



DEMENTIA SERVICES INFORMATION AND DEVELOPMENT CENTRE
promoting excellence in dementia care

The Dementia Services Information and Development Centre

ANNUAL REPORT 2015

Introduction

The Dementia Services Information and Development Centre (DSIDC) is a National Centre for Excellence in dementia and is committed to best practice in all aspects of dementia care. One of our key aims is to make Ireland one of the best places in the world for people to live well with dementia and to die in dignity cared for by family members and by service providers with a thorough understanding of Alzheimer's disease and the related dementias.



(L-R) Dr Chie Wei Fan, Mr Gerry Martin, Professor Davis Coakley, Professor Virpi Timonen, Mr Tadhg Daly and Professor Suzanne Cahill at the launch of "An Irish National Survey in Long Term Residential Care"

The year 2015 was a very active and productive year for the DSIDC starting in January with the launch of "**An Irish National Survey of Dementia in Long Term Residential Care**", the first national survey to map demographic trends in the provision of specialist long-term care for people with dementia in Ireland. During the year the DSIDC hosted four large events and participated in several international conferences. The education staff continue to deliver a comprehensive programme of education in the Dublin area and throughout the country. In December the DSIDC was the proud recipient of a Dementia Elevator Innovation award, from Dublin City University and the HSE, for its groundbreaking dementia awareness programme for secondary school students, "**Will Grandad Remember Me**".

Conferences & Seminars

During 2015 the DSIDC hosted four large conferences and seminars which attracted healthcare professionals, people living with dementia and family caregivers. The first event was the **Fifth National Memory Clinic Conference** held on Friday, 27th March in Trinity College Dublin, jointly hosted by the Mercer's Institute for Successful Ageing (MISA) and the DSIDC. The conference focused on significant changes to the dementia landscape over the last five years and addressed some of the issues arising out of those changes including a proposed national electronic referral system for publicly funded Memory Clinics.



Photo 2 (L-R) Dr Tony Foley, Dr Declan Byrne, Dr Aideen Lewis, Professor Bob Woods, Dr Siobhan NíBhriain, Dr Suzanne Timmons, Ms Daisy Robson, Professor J Bernard Walsh at the DSIDC Annual Conference



(L-R) Dr Olga Cleary, Professor Suzanne Cahill, Professor Sabina Brennan, Dr Alberto Blanco and Ms Tina Leonard.

The second event was held on Wednesday 20th May in Trinity College's Long Room Hub. The aim of the seminar was to debunk prevailing fears, myths and misunderstandings about Alzheimer's disease and the related dementias and to explore the critical impact that a diagnosis of dementia, along with the associated stigma, often has on the individual and other family members. Professor Perla Werner, Vice Rector of the University of Haifa in Israel delivered the keynote presentation. The seminar concluded by formulating recommendations on how stigma can be reduced in society today and how people with dementia can be helped to live well and enjoy a good quality of life.

In September to mark **World Alzheimer's Day**, the DSIDC and the Alzheimer's Society of Ireland, jointly hosted a seminar, designed to up-skill both health care professionals and the general public about memory problems, brain health and cognitive reserve. The seminar took place in the Stephen's Green Hibernian Club and was attended by over 100 practitioners, service planners, people with dementia and caregivers. A key message conveyed at this seminar was the importance of primary prevention; that cognitive and brain health in later life is rooted in physical and mental health from early life, and that we can all engage in lifestyle choices and behaviours which may ultimately delay or reduce the risk of developing dementia in later life.

The final public event of the year was our **Annual Conference** which took place in the O'Callaghan Davenport Hotel. The theme of the conference was dementia education and focused on a number of interventions designed to inform and develop, not only people's understanding of dementia, but also to improve their caregiving practice. We were delighted to present an excellent line-up of national and international speakers representing a number of disciplines including general practice, gerontology, nursing, psychology, academia and the voluntary sector. Professor Bob Woods from Bangor University in Wales, was our keynote speaker and delivered a thought provoking and informative presentation addressing staff training needs and the effectiveness of that training when caring for people with dementia.

