



DEMENTIA SERVICES
INFORMATION AND
DEVELOPMENT CENTRE

*promoting excellence
in dementia care*

The Dementia Services Information and Development Centre

ANNUAL REPORT 2016

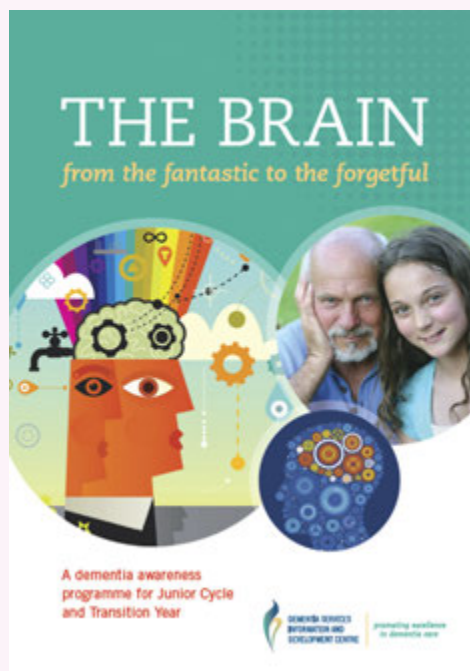
Introduction

The Dementia Services Information and Development Centre (DSIDC) is a National Centre for Excellence in dementia and staff employed at the Centre are committed to best practice in all aspects of dementia care. Our services are threefold namely (i) education/training, (ii) research/evaluation and (iii) information. Our mission is to improve the quality of life and quality of care for all those affected by dementia. This is done through research, education and training, and by collaborating with other professional groups.

These collaborations are both national and international reflecting the effective synergy between the Centre's academic research policy and service development pillars. We aspire 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 a well-educated workforce. Along with our partners, our collective mission is to reduce the impact Alzheimer's disease and the related dementias have on the individual, families, the community, and on society at large.

Highlights

In June 2016, the DSIDC relocated to its new home in the Mercer's Institute for Successful Ageing (MISA), and established its Education Centre on the sixth floor. This learning and educational facility is very well resourced with books, reports, training manuals, DVDs, sample assistive technologies and online access to top of the range medical and social science journals. The Education Centre has been thoughtfully designed to encourage interactive learning and to provide opportunities for small group tutorials, discussion and debate. Its location, with a magnificent view of Dublin city, is ideal for inspiration and quiet reflection. The DSIDC is proud to host this only dementia-specific national Education Centre, which offers a wide range of practice, policy, research and clinical dementia specific educational materials.



Key highlights of 2016 include the publication of ***The Brain - from the Fantastic to the Forgetful***, a training manual for teachers, accompanied by a workbook for school children. These training materials have been carefully researched and written by Dearbhla O'Caheny to ensure they can be integrated into Junior Cycle secondary school subjects including Social, Personal and Health Education (SPHE), Civic Social and Political Education (CSPE), and Science and Wellbeing. The intention here is to educate students about positive ageing, brain health, dementia and cardiovascular risk factors.



Other highlights during the year include the hosting of the 6th Memory Clinic conference, (see conference section), and the successful conversion and testing of two Emergency Department bays at St James's Hospital (DemPath). In September, the Centre actively participated in the Elevator Roadshow and Showcase, and in December it was part of a national radio programme on the topic of mortality rates and dementia (Newstalk programme). During the year the Centre continued to work with the Department of Health in advancing the National Dementia Strategy agenda, through its participation on the Department's Implementation and Monitoring Committee.

Hosted Conference

In collaboration with MISA, in June, the DSIDC co-hosted the 6th Annual Memory Clinic Conference, the theme for which was modifiable risk factors and the potential for dementia prevention. Professor Nick Fox, who provided a thought provoking account of pre-symptomatic treatment trials, gave the keynote address. This was followed by a presentation from **Professor Richard Cheston** who explored the importance of recognising existential concerns and how this knowledge helped inform post-diagnostic support.



Memory Clinic Conference 17th June 2016
Trinity Sciences Centre St James's Hospital

The morning finished with a "mini-symposium" based around the three Genio-funded hospital dementia projects. In the afternoon, **Professor Sarah Lamb** discussed designing and evaluating exercise interventions for people with dementia. Her presentation was followed by **John Costello**, who brought the audience up to date on the Assisted Decision-Making Capacity Act 2015. **Dr Anne Marie Miller** finished the day with a helpful presentation on the clinical use of spinal fluid biomarkers in the diagnosis of Alzheimer's disease. Over 120 health care professionals attended the conference and evaluations of this one-day event were extremely positive.

Other Conferences/Events attended by DSIDC

During 2016, DSIDC staff also actively participated at a number of other conferences, including Alzheimer Europe (September), an SPHE school conference (November) and a Social Work conference (December). The **Copenhagen 26th Annual Alzheimer Europe's Conference** was interesting, insofar as apart from current staff participation, three DSIDC alumni and former postgraduate students Dr Emer Begley, (ASI), Dr Ana Diaz Ponce, (AE) and Avril Easton, (ASI), also attended and delivered scientific papers at this same conference. Representing the DSIDC and St James's Hospital, Matthew Gibb and Natalie Cole gave platform papers based on DemPath.

