

Media Information Issued 9th August 2007

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Barbara Pointon's Wish List to improve dementia care **Malcolm's Legacy by Barbara Pointon**

In 1995, Malcolm and I agreed to Paul Watson filming our story. All three of us wanted to peel away the stigma attached to dementia and to help people to understand more about dementia and what it can do to the patient and family. For the first time on TV, the documentary revealed the physical ravages of the severe stage of Alzheimer's disease. It showed that dementia is a killer - 1 in 3 older people will end their lives with dementia.

So what needs to be done to improve dementia research, treatment, care services from diagnosis to death and carer support? Here is my personal wish list:

- **A speedier diagnosis** – Malcolm was treated for depression for 2 years before getting the right diagnosis
- **Better education for GPs and general nurses** – dementia is currently not a compulsory component of all undergraduate courses
- **Access to dementia drugs** – Ebixa could have helped calm Malcolm's aggression without sedating him and avoided my need to put him in a nursing home for 2 years.
- **Compulsory training of all care staff who come into contact with people with dementia and more continuity** - we were sent 14 different agency carers in 8 months, none of them dementia trained. Inadequate training of care home staff also means people have to move to different homes or hospital(s) because staff are not equipped to deal with the complex needs of someone with dementia, often with disastrous consequences for the individual.
- **A dementia advisory nurse as part of the mainstream community nursing team** –such as an Admiral Nurse, to advise carers and nurses in all settings.
- **Truly joined-up working between Health and Social Services at grass roots level** – our social worker did not have the power to trigger services across the board.
- **Equality of access to palliative care services, including hospices** – I was told that our local team had to concentrate almost exclusively on cancer.
- **Better funding for research and treatments at least on a par with cancer.**
- **More people gaining free NHS continuing care** – people with dementia require highly skilled, complex care that is different from that of a cognitively able elderly person.
- **Stronger carer support** - including **free regular respite as of right** (not just at times of crisis), and more use of **replacement care at home** once the patient becomes too frightened to leave the security of their familiar environment.

It was Paul Watson's honest portrayal of Malcolm and me which began to bring this illness out of the shadows of ignorance and fear and also enabled me to speak out many times on behalf of people with dementia and their carers.

I'm delighted by the Department of Health's recent announcement that dementia is to become a high priority and feel privileged to be asked to become involved in shaping the future. I shall be taking my wish-list with me. What a wonderful legacy that would be for Malcolm.

Barbara Pointon

ENDS/

Notes for Editors:

1. 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. For more information on ***for dementia***, log on to www.fordementia.org.uk. or call 020-7874 7210
2. Professional and family carers can call the dedicated Admiral Nursing DIRECT phone line 0845 257 9406 on Tuesday daytime 10 am- 4 pm, and Tuesday and Thursday evenings between 6pm and 9pm. Callers may leave a message at any time and request a call-back, or email their questions to direct@fordementia.org.uk.

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