Research Studies

In January 2015 the DSIDC was delighted to launch the results from the first national survey to map demographic trends in the provision of specialist long-term care for people with dementia in Ireland.

The report was launched by Professor Davis Coakley at a special event in Trinity College, Dublin. The study, carried out by the Dementia Services Information and Development Centre and researchers from the School of Social Work and Social Policy at Trinity College, found very low numbers of dementia specific care units throughout the Republic of Ireland. The researchers identified large gaps in service provision, especially in Leinster, and excessive numbers of patients in individual housing units. The report revealed that the private sector provided the majority of high dependency care, but received the least funding and highlighted the need for a new funding model to further incentivise the private sector in Ireland. In addition findings from the survey enabled the DSIDC to develop a resource manual for family caregivers wishing to place their relatives with dementia in a specialist care unit. The publication lists the contact details of 54 self-identified Specialist Care Units and has proved to be a useful resource for both health service professionals and family caregivers.



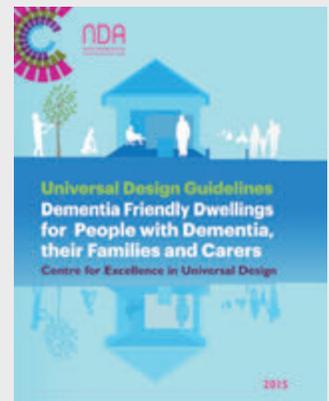
Dr Caroline O'Nolan, Professor Suzanne Cahill and Ms Dearbhla O'Cahey at the Launch of "An Irish National Survey in Long Term Residential Care"

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Universal Design Guidelines

Dementia Friendly Dwellings For People Living with Dementia

In May 2015 Trinity Haus and the DSIDC's Living with Dementia Programme were delighted to announce the official launch, by Minister Aodhan O'Riordain TD, of the Universal Design Guidelines for people living with Dementia. It is envisaged that these guidelines will be used in practice by all stakeholders and those who commission, design, build, and occupy dwellings. Subsequently, if new dwellings or alterations to existing dwellings are built in line with these guidelines, they will help people to remain living at home, and in their community, independently and safely for as long as possible.



Dr Treena Parsons

During 2015 the Living with Dementia Programme graduated its final PhD student, Dr Treena Parsons, who researched reminiscence work in four dementia care settings in Ireland. Treena's work marks the completion of the Living with Dementia programme, a six year programme of integrated psycho-social research, funded by Atlantic Philanthropies and led by Professor Suzanne Cahill. The programme mentored and graduated a total of six PhD students and eight Masters students from Trinity College Dublin. Treena's findings point to the need to educate and support reminiscence facilitators in order to carry out this work more effectively and for psycho-social interventions to be made available on the same basis as pharmacological interventions. Reminiscence work can yield multiple benefits both for the individual, for staff members and for relatives. Greater priority, by way of resource allocation, needs to be given to this area in the planning and delivery of future dementia care services.

In April staff from the DSIDC participated in the International Association of Gerontology and Geriatrics European Region Congress, which took place in the Convention Centre Dublin. The congress was opened by An Taoiseach Enda Kenny, who gave a powerful keynote address, 1400 delegates from all over the world, attended this four day event. The congress addressed topics as broad as ageism, active ageing, financial abuse and social inequalities and as narrow as personhood, age attuning, transport and intergenerational dialogues. The DSIDC had considerable input into this excellent congress with participation by staff in a total of six different platform events including hosting our own symposium entitled **"Evaluating the Impact of Education and Awareness of Alzheimer's Disease and Related Dementias"**. The symposium attracted much interest and drew together work recently conducted both at the DSIDC and at Dublin City University.

Education

Throughout 2015 staff from the DSIDC continued to provide education to healthcare professionals nationwide. Our in house workshops continued to be delivered and as always were well attended and well evaluated.

