



## Improving Quality of Life for People with Dementia in Residential Care

There is growing evidence pointing to the many benefits derived from creatively adapting the environment to meet the complex needs of people with dementia. That is according to Professor Suzanne Cahill, Associate Professor and Director of The Dementia Services Information and Development Centre (DSIDC), a Centre for Excellence in Dementia Care, located in St James's Hospital in Dublin.

There are about 41,740 people with dementia in Ireland, with the incidence rate higher than cancer and heart disease. According to estimates, about two-thirds of all people living in residential facilities have a dementia. Often the dementia is complicated or masked by other age-related health problems, like diabetes, Parkinson's, coronary heart disease, stroke or depression. Ironically, dementia can remain largely unrecognised and tends not to be recorded as the main reason for residential care admission.

While several new residential care centres have specially adapted units designed for those with dementia, older centres can nonetheless adopt practical measures to enhance the environment. According to Professor Cahill, in a wide-ranging interview with Reach, these include appropriate signage, creating corridors with meaning, use of interesting walls, appropriate noise control, stimulating interior décor, including age-appropriate furniture and carefully selected colours, providing access to a multi-sensory garden as well as a well-trained workforce in dementia care. She points to older-styled centres, where changes have been successfully made, based on a model known as "Teaghlach" – a supportive type of environment that resembles a real home environment. Examples of this can be observed in St Joseph's Hospital, Ardee, Co Louth; Mount Carmel, Clonakilty, Co Cork; and Moorehall Lodge in Co Louth.

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## About Us

This newsletter is written and produced by the volunteers who serve on the National Relatives Panel. We operate under the auspices of the Social Services Inspectorate, part of the Health Information and Quality Authority (HIQA).

The Authority is responsible for the establishment of quality standards and the regular inspection nationwide of both private and public residential care centres (otherwise known as "nursing homes").



Professor Suzanne Cahill

**“We believe that two-thirds of all people living in residential facilities have a dementia. However, many residents with a severe dementia are still capable of communicating their views and preferences about what is important to them.”**

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While residential centre carers are trained to Further Education and Training Awards Council (FETAC) Level 5, Professor Cahill believes that working in dementia care can be very stressful and that implementing a good mentoring system within the residential care centre is another key to delivering good care. “Training should be continuous, and staff should be rewarded for introducing change, which improves residents’ quality of life and which offers people in long-stay care more choice and a sense of control over their own lives.”

Meanwhile, a recent study, undertaken by Professor Cahill and Ana Diaz Ponce, reveals that many residents with a severe dementia are still capable of communicating their views and preferences about what is important. The study shows that many residents with Mini Mental State Examination (MMSE) scores below 15 could still discuss quite cogently what they did not like in the residential centre and what could be done to improve their lifestyles. The majority rated family and regular family visits as critical to their good quality of life. Good trusting relationships with staff members were also rated by many as very important. The same study showed that people with severe dementia appeared to be most lonely and most in search of human contact. For this group, even momentary pleasures such as having a cup of tea or an ice-cream were pleasurable activities and were just as important as structured activities for other residents with less advanced dementia.

**“In my view, obtaining good life story information for a resident with a dementia is every bit as important as getting a good medical profile.”**

Connectivity and ensuring that good linkages to residents’ past lives were sustained and that they remained involved and informed about former communities were also deemed important to the quality of life for many of these residents. Some people talked about the pleasure they still derived from being able to take a walk in a favourite neighbourhood, drop into their former local shop or continue to go to a familiar social event. The study also revealed that on admission to residential care, there are opportunities for residential care staff to document in detail residents’ life stories, including their family background and interests. This information can later be used judiciously in everyday care practice to promote interests, to reminisce and to encourage meaningful communication.

Professor Cahill concludes, “In my view, obtaining good life story information for a resident with a dementia is every bit as important as getting a good medical profile. It is vital that residential centre staff tap into the family’s knowledge base as they are the real experts on the resident – they have already developed and practiced competencies on how to deal with certain very complex or challenging situations.”

