Development of a National Strategy on Dementia

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CARDI is a not for profit organisation developed by leaders from the ageing field across Ireland (North and South) including age sector focused researchers and academics, statutory and voluntary with support from the Atlantic Philanthropies. The organisation was established to provide a mechanism for greater collaboration among researchers on ageing, for wider dissemination of ageing research information and to advance a research agenda relevant to the needs of older people in Ireland, North and South.

We welcome the opportunity to present this submission on the Development of a National Strategy on Dementia in Ireland. Our brief submission summarises the findings of two research projects which CARDI has funded as part of its grants programme. The research findings can contribute to the strategy in two areas – care standards in nursing homes for dementia patients, and medication use in patients with dementia at the end of their lives.

End of life care standards for dementia

More than 44,000 people in ROI currently have dementia and there will be over 100,000 people with dementia by 2036. One in 20 people aged over 65 years has dementia, and this rises to one in four in the 80 plus age group.

Despite the growing numbers, there are no specific guidelines to help institutions in the delivery of care to people with dementia who are at the final stage of their lives, either in Northern Ireland (NI) or the Republic of Ireland (ROI). A research project led by Dr. Suzanne Cahill of Trinity College, Dublin and funded by CARDI found through interviews with bereaved spouses that key elements of care when it comes to dementia patients are:

- Person-centred care
- Pain and symptom control
- Good-quality communication and involvement of family in decision-making
- The value of particular care around the time of death.
The research found that respondents favoured the care delivered to residents with dementia at the end-of-life care in nursing homes over that delivered in hospitals. The need for staff training in caring for patients with dementia at the end of their lives was also identified as important for maintaining high care standards.

From the qualitative research, a set of five guidelines was developed to help nursing homes develop policies and practices in end-of-life care for residents with dementia. These guidelines could form part of the dementia strategy in Ireland:

1. People with dementia approaching the end-of-life in nursing homes should be provided with individualised care that promotes quality of life and is totally respectful of the person dying – as that person is now and as he or she was earlier in life. There should be recognition that at the end-of-life medical interventions usually focus on improving quality of life rather than on seeking to cure.

2. All end-of-life care should promote dignity through excellent personal care. End-of-life care should ensure that residents with dementia are comprehensively assessed at regular intervals and that their needs are managed with appropriate skill and attention to detail. This approach requires consistency in the delivery of individualised care that is underpinned by a comprehensive knowledge of the person’s uniqueness and life history.

3. All staff involved in the delivery of such care to residents with end-stage dementia should receive regular training and guidance in caring for people with dementia, so that they maintain their skills in delivering quality care. All staff should also receive education and training in palliative care principles and interventions in the context of dementia. This training should be relevant to their changing roles and responsibilities. Nursing staff should also receive regular training in gerontological nursing.

4. The nursing home should be proactive in seeking integration within its local healthcare system through developing relationships with all professionals involved in the delivery of care to residents with dementia. As an active participant in such a network, the nursing home will need to demonstrate excellence in verbal and written communication in order to benefit individual residents and their families.

5. End-of-life care must reflect an understanding of, and support for, family members’ needs. It should acknowledge family members’ life-long relationships with the dying person and their need to understand the decision-making process surrounding end-of-life care and to have the opportunity to participate in the decision-making, in the best interest of the person with dementia. Optimal nursing home care also fosters the development of meaningful relationships and a sense of partnership and trust between staff, residents and their families.

Further information on this project can be found here:
http://www.cardi.ie/publications/endoflifecarestandardsforpeoplewithdementia

Medication use in patients with dementia at the end of life

Palliative care and medication use are important issues in dealing with end-of-life stage dementia. As research into palliative care for patients with advanced dementia has been limited to date, CARDI funded a project, led by Dr. Carole Parsons of Queen’s University Belfast, as part of its grants.
programme. This project aimed to evaluate the extent to which patient-related factors influenced clinical decision-making with regard to medication use in patients with end-stage dementia.

The findings show that there is considerable variability in decision-making among doctors in Ireland about continuation or discontinuation of some medications at the end of life in patients with dementia. This was especially true in relation to the prescription of antibiotics, and non-continuation of unnecessary medications such as statins. Overall, the wishes and comfort of the patient and patient’s family should be at the forefront of decision making when it comes to end of life care in dementia.

This research also showed that the presence of an advance directive (or “living will”) did not necessarily have an effect on doctor decision-making regarding medications. Proper understanding of the legal basis of advance directives is crucial for doctors, and patients in Ireland who are diagnosed with dementia should be encouraged to develop an advance directive to specify the type of care they would prefer at the end stage of their lives.

Practice guidelines for the prescription of medications such as statins and anti-psychotics for dementia patients are necessary, and building the evidence base on medication use will help doctors to make decisions. There are currently NHS guidelines covering NI but no equivalent in ROI.

This research can contribute to the dementia strategy in Ireland in two ways:

1. The strategy should encourage the use of advance directives in patients diagnosed with dementia, and these tools should have a sound legal basis.
2. Ireland should follow the example of the NHS and develop practice guidelines for the prescription of medications for dementia patients at the end of their lives.

Further information on this project can be found here: [http://www.cardi.ie/publications/cardiresearchbriefmedicationuseinpaitientswithdementiaattheendoflife](http://www.cardi.ie/publications/cardiresearchbriefmedicationuseinpaitientswithdementiaattheendoflife)

Research framework

The NI dementia strategy *Improving Dementia Services in Northern Ireland* calls for research into three areas of dementia – cause, cure and care. It also points out that dementia has a world-wide impact, which calls for a co-ordinated approach to research, pooling talents and resources, where appropriate. UK funding of research into dementia is to be increased from £26.6 million in 2010 to £66 million by 2015. Similarly in the US, the Obama administration plans to spend an additional $156 million over the next two years to help find an effective treatment for Alzheimer’s disease.

CARDI would strongly encourage a similar investment into funding dementia research in Ireland as part of the National Strategy on Dementia. The strategy document itself could indicate what areas that the Government requires more research in as part of a research framework.