These papers were well received and generated considerable interest. This was Alzheimer Europe's most well attended event to-date with over 12 keynote speakers. Conference papers were underpinned by the strong theme of human rights and disability and compared to other years, this two-day event had a greater emphasis on medical research. People living with dementia were also at the fore of this conference with platform presentations delivered by Agnes Houston, Helga Rohra and Helen Rochford-Brennan, who is now Chair of the European Working Group of People with Dementia.

Other important dementia related events attended by DSIDC staff during the year include (i) the launch in April, by former President of Ireland, Mary Robinson, of the Irish Charter on Human Rights and Dementia, (ii) the launch in October of **"Understand Together"** a nationwide HSE dementia awareness campaign, which is a direct roll out from the National Dementia Strategy, (iii) the launch in December of a report on the feasibility of Dementia Registries for Ireland, hosted by the ASI and during the same month (iv) a study day on the three hospital projects, jointly hosted by the HSE and Genio. These projects are based at St James's Hospital Dublin, Mercy University Hospital Cork and Connolly Hospital Dublin and are being evaluated by staff from the School of Nursing and Midwifery at Trinity College Dublin.

The launch of Professor Eamon O'Shea's evaluation of the Atlantic Philanthropies overall investment in dementia since 2007, was also attended by DSIDC staff in late December. During 2016, DSIDC staff also attended (i) the Sonas apc annual conference, (ii) a Person Centered Care Masterclass on the new Assisted Decision Making Capacity Act, (iii) a SAGE briefing on Mental Capacity, (iv) a symposium entitled, "Supporting the nursing home resident and their family in the journey from home to nursing home", (v) a Social Workers in Primary Community and Continuing Care and Disabilities conference and (vi) Socio-drama Tackling Ageism, Preventing Abuse conference, (S.T. AGE).

Education

Throughout 2016, DSIDC staff, continued to provide education to health service professionals nationwide. Our in house workshops were delivered throughout the year 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 such as eLearning. DSIDC continued to make a significant contribution to the hospital led DemPath project, funded by Genio. This involved providing education to 2200 staff members, designing two bed bays in the Emergency Department and developing eLearning modules.



Professor Suzanne Cahill presenting at a DSIDC workshop

During the year the extra mural classes, designed to upskill family caregivers were provided free of charge. Classes, and a module based on the schools project and manual (O'Caheny, 2016), were given in Loreto Abbey, Dalkey and CBS James's Street. As part of our programme we invited Seamus Cunningham, a person living with dementia, to speak to fifth year students about the subjective experience of dementia.

Seamus, a former CBS student, spoke about his diagnosis, his daily routine, how he keeps active physically and mentally and the importance of being patient and listening to people who are living with dementia. Lectures were also given to students enrolled on the MSc in Gerontological Nursing and MSc in Dementia, Trinity College Dublin (TCD), and to practitioners enrolled on the National HSE Dementia Programme. During the year DSIDC also assisted in the development of an eLearning module on the TCD MSc in Dementia programme titled '***Psychosocial Approaches to Dementia***'.



Seamus Cunningham with a group of fifth year students from CBS James's St

Information and Consultancy Services

We provide a professional consultancy service offering advice on a broad range of issues including architectural design, service evaluation, quality of life issues, situational analysis and strategic planning. Our information and consultancy service reflects the increased interest on the part of practitioners and the public for information on dementia related topics. These queries came from a variety of organisations and settings.

Throughout 2016, the DSIDC staff responded to queries from health care professionals and the public about topics such as quality of life interventions for nursing homes, responsive behaviours and ability assessments for activities and life story work. We also received many requests for advice and information from the general public on what to do if one is worried about memory or cognitive problems. During the year we also 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 and offers users a forum to seek out assistance, information and advice on any dementia related enquiry they may have. We aim to keep the public and professionals up-skilled with the latest thinking on best practice in dementia care.

During 2016 DSIDC staff participated in a number of national and international networks, steering committees and projects including:

- National Steering Group for Dementia Friendly Communities
- Steering Committee for Tallaght Hospital's dementia friendly project
- HSE National Dementia Education Programme
- National Dementia Strategy Implementation Committee
- Dementia Elevator Project
- Understanding Together HSE dementia awareness campaign
- Dementia and Neurodegeneration Ireland
- Living Well with Dementia (LWwD) South Dublin (Genio)
- The Social Workers Special Interest group on Ageing
- The Alzheimer Café
- Atlantic Philanthropies
- DemPath Project
- National Referral System for Memory Clinics
- Global Brain Health Institute (GBHI) Updates

Accordingly during 2016 we added a new page to the website which addresses the important topic of brain health and dementia risk reduction. The information here is classified so that our five-step guide to brain health can be easily downloaded and useful information regarding dementia risk reduction is also available.



Governance Structure

The DSIDC continues to employ five staff members, two of whom work part-time. It occasionally co-opts in the expertise of associate trainers. During the first six months of 2016, Professor Suzanne Cahill (Director) was on project leave from the DSIDC where she has been researching and writing a book on the topic of Dementia and Human Rights. This book is due to be published by Policy Press in August 2017. During the period of Suzanne's leave, Matthew Gibb was appointed to the position of Acting Director, we would like to thank Matthew for remaining steadily at the helm during that period and for his competently steering the ship through to its new location! All professional activities undertaken by the DSIDC are overseen by a Steering Committee, chaired by Dr Declan Byrne. During 2016 Steering Committee meetings were held in February and September.



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