



DEMENTIA SERVICES INFORMATION AND DEVELOPMENT CENTRE
promoting excellence in dementia care

Annual Report 2012



Events 2012: *clockwise from top left:* (1) **Autumn Conference:** Dr Ian James, Dianne Gove, Prof Desmond O'Neill, Matthew Gibb; (2) **Autumn Conference:** Prof Brian Lawlor, Dr Robert Coen, Prof Davis Coakley, Mr Maurice O'Connell, Prof Suzanne Cahill; (3) **Creating Excellence in Dementia Care:** Prof Eamon O'Shea, Prof Suzanne Cahill, the Minister for Health Dr James Reilly, Dr Maria Pearce, Dr Patrick Prendergast; (4) **National Memory Clinic Conference:** Jamie O'Toole (Lundbeck), Prof Gordon Wilcock, Matthew Gibb, Darina Kelly (Lundbeck).

The Dementia Services Information and Development Centre (DSIDC)

... is a national centre for excellence in dementia; our mission is to promote excellence in all aspects of dementia care in Ireland. To this end the Centre aims to promote an awareness of dementia, provide education and training to practitioners working in the field, conduct and support local and international research and provide an information service at both an individual and corporate level.

Our logo takes its inspiration from nature, a growing leaf uncurling protected by an older leaf. The image symbolises growth, strength and support; the changing hues represent ongoing development.

DSIDC offers three core professional services:

Education

Information and Consultancy

Research.

2012 was a significant year for DSIDC with the launch of the report *Future Dementia Care in Ireland*. The research in this report will form the evidence base for the creation of Ireland's first national dementia strategy, included in the Programme for Government 2011-2016.

Following a participative process with key stakeholders our strategic objectives are:

- to promote an awareness of dementia to policy makers, opinion leaders and others by providing up-to-date and relevant information at individual, organisational and institutional levels
- to enhance the knowledge, skills and attitudes of health care professionals and others who work with, or who provide services to, persons with dementia by identifying needs and by providing the most appropriate educational response
- to find out what works best or makes a lasting difference to the lives of persons affected by dementia through conducting and supporting research and disseminating research findings
- to ensure the relevance, viability, growth and development of the DSIDC through regular review of strategy and policy, increased resources and capabilities, good governance and management.

Promotion of awareness of Dementia

We were pleased to have hosted three major conferences this year. All proved to be great successes.

In January DSIDC's LiD Programme, in association with NUI Galway, hosted an international conference addressing the topic *Dementia Strategies Internationally and Nationally*. The Minister for Health, Dr James Reilly, opened the conference with the launch of the report *Creating Excellence in Dementia Care*. More than 120 delegates attended the event, which was held in the Science Gallery, Trinity College Dublin.

In April DSIDC co-hosted the second national Memory Clinic Conference, *Memory Clinics, Intervention and Assessment*, at the Guinness Storehouse, Dublin 8. The purpose of the conference was to share best practice experience of memory clinics operating in Ireland as well as ensuring that they become an integral part of the early diagnosis and care for people living with dementia. The conference was attended by leading physicians and allied health personnel involved in the assessment and diagnosis of neurodegenerative disorders in Ireland and experts from both home and abroad kept the large audience engaged and entertained.

The Autumn conference, held in November, had the theme of *Ethics and Dementia Care* and was attended by 140 healthcare professionals. The event brought together many expert speakers who provided a deeper understanding of pertinent ethical issues in relation to improving care for people with dementia; the conference provided a forum for interdisciplinary sharing and networking. A broad range of issues in relation to dementia and ethics were explored and participants brought up to-date with the latest thinking in this important area of caring.

In June RTE broadcaster Miriam O'Callaghan officially launched Ireland's first Alzheimer Café at the Avila Carmelite Centre in Donnybrook. The Alzheimer Café is a collaboration between DSIDC, Sonas aPc, the Alzheimer Society of Ireland, NHI, the HSE and Third Age. The Café has been running since December 2011 and is attracting large numbers of people with dementia, their families, carers and interested healthcare professionals.

In September 2012 the DSIDC participated in an information forum at the Arklow Bay Hotel in Co Wicklow for the launch of **Age Action Week** and in November there was an information stand at the Science Gallery, TCD.

At this event film-maker Annette Wagner attended a showing of her movie *Squeeze me*, which examines the current scientific and ethical debate around the use of robots in dementia care. The event was co-hosted by DSIDC as part of **Dublin City of Science 2012**, where Activage brought together engineers, designers, artists and older people in the community in a public engagement process to challenge, inform, debate and subvert ideas on current and future technologies for the support of successful ageing.

During 2012 DSIDC staff participated in a number of national and international networks, including

- The National Dementia Strategy Group
- The Social Work Special Interest group on Ageing
- The National Educational Dementia Group
- The Alzheimer Café
- Atlantic Philanthropies
- European Reminiscence Network
- Dementia Palliative Care Expert Advisory Group
- National Council for the Blind of Ireland
- DeafHear
- ALONE
- Siel Bleu
- St John of God Task Group
- Azure Project
- Activage 2012
- Clinical Roundtable Group.