Professor Cahill has worked for over 20 years as a social work practitioner, researcher and educator both in Australia and in Ireland in the area of ageing and dementia. She was the Principal Investigator behind a recent dementia research review, which will lay the foundations for the Strategy on Dementia in Ireland, now embedded in the Programme for Government. Professor Cahill has compiled a useful guide, *Life for Caregivers after Placing a Relative with Dementia in a Nursing Home* – available online at: [www.nhi.ie/iopen24/pub/placing%20a%20relative%20with%20dementia%20in%20a%20NH.pdf](http://www.nhi.ie/iopen24/pub/placing%20a%20relative%20with%20dementia%20in%20a%20NH.pdf). For further information on dementia, visit the DSIDC website: [www.dementia.ie](http://www.dementia.ie) and the Living with Dementia website: [www.socialwork-socialpolicy.tcd.ie/livingwithdementia](http://www.socialwork-socialpolicy.tcd.ie/livingwithdementia).



## Sharing the Best – Keeping the Mind Alert

We continue our spotlight series, looking at best practice in activities. In this issue, we look at how to keep the brain stimulated.



Older people can have fun and exercise their brain power at the same time by playing a variety of mind-stimulating games that enhance memory and help prevent boredom and stagnation. The DANA Alliance for Brain Initiatives<sup>1</sup> says that engaging in active lifelong learning is essential to your brain health as you age. According to the US National Institutes of Health<sup>2</sup>, practising mental exercises can improve brain health and help maintain thinking skills. Even eating or brushing your teeth with your opposite hand is a good exercise to keep your mind healthy. A walk is a great option – moderate exercise has proven health benefits for the mind as well as the body.

### Reading and Memory Games

According to the Mayo Clinic<sup>2</sup>, reading can help decrease the chances of cognitive impairment by 30% to 50%. Whether it is a novel or the daily newspaper, reading exercises the brain by making it perform several processes at once – interpreting letters and words and processing overall concepts and ideas. Likewise, a study published in the *Journal of the American Medical Association* says that memory games are among the brain exercises most likely to maintain healthy cognitive function in the older person. The classic game of Memory is a good example. In this game, cards with pictures of ordinary objects are laid face-down on a table with two cards of each picture in each stack. Participants then take turns turning over the cards to try and match up the pictures.

### Trivia Games

Trivia games such as Family Feud, Jeopardy or Trivial Pursuit may aid those with dementia in retaining some of their brain functions. Some of the best games feature questions from when the patient was younger. Trivia games also can be played in a social setting with friends or even online if the older person has Internet access.

### Video Games

Video games are not just for children, especially with the advent of games like Brain Age or Big Brain Academy for game console systems and websites like Lumosity, Scientific Psychic or Games for the Brain. With all of these, you can exercise your mind by playing games, targeting intelligence, memory, focus, speed and response time. Choose logic, visual or spatial exercises.

### Games and Puzzles

Word and number games, such as Scrabble and Sudoku, use rational thinking, spelling and the logic of placement and space. Since many word games allow for multiple players, they also provide important opportunities for the patient to socialise. Try three-dimensional puzzles and games that require you to add a spatial dimension to your brain's repertoire.

Crossword puzzles also provide an intellectually stimulating exercise that requires a variety of mental activities such as logic, geometrical skills and word skills. Various card and strategy games – like chess, draughts and bridge – offer the older person a combination of social skills, planning skills and logic. Remember, even a simple game of Snap can keep the mind sharp and focussed.

<sup>1+2</sup> Learn more by visiting [www.dana.org](http://www.dana.org) and [www.livestrong.com/article/92447-brain-exercises-seniors/](http://www.livestrong.com/article/92447-brain-exercises-seniors/)

## The Role of the Advocate - Meet Mary Fletcher-Smith



Mary Fletcher-Smith (second from right) at the 2011 Healthcare Innovation Awards

**When Mary Fletcher-Smith's father was a patient in Leas Cross Nursing Home, in north Dublin, she found huge shortcomings in aspects of his care during the final weeks of his life. The subsequent, damning report on the abuse and neglect at that centre inspired her to become involved in a campaign to improve standards of care in residential care centres in Ireland. Mary shares her story and explains the important role of the advocate.**

"I can remember feeling so helpless, frustrated and powerless as I lived in fear that my father might suffer more. When I tentatively remarked that he needed more nursing care, or nutrition and even a consultation with the local doctor, I was seen by some staff to be over-anxious and possibly a nuisance. This resulted in my spending a great deal of time there checking up on his wellbeing." In fact, she says she found it necessary to do most of the final caring herself as she had become all too aware of the inadequacy of Leas Cross when residents became very ill. Mary's father died in Leas Cross in June 2005.

