

The Government launched the national Dementia Strategy on 3<sup>rd</sup> February 2009. The publication, entitled **Living well with Dementia: A National Dementia Strategy** sets out the Government's ambition for transforming dementia services. The Strategy has three key themes:

- to raise awareness and promote better understanding of dementia,
- to offer improved access to assessment services to ensure that people with dementia are diagnosed early
- and to improve the quality of care.

The full report and supporting documents can be accessed on the Department of Health website by following the link:

[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_094058](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_094058)

**for dementia** offers the following response:

**for dementia** welcomes the launch of the national Dementia Strategy. The challenge of meeting the needs of families affected by dementia in England is enormous and this strategy will go a long way to improving access to services and enhancing the quality of care.

- The strategy is very ambitious and will take time to deliver. There is a huge amount to do to achieve all 17 objectives and each locality will be at a different starting point.
- The emphasis on early diagnosis and intervention is welcomed. For dementia believes that assessment is best carried out close to the patient's home environment and, whilst a 'Memory Clinic for every town' is a commendable goal, the success of this initiative will depend on the services being responsive to families' needs and emotions and easy to engage with.
- Enabling easy access to care following diagnosis is vital and it is the experience of many families that early stage support, irrespective of the type of dementia diagnosed, is not available. This is about bridging the distance between early stage dementia, when the person with dementia has capacity and is capable of living a near-normal life, and the stage at which secondary care services are needed to help care for the person with dementia and provide support for carers. To effectively bridge this gap, primary care teams will need to be equipped to respond to individual's issues as their dementia progresses and to trigger appropriate onward referral at key points in the journey.

*Memory clinics and getting an early diagnosis is great but what happens next? My concern is that as carers we will be given an earlier diagnosis and a bit more training but unless there is a real improvement in care homes, day services and support at home we will*

*just have to carry on struggling without any real choices (Michele Poole, family carer)*

- The proposed Dementia Care Advisor role to facilitate, but not case-manage, a person's journey is an under-developed concept. The needs of families are highly complex and the facilitation of the journey requires a high level of skill and expertise.

*I worry about the dementia advisors, will they be support workers or skilled professionals. It will make a difference (John Sprange, family carer)*

- The Admiral Nursing model has much to offer in taking this work forwards. The Admiral Nurses have developed a Case Management Model which offers a 'whole journey' framework, involving families being 'stepped up' for services at points in the journey when needs are increased – eg in transitional phases when there is increased stress and burden on carers. Signposting alone will not be sufficient for families to experience a 'seamless journey'.

*After my mother moved into the second nursing home I tried to get a purpose adapted wheelchair for her. The Alzheimer's Soc carer support worker told me I needed to go to the local rehab hospital, which I duly did (in Dec 2003). At reception the woman told me to go to room x, which was difficult to find. The door was locked. Someone else said 'you need to go to room y'. Once again, door locked. It happened a third time before I left, in tears. I can't remember how I managed to get hold of a man who measures people for such chairs, but I eventually did in Feb 2004. He came along, measured her, said 'I can't promise, but I'll do my best to get it this financial year. Nothing. Silence. Phone calls. Unreturned. I gave up, exhausted by banging my head against a brick wall. In September I spoke to my brother, who worked for the local authority, and a wheelchair arrived in October.. My mother died in December. So much for signposting. (Rosemary Clarke, family carer)*

- *for dementia* is particularly pleased that a link with the Carers' Strategy has been included and that the important contribution of family carers is recognised. Two thirds of people with dementia live in the community and therefore the lion-share of responsibility for care rests with family carers. Investing in support for family carers makes good economic sense: carers of people with dementia are vulnerable to high levels of stress and depression. When a home caring situation breaks down this is often as a result of the family carer becoming ill and this can precipitate unplanned (and avoidable) admission to hospital of both the family carer and the person with dementia. Carers need expert information, emotional support, practical advice and to be equipped with skills to successfully care for a person with dementia in the home environment. This is key evidence on which the Admiral Nursing model

was founded. Admiral Nurses have much to offer but this specialist resource is only available in limited parts of the country currently.

- *for dementia* welcomes the inclusion of end-of-life care in the Dementia Strategy. Feedback from carers reflects that 'whole journey' support is vital and this includes involving families in end-of-life decision-making about interventions and care; also, post-bereavement support for families.
- A key objective is devoted to creating 'an informed and effective workforce for people with dementia'. This is a pivotal issue. All health and care professionals who, as part of their role, have responsibilities for providing services for people with dementia and their carers should have access to specialist dementia training and education. This includes non-specialist staff in acute hospitals, public services, generic care settings and primary care. Training and information alone does not change practice: health and social care staff need to be supported in their work settings in order that learnt knowledge and skills can be applied in practice. *for dementia* is in a strong position to help deliver this aspect of the strategy.

### **Implementation of the Strategy: *for dementia's contribution***

**for dementia** has a 20-year track record of working with NHS and social care partners in the field of dementia care and is in a strong position to offer expertise and leadership to support implementation of the Strategy;

- **Admiral Nursing** is an expert nursing leadership model, working in partnership with health and, social care colleagues and the voluntary sector to deliver evidence based interventions for family carers and people with dementia. Admiral Nurses operate in parts of London, Kent, the West Midlands, North West, North East Lincolnshire and Southampton.
- **Admiral Nurses** work in partnership with universities to deliver higher-level educational programmes for professionals working in the field of dementia care.
- **Admiral Nursing DIRECT** is a telephone and email service offering information, emotional support and guidance for family carers, people with dementia and professionals on all aspects of dementia care: 0845 257 9406 [direct@fordementia.org.uk](mailto:direct@fordementia.org.uk)
- **for dementia training** provides training, staff development services for health and social care providers at vocational level.
- **Uniting Carers for dementia** is a national network of family carers committed to empowering family carers, raising awareness of dementia and carers issues and making a difference to the lives of all people affected by dementia.

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