The DSIDC website continued to be widely used during the year, as evidenced both by the number of hits received and by the increase in the number of queries in relation to dementia being processed by the Centre. Work is currently in progress to re-design the existing website and we are looking forward to launching the new site in Summer 2013.

Throughout 2012 DSIDC responded to many queries in relation to various aspects of dementia. We conducted a number of design consultancies, which enabled organisations to enhance the living experience of people with dementia by improving their environment.

Education

The education work of DSIDC continued to develop in 2012 and a total of 47 separate courses or sessions were delivered to 1,077 participants nationwide, including those from different professional groups and organisations and individuals concerned with the care of people with dementia. A new one-day course in *Responsive Behaviours* was developed in concert with other stakeholders including the Alzheimer's Society of Ireland and the HSE. Course content was divided into nine areas relating to various aspects of dementia care. These included communication, behaviours that challenge, dementia design, dementia policy, life story and activities. Category 1 approval by An Bord Altranais was awarded to all of our relevant courses and seminars.

Staff from the Centre were very much involved in the development and implementation of the National Dementia Education Programme; this provided dementia education for a further 1,200 participants at venues around the country. New working partnerships were established with organisations involved in sensory impairment with a view to establishing short education programmes focused on multiple disabilities including dementia.

In the final quarter of 2012 our new education brochure was produced providing details of our scheduled education programme for 2013. The brochure was widely disseminated through our e-contacts database and is also available to download from the DSIDC website dementia.ie. In addition to scheduled course details the brochure provides information on how to access tailored courses designed to meet specific dementia education needs.

During 2012 staff from the Centre contributed to a number of conferences, seminars and lectures. In addition the DSIDC had significant involvement in the development of the educational programmes of other organisations such as the NMPDU Programme and Trinity College Dublin. Ultimately this will improve general dementia education for healthcare professionals in Ireland.

Governance, Strategy and Staff

Steering Committee meetings were held in February, May, September and November 2012. The annual Advisory Group meeting was held in September; this event was timed to coincide with the DSIDC Awareness Campaign which highlighted our three core professional services.

Staff from DSIDC promoted the library and resource centre from our stand in the main concourse of St James's Hospital. Members of the public and hospital staff visited the stand throughout the day and availed of our many information leaflets. The day was a great success and we hope this will continue to be an annual event for the DSIDC.

During 2012 Dr John Gibbon made the decision to resign from the Advisory Group following twelve years of service. We would like to thank Dr Gibbon for his commitment and advice during his tenure and wish him well in the future. We would like to extend a warm welcome to Ms Catherine Keogh who joined the Advisory Group during 2012.

The services of the DSIDC were provided by five staff and a number of associate trainers. During 2012 Matthew Gibb, Senior Social Worker with DSIDC, continued in the post as Acting Director of the Centre.

Research

The **Living with Dementia Programme (LiD)** aims to tackle the marginalisation of people with dementia and to overcome some widespread misconceptions held in society about Alzheimer's Disease and the related dementias. Ultimately the LiD Programme is designed to help ensure that person-centred dementia services become normal routine practice and that the old culture of dementia care is eroded.

During 2012 the LiD Programme hosted three new public educational seminars and in June launched a new guide to dementia, *Future Dementia Care in Ireland; Sharing the Evidence to Mobilise Action*. This guide is the first of its kind in Ireland and was written for the general public, including persons diagnosed with dementia, their family caregivers and those experiencing the symptoms of dementia.

Future Dementia Care in Ireland sets out the key facts about dementia, both in Ireland and internationally, including new estimates on the prevalence and costs of dementia; what other countries are doing to plan for dementia; potential core elements for inclusion in the forthcoming National Dementia Strategy for Ireland and the next steps for public policy on dementia. It was launched in Trinity College Dublin by Kathleen Lynch TD, the Minister with responsibility for Disability, Older People, Equality and Mental Health.

The guide was developed to disseminate to the public, in laymen's terms, the key findings contained in a report entitled *Creating Excellence in Dementia Care: A Research Review to inform Ireland's National Dementia Strategy*. This report was the outcome of a research review commissioned and undertaken to provide the evidence base for Ireland's forthcoming National Dementia Strategy.

During the year LiD staff presented work at the Alzheimer's Disease International conference, InterDem and Alzheimer Europe conference. Dr Maria Pierce gave a presentation at the London School of Economics International Social Policy Conference and Janet Convery received the President's award for her PhD presentation at the IGS in Cork. In November a talk was given by LiD staff on the topic of Design for Dementia to more than 150 architects at a seminar organized by the Royal Institute of Architects of Ireland and in December an invited paper was presented by LiD at the Irish Association of Palliative Care conference in Dublin.

Two book chapters based on LiD research were written during 2012, two research papers were accepted for publication in peer-reviewed journals and a report on formal and informal caregivers was written for the London School of Economics.

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