Later revelations of abuse and neglect of other patients in Leas Cross prompted the publication of Professor Desmond O'Neill's detailed report. This inspired Mary's passionate involvement in a campaign to improve standards of care and monitoring in residential care centres in Ireland.

After Leas Cross, the Consumer Affairs Office of the HSE met members of the 75 families, whose relatives had resided at the centre, and subsequently established a Forum on Services for Older People to examine the issues arising from the Leas Cross inquiry. The Forum made three main recommendations – training in personal excellence for staff, training for independent volunteer advocates to represent the needs of residents, and the development of a website offering information on residential care centre options for families.

An advocate is someone who puts forward a case on behalf of another, and the role of the advocate is being increasingly recognised in Irish life. Health advocacy supports and promotes patients' healthcare rights as well as enhancing community health and policy initiatives that focus on the availability, safety and quality of care.

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Established in 2007, the HSE National Advocacy Programme Alliance (NAPA), working with the help of trained independent advocates, has the goal of enabling people in residential care to effectively express their wishes, access their entitlements and assert their rights. Mary was involved from the outset in the delivery of volunteer training, with her professional background, personal experience and commitment proving an invaluable combination. As a former director of nursing, Mary now works as an independent consultant and was previously Chairperson of the National Advocacy Committee.

Training was delivered over 14 weeks, designed up to FETAC Level 6, and included a five-week work placement in which Mary acted as academic mentor. The training included personal presentation skills to help to facilitate the beginnings of the relationship between advocate and resident – a relationship in which trust and confidence is paramount. To date, 250 volunteers have been trained as advocates with over 89 residential care centres nationwide currently involved. Each residential care centre identifies a link-staff member, who in turn introduces the advocate to up to 15 residents who could benefit from the contact. Family members are also informed of the service, which can provide support to their relatives.

### **Our motto is “An ear to listen, a voice to speak”.**

The National Advocacy Programme Alliance was externally evaluated in 2010, where it was found that “the achievements and outcomes of the programme were significant”. A key recommendation in the evaluation of NAPA was that the governance should be outsourced by the HSE to an independent agency. On 30 September last, the National Advocacy Programme Alliance was formally handed over by the HSE to Third Age at the second annual conference for Independent Advocates for Older People, entitled *Valuing the Voice of Volunteers*.

A voluntary organisation, Third Age, promotes the value of older people as active and valued members of society, and views the third age as a valuable life stage where older people continue to contribute to their communities. Indeed, an innovative feature of the new programme is the partnership it represents: a statutory body, the HSE; a not-for-profit organisation, Nursing Homes Ireland; and Third Age, a voluntary organisation with 25 years’ experience in working with older people.

Now taking responsibility for the National Advocacy Programme Alliance, Third Age has over 1,000 trained volunteers working throughout Ireland as listeners, tutors, peer nutritionists – and now advocates. The motto and ethos of the programme is “An ear to listen, a voice to speak”.

Additionally, the other two HSE initiatives, the information website, and training for carers, have also been developed. A training programme for care workers in personal excellence was delivered by Michael Brophy, a Healthcare Values Education Specialist, to over 150 staff. This enables the employee to value his/her own caring role and to deliver their skills out of their own humanity in the participating residential care centres. The external evaluation noted that, “this course has added a new dimension to the capacities of staff in relation to compassion in care and was positively received by staff.” Currently being expanded, the website [www.myhomefromhome.ie](http://www.myhomefromhome.ie) offers information and choice to families who are seeking suitable residential care centres for their relative.

