

**Uniting Carers for dementia respond to National Dementia Strategy Consultation  
Carers 'often the key to understanding the person with dementia.'**

The *Uniting Carers for dementia* network, which is supported by the charity *for dementia*, have handed in their response to the National Dementia Strategy consultation. The consultation exercise closed on 11 September 2008 with publication of the Strategy and Implementation Plan for dementia care services expected in November.

In their response, *Uniting Carers* stressed the importance of taking the views and knowledge of those most affected into account and said that too many carers "*had to continually battle to find out what was going on and where to get support ....that isn't right.*" They added "*The Strategy needs to acknowledge the family carer and their work, their unique knowledge of the person with dementia – and this knowledge needs to be placed at the centre of that person's care.*"

*Uniting Carers* point out in their response some significant omissions. "*There is little emphasis on the needs of people from Black and Minority Ethnic and elder groups .... There is little mention of younger people with dementia (under 65), an area where there is much ignorance and minimal support; their needs are different and services are limited.*"

Not enough emphasis on the need to look after the carer to enable more people to stay at home for longer was also raised by *Uniting Carers*, particularly the need for regular respite breaks. "*Without our support and unpaid care for people with dementia, the system would collapse overnight. The strategy doesn't really address this.*"

No financial commitment, no realistic timetable, no explicit standards, no focus on supporting low-paid and low-status care workers are also cited as omissions which *Uniting Carers* expect to see in the final Strategy & Implementation Plan.

Fundamentally, members of the *Uniting Carers* network said they need an expert friend – a partner such as an Admiral Nurse - on the journey of dementia, through all the twists and turns that road may take. "*We need professionals to work with us not exclude us and realise we are often the key to understanding the person with dementia.*"

Admiral Nurses in their response to the consultation agreed: "People with dementia and their carers must be listened to and offered care that is driven and led by compassion with the views of people with dementia and their carers used to shape future provision."  
**ENDS/**

**Note to Editors:**

1. Photographs available of **Uniting Carers for dementia** and **Admiral Nurses** handing in their Strategy documents at Richmond House, Department of Health, received by Catherine Davies, Private Secretary to David Behan, Director General for Social Care at the Department of Health.
2. The **Uniting Carers for dementia** full response, based on general responses from the whole network (c650 members) and detailed comments from 45 members, to the National Dementia Strategy can be viewed at [www.fordementia.org.uk](http://www.fordementia.org.uk). The aim of the **Uniting Carers for dementia** network is to give carers a voice and enable them to make a difference.
3. The mission of *for dementia* is to improve the quality of life of people with dementia by promoting and developing **Admiral Nursing**; providing high quality **training** and promoting best practice for professionals working with older people, carers and people with dementia; supporting the **Uniting Carers for dementia** network giving carers a voice. For more information log on to [www.fordementia.org.uk](http://www.fordementia.org.uk)
4. Admiral Nurses, supported by the charity *for dementia*, are registered community mental health nurses specialising in dementia care who offer support and expertise to families caring for someone with dementia, work in partnership with other health and social care providers, and provide leadership in working with others to improve the delivery of dementia care. The Admiral Nurses' full response to the National Dementia Strategy consultation can be viewed at [www.fordementia.org.uk](http://www.fordementia.org.uk). To extend the availability across the UK of the expertise of Admiral Nurses to family and

professional carers and people with dementia, **for dementia** has established the Admiral Nursing DIRECT helpline 0845 257 9406 and email service [direct@fordementia.org.uk](mailto:direct@fordementia.org.uk) manned exclusively by experienced Admiral Nurses.

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