

Media Information

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Carers need all the support they can get to help them cope with the ‘ethical minefield’ of dementia care

Admiral Nurses, supported by the charity *for dementia*, welcome the publication of *Dementia: Ethical Questions* published by the Nuffield Council on Bioethics (1 October 2009), and the opportunity to debate the issues raised and recommendations made.

Karen Harrison Dening, Consultant Admiral Nurse, supported by the charity *for dementia*, says:

“Family carers are ‘key partners’ in the provision of care for those with dementia and this is why we, Admiral Nurses, have made the family unit – carers and those with dementia – the focus of our specialist support.

Day in day out carers are faced with having to make decisions on difficult and sensitive issues that affect the lives not only those with dementia, but also their own and their family’s lives.

How to manage the repeated questioning? How to manage the potential risks of allowing people with dementia maintain independence and quality of life?

Sometimes there is a ‘mis-match’ of needs, wishes and emotions between family members that are difficult to resolve.

Our one-to-one work with families provides help with navigating these difficult questions and decisions, supporting them to come to decisions that work for that family at that time.

Putting families in touch with others also coping with dementia is an important part of our work and many Admiral Nursing teams run cafés to facilitate this interaction, helping to mitigate the feelings of isolation and stigma that people with dementia and their carers often experience.”

Currently there are 74 Admiral Nurses in post in 31 locations across England. The Admiral Nursing DIRECT national helpline, manned exclusively by Admiral Nurses, provides telephone and email support to all carers wherever they live.

Ian Weatherhead, who heads up Admiral Nursing DIRECT, adds:

“Admiral Nursing DIRECT receives calls daily from families and carers about the questions and dilemmas they and their family members are facing whilst caring for someone with dementia.

Families do find ways of coping and managing these problems and risks but often through trial and error with little advice and support. Admiral Nursing DIRECT helps to ‘plug this gap’ and provide guidance and advice, and helping to assuage the guilt that often accompanies important decisions concerning care.

But we cannot fulfil all these needs and more formal mechanisms of support, plus education of all healthcare professionals are needed.

Our experience tells us that the earlier support is given the better and can make the dementia journey far less stressful for both the person with dementia and their carer.”

Jean Tottie who cared for her father who had dementia and is a member of **Uniting Carers for dementia** states:

“As the main family carer, I was increasingly concerned at the level of risks we were taking in letting Dad continue to live alone. A major flood from taps left on upstairs – Dad locking himself out of the house and sitting in the greenhouse for hours.

Working with our Admiral Nurse we positively managed these risks so Dad was able to stay at home for longer - and to continue the long walks which he adored. I never wanted to stop him from doing this as it was such an important part of his life.”

As well as providing Admiral Nurses and the Admiral Nursing DIRECT helpline, the charity provides training for carers through an extensive programme of affordable courses at a number of levels. The charity also supports the **Uniting Carers for dementia** network, putting families coping with dementia in touch with one another and helping them to make their voice heard. Full details at www.fordementia.org.uk.

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Karen Harrison Dening Admiral Nurse, Ian Weatherhead, Lead: Admiral Nursing DIRECT and Jean Tottie, former carer and member of Uniting Carers for dementia available for interview.

Note for Editors

The mission of *for dementia* is to improve the quality of life of people with dementia and their carers by promoting and developing **Admiral Nursing**, providing high quality **training**, promoting best practice for professionals working with older people, carers and people with dementia, and supporting the carers network **Uniting Carers for dementia** and the national helpline **Admiral Nursing DIRECT** (0845 257 9406) provided exclusively by experienced Admiral Nurses.

For more information log on to www.fordementia.org.uk .