

Helping family caregivers cope with the daily stress of providing care to a relative with dementia

May 29 2014

A Symposium on Dementia and Caregiving featuring leading US Dementia Expert, Professor Steve Zarit, an eminent clinician and academic, working in the field of ageing, dementia and caregiving for over 40 years took place in Trinity College Dublin on May 23rd last. On the occasion of the seminar new research on long-term residential care in Ireland was also launched. The event was organised by the Dementia Services Information and Development Centre (DSIDC) a national centre of excellence, involving St James's Hospital and Trinity College Dublin.

Professor Zarit has had a lifelong interest in caregivers, particularly family caregivers and much of his earlier work focussed on ways by which family caregivers could be helped cope with the daily stress and strain of caregiving. One of his earlier major contributions to the field was in designing a tool/scale – the Zarit Caregiver Burden Interview, used to measure levels of stress experienced by family caregivers providing home care to their relatives diagnosed with dementia. Although this tool was first developed in the 80's, its use continues to be widespread throughout the world today. The Zarit scale which contains 22 questions, measures the degree to which family caregivers perceive their care-giving responsibilities are having an adverse effect on their health, personal and social life, psychological wellbeing and finances. Throughout Ireland, the Zarit scale is used in several different dementia care settings including Day Care and at Memory Clinics. It has been

successfully used in the recent evaluation of the Genio Dementia Care projects in Ireland.

His presentation titled: 'Caregiving at a Crossroads: Bridging the Gap between Science and Practice', examined treatment techniques shown to be effective in helping family caregivers cope with the daily stress of providing care to a relative with dementia. In his presentation, he drew on scientific studies and empirical evidence to demonstrate the type of outcomes, which could be derived from such person-centred interventions. Key questions, which were addressed by him, included: (i) what interventions best help [family caregivers](#) to lower the stress of dementia care? (ii) Does using Day Care lead to improvements in emotion and can using this service have any physiological benefits? (iii) How can we provide people involved in dementia care with the help they need?

His most recent book titled: " Mental Disorders in Older Adults" and co-authored with his wife Dr Judy Zarit, draws on both his academic research and his wife's many years of practice as a consultant to Nursing Homes and Retirement communities and provides a very insightful overview of mental health issues, assessment and treatments in older people.

On the occasion of the seminar new findings based on a national survey on long-term residential care in Ireland were also launched.

This study which was recently led by Trinity's Associate Professor Suzanne Cahill involved a national survey of nursing homes public, private and voluntary, not for profit across the Republic of Ireland. The research was primarily undertaken to gain a better understanding of the numbers and location of dementia specific residential care settings for older people in Ireland. Until recently no register of such specialist care facilities existed. A total of 602 nursing homes were surveyed in relation

to the provision of [dementia care](#) to their resident, yielding a response rate of 78%. Commenting on their significance, Associate Professor, Suzanne Cahill said:

Key findings:

- Two thirds of all nursing homes (N=602) operate under the auspice of Private Providers, about one in five are HSE operated and a small minority one in eight (13%) are Voluntary Not for Profit.
- A total of 54 (12%) of these Nursing Homes have Specialist Care Units (SCU) i.e. facilities catering exclusively for the complex needs of people with dementia;
- Of these 54 SCUs, 63% were privately run, 30% were HSE operated and 7% were Voluntary Not for Profit.
- SCUs are unevenly distributed throughout the ROI; Some areas over-supplied (Cavan/Monaghan, Cork, Donegal, Galway), and others such as Dublin Carlow Wicklow there is no provision
- A total of 1034 people with dementia were resident across these 54 facilities. This figure represents 2% of all people estimated to have dementia in Ireland or 4.5% of the total number of older people living in long stay residential care
- Only 5% of residents in these SCUS were aged less than 65 and only 1 person had Alzheimer's disease related to Down's Syndrome.
- Only 66 respite beds were available across the 54 SCUs. Based on the estimated 30,000 community-dwelling people with dementia in Ireland, this figure suggests one respite bed for every 450 people with dementia
- The average number of people living in each SCU was 19, a figure far in excess of best practice recommendations. The average number of residents in the Voluntary sector was 29, in Private Sector 19 and in HSE was 16

- Admission criteria varied considerably across the three different service providers- however a surprising finding (given the higher payments to and supposedly higher dependency levels of older people in public long stay care facilities), was the fact that two thirds of HSE providers stipulated that residents be independently mobile
- Therapeutic activities including Aromatherapy, Music, Reminiscence, Art Therapy, the Sonas programme and Yoga were standard practice in virtually all SCUs but domestic activities not always offered. Ten of the 54 SCUs afforded their residents no opportunity to undertake domestic activities.
- A significantly larger proportion of privately owned SCUs, compared with HSE and Voluntary /Not for profit, reported that all nursing staff and health care attendant staff had undergone dementia specific training
- End of life policies in evidence in most SCUs. However a small minority (N=7) either always or sometimes discharged their residents dying with dementia out to other [nursing homes](#) or to acute care.
- Despite the expected increase in prevalence of dementia in Ireland, no significant expansion in supply is likely in the foreseeable future
- Survey found that private operators are the dominant providers even though no premium bed-rate paid and no financial incentive to encourage necessary capital investment
- Findings raise important questions about funding models, payments for long term care (NTPS) and the overall cost of [dementia](#) specific long term care in Ireland

Provided by Trinity College Dublin

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