The Centre also partnered with other organisations including Our Lady's Hospice, Trinity College and the HSE in delivering other educational initiatives. Throughout the year DSIDC made a significant contribution to the hospital led DemPath project, funded by Genio. St James's is one of three Irish hospitals, which was successful in being awarded dedicated funding to make the hospital more dementia friendly; train staff in dementia care, and improve partnerships between community and hospital staff.

During the year the extra mural classes, designed to up skill family caregivers about dementia, continued and were well attended. These evening classes, delivered by St James's Hospital staff, covered topics relating to dementia, quality of life and care and aim to help family members deal with the stresses and strains of providing care in the home. Smaller projects were commenced late in 2015 regarding dementia specific care plans and the development of a course for health care assistants, in conjunction with allied health professionals in Cork and Limerick, looking at suitable seating for people with dementia.



Sixth year students from James's Street CBS who completed the programme in 2015 with School Principal Mr Paul McEntee and Vice Principal Ms Joanne Burke

Awards

In December 2015 the DSIDC received a Dementia Elevator Innovation award, from Dublin City University and the HSE, for its groundbreaking dementia awareness programme, **'Will Grandad Remember Me'**. The aim of the programme, which is now in its second year, is to increase awareness among secondary school students about ageing and dementia and in particular how young people can help a person to live well with dementia.

It provides students with a comprehensive understanding of Alzheimer's disease and the risk factors associated with dementia such as smoking, alcohol, and obesity and how these lifestyle choices can also affect the young developing brain. It also promotes a positive message about growing old and ageing well and how the brain and memory work.



Ms Dearbhla O'Cahey at the Award Ceremony in December 2015

Information Services

Throughout 2015, the DSIDC staff responded to many queries, from health care professionals and the general public. We conducted a number of design consultancies which enabled many organisations to enhance the living experience for their clients with dementia by improving their environment.

The DSIDC website, facebook and twitter accounts continue to be a valuable information source for both health service professionals and the general public. During 2015 we posted new materials on the website around Assistive Technology (AT). AT refers to any practical intervention available to support and promote the functional needs of people experiencing age related or disability related difficulties. AT has the potential to greatly benefit people living with a dementia provided it is used ethically and the choice of product is based on the assessment of individual circumstances.

During 2015 DSIDC staff participated in a number of international conferences and forums these included the First World Health Organization Ministerial Conference; Global Action Against Dementia in Geneva, the Swedish Dementia Forum X, held in Stockholm, and the International Brain Health Conference held in Havana, Cuba.

National and International Networks

During 2015 DSIDC staff participated in a number of national and international networks, steering committees and projects including:

- National Steering Group for Dementia Friendly Communities
- HSE National Dementia Education Programme
- Scientific and Advisory Panel Alzheimer's Society
- Trinity Haus and National Disability Design Project
- Dementia Elevator Project
- InterDem
- Living Well with Dementia (LWwD) South Dublin (Genio)
- The Social Workers Special Interest group on Ageing
- The Alzheimer Café
- Atlantic Philanthropies
- HIQA Advisory Group for Thematic Inspections focusing on Dementia Care
- DemPath Project
- National Referral System for Memory Clinics

Governance Structure

The DSIDC continues to employ five staff members, two of whom are part-time. It occasionally co-opts in the expertise of associate trainers. During 2015, three Steering Committee meetings were held in January, June and October and the annual Advisory Committee Meeting took place in February.

During the year Mr Brian Fitzgerald stepped down from the Committee, we would like to take this opportunity to thank Brian for his help and support during his tenure and extend a warm welcome to Mr Lorcan Birthistle, Chief Executive of St James's Hospital, who joined the Steering Committee in 2015.



(L-R) Professor Suzanne Cahill, Ms Lorraine Lovely, Ms Cecilia Craig and Mr Matthew Gibb pictured at the Stephen's Green Hibernian Club on World Alzheimer's Day.



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