visiting some Specialist Dementia Units and I was fortunate to have gained access to three, including a Finnish home based in Stockholm where to my amazement the facility was also specially equipped with a residents' sauna! It is interesting how Swedish legislation outlaws the locking of doors in residential care environments so, much thought goes into developing ways of disguising exit and entry points

and of camouflaging operational buttons even those belonging to lifts. I think more than anything what came home to me from these respective visits is how simple safe and homely their group dwellings are and how relatively easy it would be for us here in Ireland to take on board some of their very practical person-centred approaches towards creating safe welcoming and stimulating environments for people with dementia- the type of place wherein we would all be very happy to work or live.

S. Cahill

Education & Training

Since our last newsletter it is great to be able to report that demand for workshops and study days continues to grow. An analysis of the requests for training has shown us that word of mouth is how the service is best communicated. While the traditional holiday months of July and August are usually quiet, this allows time for reading and developing new materials in addition to tidying the desk and sorting the filing cabinet! The period between September and Christmas promises to be busy with 17 workshops booked into the diary. We will continue to hold our Extra Mural Course in Dementia Care, on a Monday evening, for Care Attendants and Home Helps. The next course commences in September and is fully booked. There are places available on the course which will be held from November to Christmas commencing 4th November. Facilitating workshops offers a real insight into the struggles & challenges for staff who work in this field and to their commitment to improving their approach and response to people with dementia.

One of the most heartening changes we have noticed, results from the significant increase in the numbers of staff seeking further information following training. This is reflected in requests for up to date research articles about a whole range of issues from life story work, music, personalising space, involving families as partners in care etc. The level of demand has grown to the degree that one has to feel that there is a groundswell of creative change out there and that perhaps the possibilities within dementia care practice are at last being realised.

Practice tip for Care Staff

Do some of the people with dementia in your care, spend time sitting at a table with nothing to do? Do some people have 'picky' hands?, pull at you or others, or pull at their clothes?

Have you tried a **RUMMAGE BOX** ?

A Rummage Box could be a shoe-box, covered in coloured paper, containing articles which are safe, colourful & perhaps reminiscent of the persons era and context.

For example: For a lady, a silk scarf, a soft toy, a skein of wool, a lace mantilla, a handkerchief sprayed with Eau de Cologne, etc., For a Gent: Tobacco tin, cigarette card/ playing cards, small soft ball to squeeze and if religious, rosary beads, etc., The objective of the rummage box is that the person with dementia can fiddle, touch and stroke items that are small, light, safe, easy to manage and may have a reminiscent component. Every care setting should have several of these boxes and staff can derive great satisfaction in collecting the bits & pieces and engaging in the activity with the person.

Library and Information Service

The Library at DSIDC is constantly in receipt of new materials as new texts come on the market. Thirty eight hard copy Journals are currently available with Ovid providing the platform for access to Ageline, Psych Info and The Wilsons Social Science Index. Why don't you make some time for yourself to read up on your area of interest, just telephone (01-4162035 / 4162060) before you visit, so that we can ensure one of our 4 chairs will be free for you to sit on!

New book in the Library:

Healing Arts Therapies and Person-Centred Dementia Care. Edts: Anthea Innes & Karen Hatfield. Jessica Kingsley 2002

This small text is from the Good Practice Guide series published by the Bradford Dementia Group. The book is practical with a holistic approach to caring for the person with dementia. It is also set against the theoretical perspective espoused by the late Tom Kitwood. Themes covered include Dance and Movement, Person-Centred Music Therapy and Art therapy. The emphasis is very much on the process involved in an activity rather than the final product or outcome of a session. In this it resonates with what other practitioners have written about activity and dementia where they have stressed that the overall objective is as much about the person "being" as "doing". The use of case studies in this book helps to put flesh on some of the ideas being explored. Overall it is a thoughtful, easy read taking no longer than an hour to read from start to finish.

Enable Update

The ENABLE project (enabling technologies for people with dementia), which began in March 2001, is now well under way. The project aims at facilitating independent living for people with early dementia and at promoting their well-being through access to enabling systems and products. Pleasure, memory support, quality of life, entertainment and own activity are key words in the project. The project is funded under the EC Programme Quality of Life and Living Resources, and will continue for three years. It started in March 2001. The partners are situated in England, Ireland, Finland, Norway and more recently Lithuania joined the consortium. The partners are multidisciplinary and have wide experience in dementia care and research, technology development and human factors. The Dementia Services Information and Development Centre is responsible for the Irish part of the evaluation study.

At the moment we are nearly half way through data collection with seventeen respondents included in our sample. Recruitment is still ongoing. Nick Clarke has joined us as a research assistant on the project and is responsible for the trial and assessment of one of the assistive devices, a Picture Gramophone, in a dementia specific day care centre in Dublin. Nick who is a student in Trinity College is presently completing a Masters Degree in Applied Social Research. The project will run until the end of August 2004.

Nursing Home Design and Dementia Project

Over the past year the DSIDC in conjunction with the Alzheimer Society of Ireland has conducted a research study examining design features in Irish private and voluntary sector nursing homes offering care to people with dementia. The purpose of the study is to compare Irish provision with an emerging international consensus on best practice in design for people with dementia. A further aim is to examine the experiences and attitudes of family caregivers of people with dementia in this regard. The data collection aspect of this study is now completed and a report on the key findings has been provided to funding bodies and to participants. Further analysis of a very rich data set has now commenced, so watch this space in future issues. Our thanks go to all those who helped us to successfully complete this study and to Anne Timoney the Research Officer who competently co-ordinated the project. It is hoped that results will be published and will contribute to the development of guidelines for best practice in design for people with dementia in long-term care.

Attending a Memory Clinic for the first time: What are the issues?

A pilot study looking at the subjective experiences of people being assessed for memory problems is now underway. We hope this study will help gain a better understanding of what it is like for people attending hospitals / clinics being assessed for memory and cognition function. In keeping with the philosophy of DSIDC we have the person's own views and feelings at the centre of this study. An assessment of this type, whether it happens in a specialist memory clinic, a GP surgery or a hospital outpatient department, can have a significant impact on the person given that the 'result' of such an assessment may be the diagnosis of a 'dementia', a condition many people greatly fear. The follow-up after such an assessment is crucially important both for the person being assessed and those close to him or her especially if a diagnosis of dementia is made. To date, of the 16 people approached to participate in the study 13 have agreed to be interviewed both immediately prior to and after their assessment. The carer / family member who accompanied the person to the clinic has also participated in an interview about his/her experiences and expectations about the appointment.