### **“My father would be very thankful to realise that his negative experience led to my involvement in this very worthwhile project.”**

The National Advocacy Programme Alliance has been successful in a number of recent awards including the Inspirational Life Award from *The Irish Times* and the Health Innovation Awards. The first group to qualify as graduate advocates was also received in Áras an Uachtaráin by former President, Mary McAleese, who was very impressed with the concept of the programme and its implementation.

The HSE recommends that an advocacy programme should be introduced to all residential care centres. Mary feels strongly that this should be incorporated in legislation to ensure its optimum efficacy. “My father would be very thankful to realise that his negative experience led to my involvement in this very worthwhile project,” she concludes.

**If you are interested in becoming an advocate, please contact:  
Third Age Ireland: Tel: 046 9557766; Email: [info@thirdageireland.ie](mailto:info@thirdageireland.ie)**

## We Want to Hear from You



We are relatives – just like you. Our mission is to work with HIQA and the providers of residential care centres around Ireland to drive excellence in standards of care for older people. This newsletter is designed to inform and empower you. Do you have ideas for inclusion in this newsletter? If so, we would love to hear from you. If you know friends, neighbours or acquaintances with relatives in residential care centres, please tell them about this newsletter. Help us spread the word! Please contact us as follows:

### By email:

[acarroll@hiqa.ie](mailto:acarroll@hiqa.ie), marking the subject of your email Reach – Relative Newsletter Contribution.

### By post at:

The National Relatives Panel, c/o Andrea Carroll,  
Health Information and Quality Authority,  
Social Services Inspectorate,  
George's Court, George's Lane, Smithfield, Dublin 7.

If you are interested in receiving this newsletter by email or would like to receive back copies, please subscribe by sending your name and email address to the following email, [acarroll@hiqa.ie](mailto:acarroll@hiqa.ie), marking the subject Subscribe to Reach.

## Learn More

### HIQA Standards

[www.hiqa.ie/system/files/Residential\\_Care\\_Report\\_Older\\_People\\_20090309.pdf](http://www.hiqa.ie/system/files/Residential_Care_Report_Older_People_20090309.pdf)

### The Health Act 2007, Regulations 2009

[www.dohc.ie/legislation/statutory\\_instruments/pdf/si20090236.pdf?direct=1](http://www.dohc.ie/legislation/statutory_instruments/pdf/si20090236.pdf?direct=1)

## Useful Phone Numbers and Websites

Age Action Ireland	01 4756989	<a href="http://www.ageaction.ie">www.ageaction.ie</a>
Alzheimer Society of Ireland	1800 341341	<a href="http://www.alzheimer.ie">www.alzheimer.ie</a>
Diabetes Federation	1850 90909	<a href="http://www.diabetes.ie">www.diabetes.ie</a>
DSIDC	01 4162035	<a href="http://www.dementia.ie">www.dementia.ie</a>
HIQA	01 8147400	<a href="http://www.hiqa.ie">www.hiqa.ie</a>
Parkinson's Association	1800 359359	<a href="http://www.parkinsons.ie">www.parkinsons.ie</a>
Third Age	046 9557766	<a href="http://www.thirdageireland.ie">www.thirdageireland.ie</a>
Western Alzheimer Society	094 9364900	<a href="http://www.westernalzheimer.ie">www.westernalzheimer.ie</a>
HSE information on centres		<a href="http://www.myhomefromhome.ie">www.myhomefromhome.ie</a>
Irish Centre for Social Gerontology		<a href="http://www.icsg.ie">www.icsg.ie</a>

## Did You Know?

### The Residents' Guide

In any aspect of our lives, access to information is so important. This is even more pertinent when we rely on others to provide us with care and support. Did you know that Regulation 21 of the Care and Welfare Regulations requires the provider or owner of residential care centres to give each resident a copy of a Residents' Guide?

The Guide must include:

- A summary of the statement of purpose, a legal document that is included in the conditions of registration of the centre.
- The terms and conditions of accommodating the resident in the centre.
- A copy of the most recent HIQA inspection report.
- A standard form of the contract of care.
- A summary of the complaints procedure.
- The name and contact details for the Chief Inspector of the Health Information and Quality Authority.

Regulation 21 also requires the person in charge to make information available in an accessible format to residents appropriate to their needs to assist decision making.

**What would you like to see covered in future Did You Know features?**